BODY TROUBLE: EMBODIED POLITICS IN THE LIVES OF YOUNG WOMEN WITH CHRONIC ILLNESS AND PHYSICAL DISABILITY

By

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To Mom and Dad, who worked tirelessly on teeth and on tile to get me this far
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The first page of this dissertation just might contain a lie. I didn’t actually toil in isolation. So many people contributed to this work—sacrificing their convenience for my own sustenance, spirituality, and support—that sometimes I wondered if true “sole” authorship is ever really possible.

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To the unnamed: thank you for sharing your peace, love, and empathy.
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<td>Center(s) for Independent Living</td>
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<td>Emergency Room</td>
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<td>ESE</td>
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<td>ICIDH</td>
<td>International Classification of Impairments, Disabilities, and Handicaps</td>
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<td>Vocational Rehabilitation</td>
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BODY TROUBLE: EMBODIED POLITICS IN THE LIVES OF YOUNG WOMEN WITH CHRONIC ILLNESS AND PHYSICAL DISABILITY

By

Meggan M. Jordan

December 2012

Chair: Constance Shehan
Cochair: Charles Gattone
Major: Sociology

Inside the field of disability studies, a debate persists between social model activists, who strive to show how disability is a societal creation, and scholars of embodiment, who wish to recover the lost experience of impairment from the dominance of the social model. Sociologists writing on illness and disability, meanwhile, often produce a de-politicized picture of disability as something that causes certain social consequences. My dissertation attempts to reconcile these shortcomings and debates by showing how embodiment is shaped by vectors located between social disablements and physical impairments. I observe an overlap between the two phenomena and present empirical evidence for how people make sense of impairment and disability oppression in their everyday lives.

This analysis is based on individual and group interviews with 20 women transitioning to adulthood (age 18-30) living with a combination of chronic illnesses, physical disabilities, and skin conditions. I reveal four insights into the creation of embodiment/disability oppression, or what I call “body trouble”. First, medical and health systems enable embodied difference by negating claims to pain and personhood.
Second, subtle social exclusion in the workplace, education, and social networks constructed difference relationally through policies, schools, and public reactions. Third, participants politicized physical pain by refusing to passively accept it, illustrating how physical realities are socially constituted. Finally, the women parsed through meanings of gender and ability as they collided with attitudes that framed their own sexuality, marriage potential, appearance, and fertility as feminine “impairments.” Overall, I show how physical realities are contingent on moral attitudes about how bodies “ought” to work, look, move, and live.

The study concluded with consciousness-raising sessions among the participants. Discovering that they shared similar social barriers to employment, community accessibility, health insurance, social networks, and public assistance, the women decided to speak in college classrooms to transform able-bodied thinking about “normal” bodies. Their public testimony demonstrated the power of disability as a tool for exploring constructions of difference and human identity. Such research enterprises, if practiced in the future, could move disability politics into the new millennium as democracies struggle to respect people’s rights to be both different and equal at the same time.
“Someday you will ache like I ache.”
- Hole, “Doll Parts”

Body Trouble: Five Definitions

Thinking about disability is a constant exercise in balancing personal troubles with public issues, pain with prejudice, bodies with selves, and everything in between. In this project I am interested in how people experience embodiment and oppression, simultaneously. I attempt to see disability nondualistically, to recognize impairment/disability not as something that is either-or but ontologically personal and public (Williams, 2001). I detect clamoring harmonies between the body, the self, and society. I call this inarticulate noise “body trouble,” and even though it is “inarticulate,” I hope to make its notes more clear by way of this project. To better understand the myriad uses of this concept of “body trouble,” I offer five classic definitions of the word “trouble” alongside quotes from writers and authors whom I believe best illustrate that definition. I argue that enough flexibility exists in the word “trouble” to potentially mend the debates currently upending disability research.

Embodied Distress

Trouble, n. a physical disorder, disease, ailment.

I felt the chaos of disruption at a visceral, bodily level long before my chronic illness–asthma–began to emerge when I was ten. I listened to my body continuously as I tried to monitor symptoms such as wheezing and swollen eyes that identified me as ‘sick.’ My struggles to breathe left indelible memories that were embodied in my subsequent actions. My bodily response to symptoms of asthma is informed by these memories even today (p. 11)
In the quote above, anthropologist Gay Becker (1997) describes her life troubled by asthma. As people with chronic health conditions complain about their ailments, I listen attentively. In narratives like this the words “struggle” and “trouble” may be used interchangeably. Living in a body is a constant effort. People wrestle with disorderly appendages, organs, tissues, and nerves that vex, inflame, and exasperate. My eye, my knees, my stomach, my nerves, my heart, “gives me trouble,” they say. An entire world exists underneath that phrase, yet our expression is suppressed by a lack of language to accurately describe these troubles. The body is a fragile container. This fact is distressing, and even more distressing to convey it to others. But not all is lost. Impairment is a powerful tool: I believe people with illnesses and disabilities voice truths that able-bodied folks wish to avoid. Like car trouble on the road, all of us will eventually become stranded, lost, or dependent on others for help. Body trouble is a universal human experience, shaped by the contours of timing (point at which it begins in one’s life) and society (how we choose to respond to it). Thus, the first property of body trouble is embodied distress (Becker, 1997) and the new social configurations that this distress creates.

**Embodied Difference**

Trouble, n. a personal quality that is regarded as a weakness, handicap, or cause of annoyance

The difference between Eli and me is that it is not my body that the kid is pointing to, or my body that people do double-takes about. It is my face. The stare is the same, but the target is different...Eli’s body is in question, his undertaking of tasks like walking or talking or writing or eating requiring much more time and attention than I would ever have to consider. I can cover my birthmark. Eli cannot hide his tremors, control his gait, or drink easily without a straw. I have a body that measures up to norms, but a face that does not. I feel an uneasiness about this that verges on able-bodied guilt. On a continuum of disability, I can blend into a normative body culture more easily than Eli, should I decide to “camouflage” my birthmark (p. 7)
In her essay *Bare Staring: An Essay on Looks Taken*, Patricia Fontaine (2003), a woman who has a port wine stain on her face, discusses how her condition contrasts with Eli Clare, a disability activist with cerebral palsy. The power of the stare connects Clare and Fontaine. Their bodies are disabled insofar as they are socially constructed as different and subject to public commentary. Moreover, both evoke what Whittington-Walsh (2002) calls “attitudinal violence,” in which difference invites verbal harassment by strangers in both public and private places. Body trouble, then, also refers to the way that difference is maintained through cultural beliefs about normal bodies.

**Exclusion and Troublemaking**

Trouble, n. civil disorder, disturbance, or conflict.

I'm reading Michael Taylor's statement. He desperately wanted to be here but the nursing home would not let him out. He says, “I first went into the nursing home about a year ago...a couple months ago they were trying to drug me up to control what they thought was improper emotions. I refused to take the meds and they put a label on me as a trouble maker. I call them drug pushers. I so wanted to be here myself to give this testimony, but the way this messed-up system works I don't have the freedom to go out of town for these things.”

Here we have another type of trouble: the kind that is made. That is, people who create a disturbance simply by insisting on a modicum of control over their lives. I mean folks like Michael Taylor (2006), above, who have the “audacity” to stop taking their medications. Or wheelchair users who participate in direct actions, dragging themselves up stairs with political intent. Testimonies of people with illnesses, disabilities, and health conditions are filled with troubling accounts of living in an inhospitable world that purposefully excludes them. One senses that this world is not intended for broken, blemished bodies. Thankfully many refuse to comply with a moratorium on their existence. To my mind, these trouble-makers are simply exchanging one trouble for
another. Reciprocal agitation, then, is the second property of body trouble. And it subsists on righteous anger.

**The Self-Improvement Industrial Complex**

Troubled, adj. confused, in disorder, scattered, thrown about.

Here is my troubled body, dreaming myself into life: a guttering candle in a mound of melted wax, or a bruised pear, ripe beyond palatability, ready for the compost heap. The images, though they vary, always bear the whiff of spoliatio. If there ever was a time of unalloyed love, I have long forgotten it, though I had hopes in early adolescence: that my breasts would grow magically larger and my mouth magically smaller: that I would become a strong swimmer and sailor and cyclist; that men, irresistibly drawn, would touch me and I’d burst into flame. Mostly I was, as I was trained to be, disappointed in myself (p. 44).

Some women train to stave off disappointment in their bodies, while others are taught to succumb to it. Nancy Mairs (1997), above, describes herself as the latter, coming to terms with multiple sclerosis, womanhood, and the cultural weight of perfection on her shoulders. Someone in “good” health may believe themselves to be in absolute control of their physical body. Mairs learned otherwise, describing her body as a “warier and humbler creature,” apt to understand how her illness amplified the tendency in all women to see their bodies as in need of repair. Hence, the third property of body trouble is American culture’s relentless zeal to cure or fix imperfections. That is, deficiencies that multiply at a dizzying rate as the demand for (women’s) perfection intensifies in all areas of life.

**The Hidden Underworld of Illness**

To Trouble, v. to distress or agitate mentally, worry.

I don’t see myself as morbid or obsessed, but I think about death a lot…my relationship with death becomes part of me. I can handle it, even if normal people can’t. I decided to be discreet…and live quietly among normal people. No need to trouble them with the details. No need for them to know about the coffin I keep in the basement (p. 10-11).
When not making it for political reasons, trouble can be politely withheld, creating what Duff (1993) calls a “hidden underworld of illness.” Harriet McBryde Johnson (2006) made the conscious decision to keep upsetting facts about dying to herself. While this may seem like quiet suffering to some, McBryde insists that she’s fine—that she can handle death looming so close to her. Contrary to our confessional social media culture and every law of psychotherapy, McBryde implies that some problems are much easier to manage when not shared with others. If this particular problem is shared, chaos erupts. Sharing evokes pity, and pity prevents the pitied from feeling anchored to a familiar state of being. The fourth and final property of body trouble, therefore, is also the hardest to reconcile with the others: the struggle to affirm privacy and quiet satisfaction in the body’s secrets to live a normal life (not a life full of “special needs”). In some ways, this property goes against everything this project stands for: the power of telling.

To be sure, trouble is a great word. It nimbly maneuvers between three parts of speech: adjective, noun, and verb. Our language needs flexibility when discussing bodies that challenge normalcy—which this project attempts to do. I chose young women as the object of study, simply because I am one myself. However, I am able-bodied. Unfortunately, this fact draws me to issues of disability and illness for very trite reasons. Simply put, I challenged myself with this project to think about something that I have had the luxury to avoid my entire life. What trouble has my own obliviousness (compounded by a cultural obliviousness) wrought? This dissertation is a humble attempt to rehabilitate our thinking to reverse the damage.
Statement of the Problem

This project aims to ameliorate two problems in the social science literature on disability. The first problem is a theoretical or epistemological concern; the second is a gap in ontological knowledge. Conceptual difficulties surround the role of the body in theorizing disability. For the past forty years, the social model has been the dominant force inside disability theory and activism. This model asserts that people with disabilities are an oppressed group. From this position, disability is not located within a person, but in the constellation of exclusionary attitudes, policies, and environments “imposed on top of” impairments (UPIAS, 1976). The social model was valuable for gaining political recognition of disabled people as an oppressed class. It had the residual effect, however, of exclusively focusing on social barriers as the “cause” of disability. Social model advocates shunned introspective studies on the experiences of the body or impairment, especially if they were not in the service of galvanizing the broader struggle for social change (Finkelstein, 2001). Similarly, social scientists elevated “strong” social constructionist theories, perceiving bodies merely as “representations” in an array of discourses (Foucault, 1988; Siebers, 2008). These histories have worked together to neglect bodily experiences or impairment and impoverished their understanding. In addition, the body has been discounted as a platform to challenge the social exclusions that constitute disability.

A statement of the theoretical problem, then, branches off into two related questions: how do we think about the radical potential for impaired bodies without privileging the tame sociological concern with “restricted activity,” the simplistic social model concern with social barriers, or the abstract constructivist concern with representation? Moreover, how do we include the situated knowledge of individual
agents and use that to change their compromised positions in society? (Gabel & Peters, 2004). Other theorists have offered some ideas. Gabel (1997) suggests theories that could actively oppose dehumanization, promote alternative representations across individual and structural levels, or promote an affirmative model of disability based on a culture that is “proud, angry, and strong” (Swain & French, 2000, p. 569). I see how theories could be housed within the burgeoning sub-disciplines of sociology of impairment, sociology of the body, or resistance theories to disability.

A second problem, moreover, involves the lack of empirical research on the potential application of such theories. Here, the problem for disability research becomes ontological. We lack certainty about the nature of oppressions and connected embodiments for people with a wide variety of physical impairments. We have a plethora of theories attempting to balance the complexity of impairment with the urgency of civil rights (Linton, 1998). Yet we lack empirical studies to resolve them. I also note in my literature review how young women are absent from the majority of the research on disability. Hence, a second statement of the problem could be phrased this way: why do we know so little about the nature of oppressions and connected embodiments for young women with a variety of physical impairments? While Hughes (2009) encourages us to examine the “borderlands where impairment and oppression meet,” I do so between the borders of womanhood/girlhood and adolescence/adulthood.

Research Questions

On the whole, this research strives to answer three important questions about the way that young women experience the body and oppression, mainly:

- How do women become aware of and express embodied difference in the liminal space of young adulthood?
• How do women interpret and find meaning from the realities of disability oppression and physical impairment?

• How do these women express and act on their desires for changing cultural attitudes about different bodies?

Across all of these questions I focus on the narrative strategies young women use to tell stories about the body. The expansive goal of this project is to map the experience of embodiment from structural (outside the body) and sensory (inside the body) perspectives. In doing so, I present a sociological ethics of embodiment that will allow us to take a less constricted view of disability in the discipline. Bodily variability allows sociologists to uniquely explore what it means to be human. If we were truthful to ourselves about our own frailty and mortality, if we recognized that bodies are neither infinite nor invincible, and if we embedded this attitude in policies to plan for illness in daily life, perhaps body oppression could be lessened considerably. As Mairs (1997) asserts, we are all questing to find our own hospitable body that lives inside a more hospitable world.

**Overview of Dissertation**

I organize my project according to three schemas of body trouble: 1) social significance and institutional forces, 2) the lived body, gender, and the self, and 3) consciousness and social change. I chose to organize the analysis Chapters (Chapters 5-7) according to a different layer of the concept of “trouble.” The literature review traces the current debates in disability research. I also provide a brief history of disability consciousness and activism. Chapter 4 details the methodologies and methods that I used during data collection and analysis. In Chapter 5, I argue from the position of the social model, positing that “body trouble” is not inherent in any one particular individual;
rather, the “trouble” results from social arrangements that distance people from their bodies and prevent them from accessing certain privileges. This argument allows me to switch gears in Chapter 6, in which I focus less on representations and more on the “lived body” in everyday life. Here I conceive “body trouble” in connection to “gender trouble,” or ways that constructed womanhood informs corporeal experiences. Finally, in Chapter 7, body trouble becomes body activism, as the data itself moved from understanding social phenomena to enacting public testimonials. In this sense, the women made “trouble” by speaking out in places where their voices were typically silenced. Chapters 5-7 are grounded in conceptual lenses. The medical model and the social model inform Chapter 5. Phenomenological theories of the lived body, feminist theories on body work, and the social structures of gender and age make up Chapter 6. Finally, Friere’s critical pedagogy and feminist disability studies inform Chapter 7. These orientations, developed from the theories discussed in Chapter 3, potentially overlap. For instance, in both Chapter 5 and 6, I analyze the ways that women in my sample confront institutional obstacles that impact the self. I conclude the dissertation with a unifying theory of body trouble, limitations for future research, and implications for sociology, feminist scholarship, and the disability rights movement.
CHAPTER 2
LITERATURE REVIEW

One challenge in studying disparate groups of people is the absence of a cohesive body of literature to understand these groups. Since I am studying embodied difference, sometimes seen as a disability, other times seen as a chronic illness, I must cast a wide net to synthesize previous research. I choose to draw on three areas of literature to understand the elusive and shifting phenomenon of disability: medical sociology, disability studies, and the disability rights movement. The literature review contains four substantive areas: current trends and debates in disability research, defining and counting disability, illness and disability as experienced in adolescence and young womanhood, and the meaning of body politics.

Illness and Disability: Current Trends and Debates

Researching disability is an exercise in juggling competing interests, multiple perspectives, and opposing interpretations. A verbal struggle persists between the fields of rehabilitation science, medical sociology, and disability studies. Each discipline advances divergent theories that are not inconsequential, abstract divisions—they have wildly different implications for the way in which people with disabilities are likely to be treated. At the heart of the problem is a lack of interdisciplinary cross-pollination. Williams (1996) suggests that researchers have tunnel vision about the complexity of disability. Rehabilitation science, medical sociology, and disability studies are walled off from the other’s strengths, oblivious to their own weaknesses, and fragmented by different levels of analysis (bodies, selves, and structures, respectively). In this project, I attempt to find a compromise in this debate. My research is participatory, political, empirical, and theoretically grounded. I create a methodological model for how
sociologists can conduct research on disability just as I produce new knowledge about impairment as an embodied experience and oppression. Before I can explain my contribution, however, I will describe the tensions within disability research.

In general, medical sociologists and disability theorists share similar criticisms of the “medical model.” This model places a person’s functional limitations (impairments) as the root cause of disadvantages (Crow, 1996). To address the disadvantages, the body must be cured or fixed. This approach is, according to Williams (1996), “reductive.”

[The medical model] is rooted in biology and serves the interests of the medical profession and those professions and other economic and political groups allied to it. It is an intellectually and politically limited model for responding to the problems covered by the term “disability” in the modern world. It neglects the subjective experience of illness and impairment and reduces it to a set of discrete problems requiring technical interventions. In this sense the clinical approach to rehabilitation is dehumanizing. Secondly, it deflects attention from many of the material and social bases of the difficulties people experience. In these terms it depoliticizes disability (p. 209).

This critique is difficult to maintain when many people clamor for surgery, gene therapy, or movement therapy to end their constant pain, fatigue, or early death. Broadly speaking, alleviating political, material, and institutional inequalities of “the chronically ill” (as a collective) ranks low on a list of priorities for a person in pain, especially when bodies are easier to manipulate than entire social structures. Moreover, the field itself is not exclusively medically-focused (Hayes & Hannold, 2007). Many rehabilitation counselors, for instance, collaborate with the important work done by independent living centers as they seek to match people with disabilities with jobs, transportation, education, and housing. Rehabilitation science, then, has a diverse counseling culture that does not simply fit into the “medical model.” Yet, in its most general form, whether re-skilled or corrected surgically, the individual disability as a “case to solve” remains at
the forefront of rehabilitation science. From this juncture, it seems almost impossible to convince policy-makers, granting agencies, and donors that they should focus their energies on social oppressions and not individual bodies (especially when people are eager participants in their own rehabilitation).

Medical sociology is a different matter. Rather than the biological properties of disease, its starting point is sickness as a social state (Barnes & Mercer, 1996). Medical sociologists are concerned with the meaning of disability, including the adaptations to disability that people find most difficult (Bury, 1996). The field is phenomenological, interpretive, and subjective. I believe that this quality is its strength as well as its weakness. Medical sociology’s strength emerges in its interrogation of the meaning of disability, not simply its prevalence or prevention. Blaxter (1976) and Strauss and Glaser (1975) both explore the difficulties that structural systems pose to adaptations to disability and maintaining a normal life. Another strength is sociology’s interpretive framework for examining how people assign meaning to their illness, or what Bury (1982) calls “biographical disruption.” This concept allows researchers to explore disability not simply as a physical challenge, but as a “fundamental re-thinking of a person’s biography and self-concept” (Bury, 1982, p. 169). Sociologists like Charmaz (1999), Kleinman (1988), Schneider (1985, 1988), and Faircloth, Boylstein, Rittman, and Young (2004) continue to produce valuable work in the interpretive framework. Williams, however, sees a danger in their approach:

Many sociologists starts off by viewing the experience of chronic illness and disablement in its context of social and economic circumstances, but get side-tracked into increasingly solipsistic explorations of identity and self…all that is left is the individual engaged in some abstract process of overcoming bodily “failure” and “coming back to normality”…the politics and history of
illness and disability become marginalized...[as] the realities of health and social care become forgotten (p. 203-208).

Like rehabilitation science, medical sociology has been critiqued by disability theorists as meddling in reductionism, limiting disability to a vehicle for voicing suffering and displacement. Williams charges that from a sociological perspective, disability/illness is not seen as an enriching life experience but a chaotic existence imparting a quasi-religious "truth" that only pain can reveal.

Disability theorists assume a different position altogether. A politically-charged group named the Union of Physically Impaired Against Segregation (UPIAS), organizing in the late 1960s and early '70s, cultivated critiques of the medical model, rehabilitation science, and medical sociology. Disability theorists in UPIAS were not interested in impairment or the "recovering self" after illness. Instead, they stated their goals clearly and angrily:

What we are interested in are ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way this society is organized to exclude us. In our view, it is only the actual impairment which we must accept; the additional and totally unnecessary problems caused by the way we are treated are essentially to be overcome and not accepted. We look forward to the day when the army of "experts" on our social and psychological problems can find more productive work (UPIAS, 1976, p. 4-5).

Here, UPIAS advocates for the elimination of disability oppression, creating what Oliver refers to as the "social model of disability." Thus far, it is the only theory upon which people with disabilities have chosen to organize themselves collectively. Critics of the social model, however, assert that it is not useful for everyone for several reasons: it denies experience of the body (Crow, 1996; Morris, 1991) and fails to incorporate intersectionality into its theories (Hearn, 1991; Hill, 1994). Likewise, Williams maintains that the social model’s hard line on discrimination renders it unable to accommodate the
subtleties of the social quality of chronic illness. Oliver (1996b) counters that the task of the social model has been misunderstood by these critics:

Pain, medication, and ill-health properly belong within either the individual model or the social model of impairment...it is not a substitute for social theory, it is not an attempt to provide a materialist history of disability, and it is not an explanation of the failure of the welfare state in respect of services to disabled people (p. 49-51).

Crow argues that the social model cannot be easily sublimated to other social justice theories like critical race theory or queer theory because the “personal struggle” of impairment will remain even when disabling barriers exist.

The question arises, then: can people with disabilities organize around impairment? Oliver mentions a social model of impairment, but does not explain it, preferring to leave impairment to the medical model. Barnes (1996), furthermore, is skeptical that social movements could even use such a concept because impairment is so unique that people can only talk about their own individual experiences with it. Nevertheless, other scholars attempt to sketch a framework for a social model of impairment in order to understand how impairment causes disadvantage. Crow would like to see impairment integrated into the social model of disability. She explains four general domains for addressing impairment:

1. Avoidance/escape, through abortion, sterilization, withholding treatment from disabled babies, infanticide and euthanasia, or suicide,

2. Management, where the difficult effects of impairment are minimized and incorporated into individual lives without any significant change in the impairment,

3. Cure, through medical intervention, and

4. Prevention, including vaccination, health education, and improved social conditions (p. 62)
Crow asserts that the disability rights movement will lose ground if it is unwilling to engage with impairment in each domain. Instead, she fears public health researchers and pro-life groups will dominate the discussions without input from people with disabilities.

Hughes & Patterson (1997), meanwhile, advocate an impairment model that moves beyond the social model’s division between body/society and its equation of impairment with frailty. They disagree with attempts by Zola (1989) and Shakespeare & Watson (2002) to universalize impairment as an experience that we all share as humans. In its place, Hughes & Patterson encourage disability studies to embrace “embodied politics” on which sociologists can elaborate from a phenomenological perspective. They confidently state that “the political impact of impaired bodies engaged in militant action cuts through prejudice like a knife” (p. 337). It is the mutual engagement of pain and oppression, and not the latter exclusively, that politicizes pain in a way that the social model cannot. While the work in the sociology of impairment is relatively new and underexplored, I believe that my research attempts to think about impairment and disability in a nuanced, dialectic way.

**Defining Disability through Statistical Counts**

Classifying, defining, and counting disability is difficult because it is a multidimensional concept. “Disability identification is a judgment on the human condition,” state Fujiura & Rutkowski-Kmita (2001, p. 69), and there is no neutral language with which to discuss these judgments (Zola, 1993). Accordingly, any definitions must reflexively explore the meaning of classification itself. Disability and illness are contested concepts—and this disagreement is productive. Still, we must be able to talk about these classifications without tautologies. For example, Stephens
(2002) asserts that if we cannot define “women” as a homogenous group identifiable with shared characteristics, how can they experience collective oppression or discrimination and how can activists claim to act on their behalf? For this reason, disability and illness are utilized here as umbrella terms for the purposes of knowledge production and activist strategizing. In this section I detail the prevalence and statistics surrounding disability and illness. Then I briefly define illness and disability as it is most useful for my research, fully aware of the slipperiness of these definitions.

First, the statistics on counts of disability: about eighty percent of people in the U.S. will become disabled at some point (Russell, 1998, p. Index), usually in the last eight years of their lives (United Nations, 2006). Globally in 2004 there were approximately 978 million people living with a disability, or 15.3% of the world (World Health Organization, 2011). Researchers note that the prevalence of disablement tends to be greatest in wealthier, developed societies (Helander, 1993; Suris & Blum, 1993). According to the 2005 Community Survey, 19% of Americans live with some level of disability, although this group is highly heterogeneous (Brault, 2008; W. A. Erickson & Lee, 2012). In the survey, “disability” included limitations in sight, hearing, and speech (15 million adults), upper and lower body limitations (27 million adults), cognitive, mental, and emotional functioning (16 million adults) and need for personal assistance with activities of daily living (8 million adults). The World Health Organization (WHO) observes that iron-deficiency anemia, migraine, asthma, and mild hearing loss were some of the most prevalent illnesses worldwide in 2004 (World Health Organization, 2008). The WHO also estimated the number of years lived with a disability in 2004;
when calculated this way, lower respiratory infections and diarrheal diseases account for the leading causes of disability (ibid).

Second, measurements on the causes of disability are based on estimates of restricted activity or impairment. Heart disease and back problems are the primary causes of activity limitations in adults. Almost half of all Americans live with a chronic health condition—a number which has been steadily increasing over the past fifty years. Reasons for this increase include rapid changes in health interventions (like greater survivability of accidents and trauma due to emergency rooms), enhanced pharmacological interventions to prolong life and manage symptoms, and medical technologies to increase life expectancy (Elliott & Johnson, 2008). Ironically, public health researchers no longer confront epidemics of death, but “epidemics of survival” where individuals are vulnerable to mismanaged, poorly coordinated care and lack of access to services (Oeffinger, Eshelman, Tomlinson, & Buchanan, 1998).

A whole industry of research is devoted to searching for “better” variables to capture the “truth” about disability rates in the population. Levels of measurement used to arrive at these statistics include nominal (one has a disability or they do not), magnitude (mild/moderate/severe), interval (quality of life), or ratio (number of years “lost”). Most of these measures locate impairment as a characteristic of a person, attributed to a pathogen in or injury to the body. Increasingly, the social and physical environment has become an essential concept in understanding the disability creation process (Fougyrollas & Beauregard, 2001). Government bureaus have been slow to

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1 I find it helpful that the Fougyrollas & Beauregard define environment as “the physical characteristics of buildings landscapes, climate” and the “social political, economic, institutional, and cultural dimensions of life” (p. 172).
recognize “the social” as a contributing factor to disability and illness; many researchers had to foreground this idea before it became an accepted fact. Nagi (1965) distinguished between pathology, impairment, functional limitation, and disability in disablement (i.e. the process of becoming disabled). Meanwhile, Goffman (1963) and Freidson (1965) delivered key insights into how the cultural values and the attitudes of others can figure into disablement. As an outgrowth of this push to incorporate social factors into disability surveys and a wish to create a comprehensive taxonomy, the WHO (1980) published the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH). This classification has undergone numerous drafts over the years and inspired critics who seek to improve it or do away with it altogether. Debates over the ICIDH are mind-numbingly intricate, and go beyond the scope of this literature review. This taxonomy evokes controversy because decisions about its contents contain political motives. Gatekeepers struggle to maintain their ideological positions on exactly where disability is located (Fougeyrollas & Beauregard, 2001).

Though useful, these statistics, taxonomies, and causes of disability and illness are riddled with inconsistencies. Hahn (1987) observes how disability is ultimately defined by government policy, so that disability is whatever public laws and programs say it is. Consequently, governments can make value-laden decisions based on these measurements, especially if disablement is viewed as a burden and that years lived with a disability are “lost.” Fujiura & Rutkowski-Kmita (2001) point out the limitation of disability “counts” or “population surveillance.” From a disability studies perspective, these measures are imperfect because,

Disability status is lodged in the interaction of the social and experiential with the physical or psychological. One does not readily operationalize,
survey, and classify such phenomena...perhaps the better perspective on counting disability is to interpret measurement operations as imperfect proxies that capture only a fraction of the complex reality that is disablement (p. 92).

They admit that disability numbers are necessary but require greater critical thinking about their meaning. We should see them less as a full portrait of reality but as a “spirit of approximation” (p. 93).

**Defining Disability through Identities and Bioethics**

Personally, I am less interested in improving disability taxonomies and more invested in relational intersections *between* chronic illness, disability, and disfigurement. I propose that any attempt to define disability should privilege *identity* before any other phenomena. Just as gender sociologists attempt to distinguish between sex and gender by empirically studying the multiplicities of gender identity, disability scholars should look at the way people move in/out/between disabled identities and the political categories that enforce them.

In their seminal work, Asch & Fine (1988) describe the difficulties in defining disability. Dialoguing with feminist researchers on gender and disability, they note that the very category that integrates their analysis (“disabled girls and women”) is a social construct. They ask,

Why should a limb-deficient girl, a teenager with mental retardation, or a blind girl have anything in common with each other, or with a woman with breast cancer or another woman who is recovering from stroke? What they share is similar treatment by a sexist and disability-phobic society. This is what makes it likely that they will be thrown together in school, in the unemployment line, in segregated recreation programs, in rehabilitation centers, and in legislation (p. 6).

Asch & Fine observe how two phenomena—similarities in treatment and locations in the social structure—make investigations of such untenable categories possible. Instead of
examining discrete biological categories, they focus on groups who experience similar constraints in family, school, employment, intimate relationships, childbearing, and self-esteem.

The multiple identities between illness and disability contain keys to understanding impairment more fully. Wendell (2001) investigates the relationship between illness and disability or as she calls it, between “unhealthy” and “healthy” people with disabilities. I summarize her definitions in two bullet points:

- Healthy disabled are those people with physical conditions and functional limitations that are relatively stable and predictable. They regard themselves as healthy, not sick, and do not expect to die sooner than any other person their age, do not seek more medical attention than other health people (p. 19-20).²

- Unhealthy disabled or chronic illness refers to an illness that does not go away by itself within six months, that cannot be reliably cured, and that will not kill the patient any time soon. Not all diseases cause chronic illness, but the definition of chronic illness should not depend on diagnostic or disease classification (instead it should be patient-centered). Acute, chronic, and normal health stages fluctuate (often by social context and access to treatment) (p. 19-21).³,⁴

Even these two categories have fluctuating and broad membership, especially across the horizon of a person’s lifespan. For instance, Pinder’s (1996) study explores the ambiguities between illness and disability as they are lived by people who must go to work “sick” with arthritis. Participants in her study had similar impairments but varied in

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² In this study, participants with congenital limbs, Mobius syndrome, or cerebral palsy could be included in this definition.

³ Participants I interviewed with conditions like Crohn’s, lupus, paroxysmal dyskinesia, or renal disease could be included in this definition, although one participant managed her renal disease with a transplant and medications.

⁴ Moreover, Wendell states that naming the other “illnesses” as “unhealthy” does not assume “that a person will never recover their health. In fact, other conditions like MS and arthritis can behave like recurring acute illnesses with periods of extreme debility, periods of normal health, or acute episodes that leave behind permanent loss of function” (p. 21). Wendell considers illnesses that go into remission chronic when they “require prolonged medical treatment or surveillance, or when patients must fear recurrences because there is no reasonable expectation of cure” (ibid).
their commitments to a disabled identity and collective discourses around it. One participant identified herself with the disability movement and claimed status as someone “sick-but-fit.” She expended energy convincing her bosses that she was capable and productive. On the other hand, other people identified themselves as fit first, sick second–fearing that a sick identity would exacerbate their already uncertain work status. Pinder shows how the workforce they operated under presented a dichotomous view that either one was “sick” or “fit,” with no grey in between. She concludes that:

We are dealing not just with the discomfort which still exists between disabled people and the wider able-bodied, or Temporarily Able-Bodied society, but between disabled people, wider society, and those with partial impairments who may occupy a liminal status between these worlds (p. 150).

At best, we can define both chronic illness and disability as a liminal status. Chronic illness discourse and embodiment weaves in and out of disability and vice versa.

If the identities between illness and disability were complicated enough, disfigurement poses additional challenges to our definitions. One reason I chose to interview people with skin conditions was because of the ethical implications of aesthetics. Deeply held beliefs about how people should look demand justification and interrogation, and I was unsure if illness and disability were fully up to the task. In general, literature on disfigurement is divided between clinical and ethical orientations.

Thompson and Kent (2001) provide a clinical definition of disfigurement through its causes: congenital malformations (e.g., cleft lip/palate and port-wine stains), traumatic events (road traffic accidents, and industrial accidents), and disease processes (dermatological conditions acne, vitiligo, and psoriasis). They note that the latter can cause disfigurement directly, while other diseases may lead to disfigurement
indirectly through treatment. A clinical psychology approach to disfigurement seeks to understand how people with unusual appearances cope with their difference with the intent to help them deal with stressful social encounters. In this case, clinical interventions treat the affected person rather than the social construction of normalcy. Very few studies have attempted to alter others’ reactions to disfigurement, except for Cline, Proto, Raval, & Paolo (1998) who attempted to alter attitudes about disfigurement inside a school curriculum through empathy exercises. On the whole, however, psychological research on disfigurement attends to the emotional costs of living in a markedly different body. In this context, psychological, surgical, and technical interventions are viewed as solutions for emotional repair; rarely do researchers politicize the cultural issues of bodily perfection and disfigurement to move beyond coping.

Disability, Illness, and Young Womanhood

Even though women with disabilities represent a relatively large minority of women (1 in every 5 women in the U.S. is disabled), the neatness of fit between constructions of weakness and femininity increase their invisibility (Fiduccia & Wolfe, 1999). Young women with disabilities are increasingly overlooked in social policies and in social research, and I believe that this lack of recognition is a form of harm. I begin this section with an overview of the research on the “status” of women and girls with disabilities. Next I link the literature on girlhood/adolescence to young women with disabilities/illnesses. I end by ruminating on the unique location between age, embodiment, and gender that this specific group inhabits.
The Social Status of Women and Girls with Disabilities

Demographically speaking, women with disabilities and/or illnesses experience serious social disadvantages in the areas of reproductive rights, access to health care, family life, education, employment, leadership, and violence/victimization. From the right to bodily integrity and the right to found a family, this group continues to experience serious violations of human rights (Frohmader & Meekosha, 2012). I will offer just a smattering of examples. Violence kills and disables as many women between the ages of 15 and 44 as cancer (Krug, Dahlberg, Mercy, & Lozano, 2002). Systematic rape, used as a weapon of war, has left millions of women and girls forcibly impregnated or infected with HIV (Watts & Zimmerman, 2002). Disbelief is a common reaction to women who report victimization, if they report it at all\(^5\). Safe environments are rare; women who live in institutions are twice as likely to be victimized as women who live in the community (Sobsey, 1994). Violence also encompasses reproduction in the forms of forced sterilization, denial of access to birth control, coerced abortions, poorly managed pregnancies/births, and menstrual suppression. These are common features for girls and women with disabilities living in Global North and South. For instance, in Australia the majority of these procedures involved girls with intellectual impairments (Brady (Brady, Briton, & Grover, 2001).

Nosek et al. (1996) authored *The National Study of Women with Physical Disabilities*. In this groundbreaking report (the first of its kind funded by the National Institutes of Health), they surveyed U.S. women with and without physical disabilities to ascertain any health disparities between the two groups. Their findings clustered around

\(^5\) Frohmader & Meekosha explain this fact as a lack in recognition of crimes, lack of awareness about services and options available to them, and lack of confidence to seek help and support
five major inequities. First, women with disabilities had limited opportunities to establish romantic relationships, and their friendships were less intimate than for able-bodied women. Second, environmental factors, not the disability itself, played a stronger role in shaping women’s sense of self-worth. Self-esteem was lowest among women not in a serious intimate relationship, who were physically or sexually abused, and who lacked gainful employment. Third, reports of abuse (physical, emotional, and sexual) were the same for both groups, but women with disabilities reported abuse for longer periods of time. Fourth, women with disabilities reported lower levels of sexual activity and sexual satisfaction, although level of activity was not significantly related to severity of disability. Finally, the authors echo the literature on the dire barriers to reproductive health, noting that women with disabilities had more difficulties locating physicians were who knowledgeable about their disability to help them manage their pregnancies.

Fiduccia & Wolfe’s (1999) report, *Women and Girls with Disabilities, Defining the Issues*, summarizes even more sobering inequalities. They report that family life is particularly challenging, beginning with the penalty to even form an “official” family. Disabled beneficiaries who marry have had their Supplemental Security Income (SSI) benefits reduced, lost their SSI, Medicaid, and PA services simply because the partner’s income makes them ineligible. In response, disabled couples have resorted to living secretly with their partners or divorcing to keep life-sustaining benefits. Parents raising girls with disabilities, meanwhile, often “help” their daughters in more ways than they would sons, leaving the daughter with less encouragement to be independent and achieve economic self-sufficiency (Rousso, 1990). To compound this problem, if they are taught that wife and motherhood roles are closed to them, then they are denied a
meaningful role in adult life (Fiduccia & Wolfe, p. 19). If a disabled woman overcomes the obstacles to reproduction that I described in the previous paragraph, then she will likely raise her child under a spectrum of hostility, from prejudiced assumptions that she is incapable of successful childrearing to forced child removal and lost custody.\(^6\) For many, however, parenthood is not a viable option when social and family supports are weak; some women report termination of much wanted pregnancies solely on the grounds of lacking these supports. In light of these disparities, it is no surprise that disabled women are more likely to be single heads of household than disabled men (Berkeley Planning Associates, 1997).

Economic concerns of disability are frustrated by depressed employment and poverty numbers. In Canada, the unemployment rate among with disabilities is as high as 75% and a third lived below the poverty line (DWNC, 2010). U.S. women with disabilities have a lower employment rate than men with disabilities. This has implications for health insurance eligibility and social security retirement to build financial security. Unemployment is highest among disabled women of color (Stoddard, Jans, Ripple, & Kraus, 1998) and those who are working remain in low paying jobs that earn less than men for comparable work. They also earn less income than women with no disability (Jans & Stoddard, 1999). These depressing facts should be weighed against positive reclamations of disability from third wave feminist movements, which I discuss in in the next section.

\(^6\) Frohmader and Meekosha state that women with intellectual disabilities and mental illnesses are widely susceptible to this practice.
The Meaning of Girlhood, Womanhood, and Illness

Erikson (1959) proposes that the crucial task of adolescence is achieving a clear sense of personal identity. Feminist scholars making sense of adolescent girlhood do not arrive at a consensus for how this task is accomplished. Bettis & Adams (2008), for instance, sketch the “landscape of girlhood” to put forward the idea that girlhood is a liminal space in which historic feminine ideals have fractured. The meaning of “girl” in the 21st century is no longer monolithic, and an indeterminate space opens up for new meanings. Optimistically, the authors argue that such spaces give girls breathing room to become a person of their own making. The burgeoning field of girlhood studies in which they work does offer an important agentive counterweight to feminist work privileging oppression and victimization.

At the same time, postmodern girlhood comes packaged with paradoxes. Douglas (1997) summarizes these paradoxes in this way: “Girls today are being urged, simultaneously, to be independent, assertive, and achievement oriented, yet also demure, attractive, soft-spoken, fifteen pounds underweight, and deferential to men” (p. 21). In her study Young Women and the Body, Frost (2001) observes how young women are seen as synonymous with the body, while experiencing their own bodies from a distance. Transitioning from girlhood to womanhood requires an increasing awareness and consciousness to “manage” the body, but girls view their bodies with suspicion and anxiety. More disconcerting is the fact that a girl’s body and her sexuality are primary indicators for her “goodness” and “worth” in society. Values of “goodness” also intersect two tightly linked moral ideals: beauty and health. Whereas Brumberg’s (1997) study of young women’s bodies illustrates how adolescent women at the turn of the century were expected to be the epitome of youthful vitality, North American
constructs of youthful femininity still promote ideals of “unblemished skin, deodorized, youthful bodies, and sexualized shapes fraught with commercialized meanings” (Klineman 1998, p. 13). All women internalize these symbols into psychological needs and corporeal desires to some degree. These studies challenge Bettis & Adams by offering support for the view that girlhood is entering increasingly dangerous and contradictory territory and that much more work needs to be done to end the persistent problem of feminine devaluation.

The literature on this group of women rarely focuses on young adult women with disabilities. I recognize that “young adult” is a variable (and very recent) concept, but the challenges facing women with disabilities overall are typically examined at the poles of childhood and old age. Cardillo (2004) observes that to live with a chronic illness or disability, especially as a child or adolescent, is to experience oneself as different. This is because illness and disability are closely linked to old age in the cultural imagination. “I only feel old when I feel sick,” says an older woman in a study by Copper (1988). I find this statement interesting, but its inverse even more fascinating: what about young women who feel old? Or, to rephrase, how might young women feel the weight of “societal aging” earlier than their peers? How we imagine ourselves aging “into” our bodies is an interesting idea on its own, but when conceived as a paradox between youth and an ailing body, we see potential possibilities for understanding the experience of disability and illness.

Wendell (2001) ruminates on these possibilities, speaking from personal experience as a young woman with a chronic illness:

My own analysis is that young and middle-aged people with chronic illnesses inhabit a category not easily understood or accepted. We are
considered too young to be ill for the rest of our lives, yet we are not expecting cure or recovery. We cannot be granted the time-out that is normally granted to the acutely ill (or we were given it at first and have now used it up, or over used it), yet we seem to refuse to return to pre-illness life. We are not old enough to have finished making our contributions of productivity and/or caregiving; old people with chronic illnesses may be seen to be entitled to rest until they die. And we are not expected to die any time soon, so we are going to hang around being sick for a long while (p. 21).

Overall (1998) suspects ageism in these contradictory attitudes since disability is easier to recognize and tolerate in older people than in younger ones (p. 162). Moss & Dyck (2002) explain that women with chronic illness are “in between” hegemonic discourses—not quite ill but not quite healthy, almost disabled and almost abled, both very nearly normal and very nearly deviant (p. 33).

Cumulatively, research presents a picture of this population as beset with disadvantages in all areas of life; I had to mentally remind myself that such oppressed portraits, however close to reality, may sometimes simplify or valorize their everyday experience. Research on women with disabilities also lacks a third wave feminist attitude. Third wave feminist research, in its concern with the “joyful, disturbing, edgy, and typically complex” world of girlhood in mass popular culture, has received less attention than second wave research on the “serious political and economic barriers to women’s equity” (Bettis & Adams, p. 3). Future work might examine how a new generation of women with disabilities and illnesses define themselves as complex actors deciding their own fate within the context of third/fourth wave feminism.
CHAPTER 3
THEORIZING BODY TROUBLE

Theorizing the body is a substantial part of this dissertation. I use multiple theoretical approaches to investigate the management of body trouble for young women. I draw heavily from the overlapping theories of symbolic interactionism, phenomenology, and social constructionism. I also apply feminist epistemology throughout for its crucial deconstruction of myths of essentialized gender, which are invariably important to understanding the body. Critical pedagogy is relevant also, since I incorporated elements of action research in this study.

**Symbolic Interactionism**

Symbolic Interactionism (SI) is a major conceptual lens for this research. Symbolic interactionists utilize a constellation of theoretical frameworks loosely tied together by the pragmatist tradition (Waskul & Vannnini, 2006). Pragmatism is a North American philosophy which rejects the quest for universal truths and instead searches for a plurality of shifting truths grounded in concrete experiences (Plummer, 2000). Pragmatism views human beings as active and creative agents with the symbolic capacity to envisage how others see them (Cuff, Sharrock, & Francis, 2006). Self-identified pragmatist William James describes this philosophy as “toward concreteness and adequacy…facts…actions…and power,” and away from dogma, and the “pretense of finality in truth” (James, 2000, p. 27). Mead (1934) maintains that the orientation of the researcher under pragmatism is toward the world as “always different.” Each morning we open our eyes to a different universe in which we are constantly adjusting. Mead coined the term “symbolic interactionism” and set out to delineate three tasks for this theory: 1) that human beings act on meanings that objects have for them, 2) that
the meaning of objects arises out of social interaction and 3) that the meanings are modified through an interpretive process used by the person when dealing with the world (Blumer, 1969). SI uses a methodology that explores social experience as it is lived by building up sensitizing concepts from human experience. Researchers check for conceptual accuracy by continuously returning to the empirical world (Plummer 2000).

SI makes an important contribution to health scholarship by revealing how disability and illness are experienced as a moral status. When thinking through the process of “becoming” disabled, scholars attempt to understand how identity is shaped and reshaped according to the social pressures and constraints. Goffman (1959) offered the idea that mental patients embark on a moral career, whereby they develop a “framework of imagery for judging [themselves] and others” (p. 123). In this sense, the disabled self is in a constant negotiation between the individual’s internal assessments of their own worth and society’s external values about the disabled. Thus, SI researchers examine how people transform lived social life into positive or negative meanings about the self (Schneider, 1988, p. 66). Recovering from an injury takes on a moral component, as the injured person is vested with moral rights and entitlements as well as moral definitions. Charmaz (1999) explains that a “sick person can make certain moral claims and have certain moral judgments conferred on him or her” by others, such as dependency, need, and admiration (p. 368).

Moral status, however, is only one chapter of how the story of disability is told among SI researchers. Recently, a wave of SI studies on disability have found how people with disabilities construct hope (Lohne & Severinsson, 2006; Warren &
Manderson, 2008), and how people frame rehabilitation as “a fight” for getting on with life (Angel, Kirkevold, & Pedersen, 2009), among others. The common thread through all SI research is understanding meaning—which is crucial to designing services that meet the needs and preferences of people with illnesses or disabilities (Lutz & Bowers, 2005).

The Phenomenology of the Lived Body

The lived body is a theoretical lens originating from existential philosophy and phenomenology, used to examine the nexus between body and self. In existentialist philosophy, a person always faces the material facts of her body and its relationship to her concrete material surroundings (Young, 2005). For phenomenologists such as Merleau-Ponty (1958), the body provides an ontological basis for the self and a way for us to “make sense” of the world. He informs this research by his analysis of human perception as embodied (Howson, 2004); that is, discovering how the perception of the world begins from the body. The body is never just an object but the medium whereby objects in our world come into being (Leder, 1990).

The Illness Experience and the Lived Body

As I refer to the lived body throughout this dissertation, I am drawing upon two competing lenses of phenomenological thought. Merleau-Ponty argues that people experience the world through their bodies, and that certain situations have practical significance for the self. Thus, one approach to the phenomenological body focuses on its presence of being-in-the-world, or how people perceive it actively mediating their sense of self, society, and the symbolic order (Crossley, 1995; Waskul & Vannnini, 2006). Another lens, offered by Leder attempts to understand the body through its absence, or how the body becomes unimportant to us when functioning
unproblematically. Leder (1992) argues that, at times of dysfunction, the body is still experienced from a state of absence of a “desired or ordinary state” such that it becomes a force “opposed to the self” (p. 5). He goes on to remark that the lived body is a unique position from which to launch new possibilities for the illness experience:

Our body is very different than other physical objects in the world...When the body falls sick, we are left not simply with a broken machine, but with a world transformed; a disease undermines our sense of self autonomy, our relations with others, our habitual experience of space and time. The lived body offers a significant and sophisticated alternative to the model of the body-machine, with the potential to help “rehumanize” medicine and to recall us to the centrality of illness-as-experienced (p. 5).

In this dissertation, I aim to document the space between a tacit relationship to the body to a more conscious and reflective one. In this space, people realize that “they can no longer count on their bodies to look, behave, or move as they once did” (Charmaz & Rosenfeld, 2006). Of course the body has a “life of its own” even in health, but I argue that in illness or disability, the body has a particular “looking-glass” that produces unique images of the self. Our sensitivity to the evaluations of others, for example, leads people will illness to go to great lengths to avoid being seen as incompetent or disordered (Charmaz & Rosenfeld, 2006). Such a phenomenological stance toward the illness-as-experienced allows me to create a sensitizing framework of the “troubled” body.

**Sociology of the Body**

From the birth of sociology with Comte to the rise of structural functionalism with Parsons, the body has been taken-for-granted, undertheorized, or ignored altogether. Symbolic interactionists like Mead examine the nexus between the self and society, but see “the self” as a separate entity from the body. Morgan and Scott (1993) speculate that sociobiology, its ties to essentialism, and the triumph of culture over nature explain the neglect of the body in sociology. Others target the Western tradition of denigrating
the body over the mind, which has had enormous influence on the construction of academic knowledge (Cregan, 2006).

The fragmentation of modernity and the rise of an unstable, irrational, and contradictory subject make social theory ripe for a re-examination of the body. The shift toward theories of embodiment did not happen by accident. Sociology lends itself to social meanings in self-expression and individuals’ ways of “valuing, forming, and adorning their bodies” (Cuff et al., 2006, p. 285). Embodiment is also important in the practice emancipatory sociology, which denounces the tendency of colonization to render bodies expendable. Feminist and queer theory has pushed sociology in the direction of embodiment, as French theorists (Butler, 1990; Irigaray, 1985), gender sociologists (West & Zimmerman, 1987), and masculinity scholars (Connell, 1987) show how people continually recreate gender and sexuality through bodily gestures, dress, posture, and hair. The experience of living in bodies—and how social structure shapes or impedes this experience—has also been explored by medical sociologists studying chronic illness (Conrad, 2001; Turner, 1987; Twigg, 2006). Moreover, modern sociology has a solid foundation in embodiment from theorists like Bourdieu (1977) and Foucault (1978, 1988), who both show how social control operates through routine and compliance on the body, rather than through the internalization of thought (Cuff et al., 2006).

Sociology of the body developed from the need to explore how societies regulate and control real, tangible bodies. Turner (1984) lays the groundwork for this sub-field of sociology. His task is to critique the Cartesian dualism of mind/body, to situate the body at the center of disability debates, and to push sociology into discussions of human
rights (Turner, 2006). Doing so involves examining embodied social actors and their paths to selfhood through three components: the frailty of human beings, the precariousness of institutions, and the interconnectedness of social life (p. 257). Hence, empirical research in sociology of the body focuses on how embodiment, as contingent on the self, shapes social relations (Cregan, 2006). Gender sociologists have also contributed to this sub-discipline, attempting to understand the meanings of how gender and sexuality work on the body (Crawley, Foley, & Shehan, 2007).

Most important to this project, sociology of the body does not theorize from a medical starting point. Linton (1998) suggests that the biomedical outlook is deeply embedded in other disciplines. She notes the fact that “impairment has almost always been studied from a deficit model means that we are deficient in language to describe it in any other way than as a ‘problem’” (p. 140). In contrast, critical disability studies theorizes from the view of disability as an enriching life experience. Turner’s later work hews closer to this vision to arrive a view of common denominators between bodies, like suffering and pain, to make ethical claims about human rights.

**Social Constructionism, Gender, and Disability**

Feminist theorists foregrounded the prevailing view that gender is a social construction. It is important to think about how disability, as a socially contingent concept, mirrors the constitution of gender. Merging the social construction of gender with the social construction of illness, Lorber and Moore (2002) examine the way that “doing illness” parallels “doing gender.” They put forth the idea that bodies matter to the social creation of gender for people with disabilities. Similar to Martin (2003, 2004), Lorber and Moore assert that difference is realized *visually* through the body. For
example, they argue that the way society constructs acceptable healthy bodies operates in the same way it constructs acceptable gendered/sexed bodies:

Gender is one of the most significant factors in the transformation of physical bodies into social bodies. The gendered body in its social context is the framework for the analysis of the social construction of illness (p. 59).

Later, they write that the “variety of bodies and social environments make all of us part of a complex continuum of able-bodiness, just as the variety of women and men calls into question gender stereotypes” (p. 67). Like gender accomplishments, bodily ability exists on a continuum that fluctuates throughout people’s lives. This applies to a spectrum of genders and sexualities as well as a spectrum of ability. Normative ideas of gender and disability are dichotomous; they are not allowed to exist in a multidimensional space. What Lorber is basically describing has been well known to many scholars and people with disabilities.

The theories fit together when applying constructionism across the board. But is social constructionism more generally (the social construction of gender more specifically) relevant to the actual experience of disability and illness? Some scholars have argued that it is not. Wendell’s work on disability has been one of the most cited because she relentlessly examines how able-bodied thinking continually denies the realities of bodily life. In *The Rejected Body* (1996), she builds a unified theory of difference in bodies that challenges the feminist work on gender. She does this in two ways. First she distinguishes between the “social construction of gender” and the “social construction of disability” (p. 35). Sociologists like Lorber (1993) advanced the concept of the social construction of gender, which clearly separates biological sex from cultural gender, and invests heavily in the latter. Wendell, meanwhile, maintains that the biological reality of a disability and the social construction of a disability cannot be
separated. Wendell is concerned with how a social situation or arrangement can make a biological reality “more or less relevant in almost any situation” (p. 35).

I take this to mean that Wendell offers the idea that people do (construct) or undo (deconstruct) disability based on social arrangements. Yet unlike “doing gender” which stresses the performativity and infinite interpretations of the body, much of the social construction of disability involves not possessing it at all. Here, Wendell is speaking of the eugenic tendency to eliminate disabilities and illness from our culture. Constructing gender is not the same as constructing disability because the former theory views bodies as infinitely malleable and adaptable. Yet Wendell reminds us that people with disabilities do not always have this choice or control over their bodies.

In addition, social arrangements, rather than performances, matter more for constructing disability. Ability itself becomes a social institution when conditions create or prevent disabling conditions that shape bodies in profound ways. Wendell illustrates how war creates disability; failure to distribute basic resources like food and clean water creates disability; medicine creates, prevents, or defines disability; and culture creates disability by setting the standard for the pace of life in a society. Hence, disability, as a defining feature of the human experience, is accomplished more so by social attitudes toward disability than the body itself. A deaf person “performing” deafness makes little sense because deafness is a sensory experience; instead we should focus on how a hearing-majoritarian structure constructs roadblocks for the deaf, how deaf identities are created out of the vast array of sensory experiences in humans, and how it feels, corporeally, to be deaf.
Both feminist sociologists and Wendell’s work attempt to explain how gender hegemony is reinforced through sexuality and beauty hierarchies. Wendell takes this further, imagining how gender hegemony becomes enmeshed in ideas about disability and bodily aesthetics. For feminist theorists like Bordo (1993) and Bartky (1990), gender hegemony is reproduced by women’s willing participation in femininity and pursuit of the perfect female body. Wendell agrees that the disciplinary practices of “physical normality” parallel the disciplinary practices of femininity. Beauty ideals affect women and people with disabilities—but only to the extent that control of the body is possible. When people with disabilities cannot control their bodies, how is disciplining the body even possible?

Hence, Wendell’s task is to break down the “myth of bodily control.” She argues that this myth encourages us to strive to meet body ideals, yet feminists reinforce it by stressing women’s right (read: ability) to control their bodies. In addition, Bartky and Bordo’s interrogations of femininity only theorize women’s able bodies, which are closer to the ideal regardless of how they discipline them. Wendell argues that most people with disabilities cannot even attempt to make their bodies fit the physical ideals of their culture (p. 91). Wendell encourages feminists to rethink the path to liberation through control of one’s body. Her point about the myth of bodily control complicates the work on gendered embodiment and resistance. If the body is a site of resistance, what happens when people cannot control their bodies or how others view them? Answering this question requires understanding the complicated relationship between disability and feminism.
Conceptual Lenses

Any serious study of disability involves sifting through competing theories and disciplines. One must “get right with the theory” before tackling an academic project on disability. This necessity is ironic, however, since many thinkers eschew purely theoretical approaches without social application. Some writers even insist that their ideas are not theories or concepts, but “practical tools” (Oliver, 2004, p. 30). Because of the urgent need for change, disability theory is intended for use by governments and people with disabilities themselves. Nevertheless, the discourse about theory and its application is contentious. Debates emerge over the extent to which a theory is useful to the people it attempts to liberate. For this reason, I draw from multiple conceptual lenses to understand young women’s situated embodiment. In the sections that follow, I discuss the medical model, the social model of impairment, the sociology of impairment, feminist disability studies, and critical pedagogy.

The Medical Model

Foucault’s theories focus on the disciplining of bodies in a carcereal society. He inspired research concentrating on critiques of medicine and power, especially social medicine (Porter, 1997; Turner, 1987). The field of disability studies has applied these theories to a concept called the “medical model.” Sharma (1970) notes that psychiatrist Thomas Szasz was the first person to use the term in 1960:

It became possible to comprehend personal distress and social deviance in the same terms as those applied to physical illness. Although the phenomenon to be understood was human social behavior, emotional upsets, and life game, it was cast and couched in physio-bio-chemical terms. Such a conceptualization of social relations, interpersonal behavior, and personal distress may be called a medical or illness model.
Perhaps the most frequent critique of the medical model is its power over all aspects of the lives of people with disabilities. People often complain of “arrogant doctors” or “insensitive medical staff.” But this critique of the medical model goes much deeper than the “attitude” of doctors. The medical model creates a constellation of governing bodies that are headed by a “professional class.” I see three ways that the medical model reproduces class authority.

First, medical power, described by Foucault as “bio-power,” is the systematic regulation of medical bodies that mimics the way prisons control prisoners (Rabinow, 1984). Hence, the medical model makes “docile bodies” in the institutional setting of the hospital. For example, Sullivan (2005) documents how paraplegics who first arrive in the rehabilitation hospital lose the ability to control the time of their meals, when they use the toilet, and how staff lay them in beds. To compensate for bodies giving up so much control, creating a docile body demands trust. Browne’s (1985) moving narrative of her struggles with doctors and corporations over her insulin pump shows how the medical model renders her powerless because she was, during all times of difficulty, supposed to trust the medical experts. In her efforts to demand that the makers of the pump listen to her complaints about the product, doctors blamed Browne herself. She wanted the experts to say “You have been wronged, this has all been a terrible mistake, and we will make it up to you,” but that never happened. An apology would mean a physician or a medical company was no longer trustworthy. Maintaining trust and denying error is, says Browne, a “consistent attempt to maintain the status-quo of powerful, profit-making institutions, from the medical profession to the companies that make these tools to the agencies that determine the availability of these tools” (p. 22). Just as prisoners lose
their rights to privacy and empowerment, the medical model affects people with
disabilities by “giving up” certain bodily violations that we assume are inalienable.

Second, medical power involves continuous surveillance. Surveillance of people with
disabilities is practiced not only by physicians, but by researchers. The Institute of
Medicine (IOM) proposes a “national disability surveillance system” that could monitor
disability’s prevalence in the population (Committee on Disability in America, 2007). The
IOM expresses an obsessive desire to measure the limitations of people with disabilities
through extensive surveys and longitudinal studies. Nothing is wrong with more
research, per se. But the repeated focus on studying people with disabilities instead of
the non-disabled implies a need to scrutinize a deviant group at every stage in their life
course. More disturbingly, the IOM expresses great excitement in the National
Children’s Study which would monitor 100,000 children with disabilities from fetuses to
age 21. Most non-disabled children are not under constant medical and research
supervision, but children with disabilities are expected to submit to medical research
from as early as the fetal stage.

Finally, medicalization is the thread running through these critiques of the
medical model. Medicalization significantly expands the range of life experiences under
medical control (Conrad, 2007; Weitz, 2001). It is the process by which a condition
becomes defined as a medical problem requiring a medical solution (Conrad &
Schneider, 1980). Hence, another consequence of medical authority is the ability to
determine who and what will become medicalized. People with disabilities resist this
tendency and propose that disability become demedicalized. In fact, the medical model
is only considered a pejorative when applied to disability when it is “felt to exclude, or at
least devalue, other forms of knowledge about disability” (Evans, 2004). Moreover, Crewe and Zola (1983) note that most public policies respecting disability require some type of professional medical presence, whether in the acute stages of disability or in long-term institutional care. People with disabilities assert that much of this medical presence is unnecessary and counterproductive. Thus, medicalization does not just have symbolic power to create medical problems when there are none; the process is assumed to be normal for all people with disabilities. Such techniques of discipline are useful when interpreting the stories of women with bodies that have been medicalized despite being completely healthy and normal in their own way.

The Social Model of Disability

The most established disability theory is the “social model of disability,” coined by Mike Oliver in 1983. As a reaction to the medical model, UPIAS and Oliver rejected the idea of disability as an individual medical case. Instead, they redefined disability as a social oppression. UPIAS makes a distinction between disability and impairment:

- Disability: the disadvantage or restriction of activity cause by contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from mainstream social activities
- Impairment: lacking all or part of a limb, or having a defective limb, organ or mechanism of the body (adapted from Oliver, 1996b, p. 22)

Decoupling disability from impairment allowed UPIAS to convince the British government to enact reforms to remedy the way in which their policies disable people as a group. The simplicity of the social model makes a great selling point in the political sphere: people are not disabled, society made them so. Impaired bodies did not need to change; the “social body,” or society, needed to change. After the social model took
hold in Britain, the burden of responsibility for solving problems shifted from disabled people to governments.

The strength of the social model is also its weakness, however. Shakespeare (1997) observes that “any researcher who does qualitative research with disabled people immediately discovers that in everyday life it is very hard to distinguish clearly between the impact of impairment and the impact of social barriers” (p. 270). Shakespeare maintains that the social model is inward and separatist—a “blunt instrument” that glosses over the difficulty of impairment (ibid). While I do not completely discard the social model (I use it in Chapter 5, in which I interpret findings through this lens), I use it parsimoniously. For the purposes of substantively interpreting the data, I align myself more with writers in the sociology of impairment like Tobin Siebers, Bill Hughes, Cheryl Marie Wade, Susan Wendell, and Carol Thomas who champion a family of theories related to a more complex embodiment.

The Social Model of Impairment

Siebers (2008) is concerned with the “hard, simple realism of the body” and its use in the political struggle for disabled people (p. 67). He searches for a theory that reconciles the tyranny of anatomy/function, the shape and quality of relationships/environments, and the violence of rhetoric/representation. On top of this, such a theory must represent the interests of persons with disabilities in the public sphere. Siebers does not pretend to easily resolve these challenges; he instead offers guide posts for future thinkers:

The greatest stake in disability studies at the present moment is to find ways to represent pain and to resist models of the body that blunt the political effectiveness of these representations (p. 61).
Disability identity exposes two features crucial to all minority identity. First, the pain of identity derives from inequitable social location; second, this pain may produce a new political awareness critical of societies based on inequality and oppression (p.190).

As an example, Siebers quotes Cheryl Marie Wade’s (1994) portrait of unruly bodies:

To put it bluntly...we must have our asses cleaned after we shit and pee. Or we have others’ fingers inserted into our rectums to assist shitting. Or we have tubes of plastic inserted inside us to assist peeing or we have re-routed anuses and pissers so we do it all into bags attached to our bodies (p. 88 in Siebers, 2008).

Siebers uses Wade to think outside the boxes of the social model of disability and social constructionism. He proposes taking the realities of impairment and turning them into political weapons to change attitudes. Impairment, he argues, could confront naive social expectations about functional independence—such as the idea that everyone beyond a certain age will toilet by themselves. Physical realities could become political realities as people consider how much work goes into maintaining dignity and equality with caregivers. Unfortunately, his ideas lack empirical examination. I will return to the potential of complex embodiment as a viable social movement theory in Chapter 8, when I put Siebers’ theory to the test.

Feminist Disability Studies

I use feminist theory because it is adept at thinking about disability as a discursive category while at the same time not losing site of the lived body. Broadly speaking, feminist theorists explore how women’s bodies are either sites for medicalization (Riessman, 1998) or bodily discipline (Bartky, 1998). Other scholars (Griffin, 1982) stress the ways that Western culture alienates women from their bodies by a male-dominated society. This theory of body alienation claims that once women “discover” their bodies—whether through a sexual awakening, the birth of a child, or the
natural aging process—all will be well. However, some scholars in fat studies disagree, challenging the hypothesis that alienation is a negative state and self-love is the ideal (Johnston & Taylor, 2008). Similarly, Wendell (1996) notes that there is little room to explore bodily suffering when the goal is to restore women’s appreciation of their bodies. Nor is there room to think of a disabled woman as already “in touch” with her body without interventions from feminism. For instance, Gill (1996) recounts meeting a woman at a conference who was born without legs or arms but who clearly loved her body by wearing bracelets on her stumps and making fashion statements with big hats. Obviously women with disabilities can be both alienated from and happy with their bodies, like all women. What is important is that feminists move beyond discussions of “normative femininity.” Feminists focus too much on idealized forms of the female body. Essentially, the focus on what is “normal” has left women with physical disabilities out of the debate.

Conversely, Garland-Thomson (2002) develops a feminist disability theory to address the scarcity of theoretical work bridging disability studies and feminist theory. She examines how disability fosters complex understandings of the cultural history of the body. By considering the ability/disability system, feminist disability theory goes beyond explicit disability topics such as illness, health, and beauty. Instead, Garland-Thomson encourages a theory that connects the “politics of appearance with the medicalization of subjugated bodies” (p. 10). Such a strategy might reveal how cosmetic and reconstructive surgeries standardize bodies, correct flaws, and eliminate disability. Most feminists err when they think of disability as simply a handicap or an identity. Garland-Thomson says that disability—like gender—is a concept that pervades all
aspects of culture: institutional, identities, cultural practices, political positions, and shared human experiences of embodiment. She argues that more researchers should think of disability in this way, especially if their aim is the total transformation the systems of sexism, racism, heterosexism, and capitalism.

**Critical Pedagogy**

Foucault’s theoretical framework, essential to understanding disciplinary practices on the body, rarely contemplates a place for change, agency, or resistance. I use another useful framework, called critical pedagogy as a counterweight to portraits of a dehumanizing society. First conceived by Pablo Freire (1970), critical pedagogy offers a roadmap to changing the power relationships between “the oppressors” and “the oppressed.” Freire is concerned with the oppressed’s “struggle” against their own dehumanization to achieve a more “authentic existence.” Freire calls this *conscientizacao*, a Portuguese word describing the process of raising consciousness in conjunction with action. Changes in consciousness begin through “critical discovery,” or the realization that oppression is not “a closed world from which there is no exit, but a limiting situation which [the oppressed] can transform” (p. 49).

I take this to mean that power is not wholly absent in the lives of the participants in this study. Women’s power can be cultivated by “critical, liberating dialogue,” as they come to realize that they “know things” and that the oppressor’s power is quite weak in the face of this knowledge. Political action created from this dialogue must eschew dependence on the oppressors and trust in the ability of the oppressed to consider their own transformation. Hence, I use Freire’s pedagogy to inform my methodology and analysis. I sketch the architecture of “the struggle” to recover women’s lost humanity by creating a space where visions for social change are explored and acted upon.
Essentially, critical pedagogy in the hands of the oppressed can challenge the creation of troubled bodies through the hegemony of health/beauty constructs. Consequently, I consider ways that this critical pedagogy might benefit people that act on women’s bodies (specifically, medical students) to recover, as one participant worded it, their own “lost humanity.” Able-bodied people cannot determine the terms of this struggle. Freire insists that “the oppressed must not, in seeking to regain their humanity become in turn oppressors of the oppressors, but rather restorers of the humanity of both” (p. 5).
CHAPTER 4
RESEARCH METHOD

As I theorize about the lives of people in this study, I aim to advance knowledge of how women create and express their identities as they transverse young adulthood. I also examine the space in which these women transformed meaning into action as they spoke publicly about living with impairment and difference. Though this study is limited in its ability to generalize results to all women with disability or illness, it expands theories relating to embodied subjectivity and the experience of illness. Therefore, qualitative research is the most appropriate method to study the processes by which women understand their bodies. Likewise, qualitative methodologies are sensitive to the individualized life experiences, the constructed nature of knowledge, and the capacity for creating meaning out of interaction.

Data for this study were gathered in 2010-2011. A state university’s Institutional Review Board approved the research in 2010. I conducted open-ended interviews with women with various chronic illnesses, skin conditions, and physical disabilities. My attempt at theoretical sensitivity meant that the research questions changed several times during the course of data collection. In the beginning I asked the participants if the social responses to their conditions impacted their self-concept and their attitudes toward their bodies. Toward the end of data collection I began to ask them about employment, friendship networks, medical encounters, and other political concerns, since these themes emerged as I collected more data. Two group interviews were also arranged with five of the same participants who were interviewed individually. The methodologies that emerged consisted of a combination of grounded theory, phenomenological inquiry, and action research.
Sample and Recruitment

My analysis draws on audiotaped, in-depth interviews with a sample of 20 women with various physical conditions affecting the body. I use purposeful sampling to include a variety of information-rich cases. Comparisons between the various conditions were not the primary objectives of recruitment. Instead of focusing on one condition and exploring it in depth, I purposefully sampled women with a myriad of experiences to better understand how emerging social structures, constraints, and historical developments shape the process of embodiment in young adulthood.

The entirety of this research was conducted in a small college town in the southern United States. Participants were recruited on college campuses and from local social service agencies. Staff at these agencies (Student Disability Services, Centers for Independent Living) helped recruit several participants by posting flyers or sending out a flyer on their email listserv. Being a female-identified woman, age 18-30, with a chronic illness, physical disability or a skin condition were the criteria for participation. An implicit criterion for participating in this study was the willingness to share experiences and actively seek social change (whether through personal transformation of political action).

In most cases, participants responded to the flyers (see Appendix D). A few had friends whom they suggested that I contact. At point of contact for each interested participant, I explained that the research sought to answer “what life is like for you, as a person with a disability/illness/skin condition.” I told potential participants that I would like to interview them in person. I also emphasized that I was not affiliated with medical research and that this was a social science project. I informed participants that I would compensate them for their time ($20) after the interview, and that their confidentiality
would be protected (I could not guarantee confidentiality if they participated in the public testimonial phase of the project, however). After I had successfully interviewed 15 women, recruitment for group interviews began. I initiated this stage by making a decision about sample selection. I chose to include women with physical disabilities and chronic illnesses because the interviews suggested a common experience around key issues (employment, medical encounters, pace of life, time, and cultural attitudes). I emailed 9 interview participants, inviting them to join the group interview. I explained that the purpose of the group interview was to present findings from the individual interviews and also have a group discussion about these findings. I also offered to compensate the participants $25 for this first group interview (the last time I offered monetary compensation for any study activities). Six participants expressed interest in joining the group interview. Four actually made it to the interview appointment. About 5 months after the first group interview, I emailed a request to the same participants for a second group interview. Four participants expressed interest and 2 participants were able to meet at the interview appointment time. I believe that recruitment was successful because a “core group” of engaged participants was created early in the recruitment process. Meeting similar people, talking about their experiences with other women, and valuing their expert knowledge gave participants a stake in the project.

Participants

The age of participants ranged from 18-29 (see Table 4-1). Fifteen of the 20 women were White, two Black, one Asian, and 2 identified themselves as mixed race (Palestinian and Caucasian/Japanese descent). Fifteen participants were registered university students at the time of the interview. One was a high school graduate and another woman, the youngest of the group, was a senior in high school. Three of the 20
women were college graduates. Nine women had skin conditions like acne, cancer scars, or vitiligo, or conditions that affected their face, like Mobius syndrome (facial paralysis). Four participants had chronic illnesses such as Chron’s disease/ulcerative colitis, paroxysmal dyskinesia, lupus, and a seizure-like condition (undiagnosed). Finally, 7 women had physical disabilities that were present at birth or diagnosed in early childhood. These disabilities include missing bones, congenital hand, spina bifida, cerebral palsy, and ataxia. Of women with physical disabilities in the sample, 2 had chronic illnesses that they managed through medication or transplants (hydrocephalus, chronic kidney disease). On the whole, participants complained of secondary complications from their conditions, such as arthritis, irritable bowel syndrome, muscle spasms, migraines, fatigue, and sleeplessness. All were able to perform their activities of daily living independently without personal assistance, although 4 women did not drive (relying on family members or public services for their transportation). Assistive devices were varied among the sample: Tammy, 21, used a guide dog and Darcy, 25, occasionally used a cane. Saundra, 25, alternated between a manual wheelchair, Canadian crutches, and a cane she kept on her at all times. Ericka, 29, had used both a manual and electric wheelchair for most of her life. None of the women with chronic illnesses used assistive devices, although Julianne, 28, used a colostomy bag for a year in between her numerous surgeries.

Overview of Interviews

Table 4-2 details the four types of interviews that were conducted at each stage of data collection. I began with individual and follow-up interviews in the first stage, and group and action interviews in the second stage. The same participants were interviewed throughout each stage (no new participants were recruited in stage 2 and
3). All interviews were tape-recorded and transcribed (word for word) by the researcher with assistance from a professional transcriptionist. Interviews took place in a quiet room in a library, a coffee shop, or in the participant’s home. In the first stage, interviews were conducted to explore the constructions of identity and embodiment among women with disabilities, illnesses, and skin scars. After each interview I wrote memos to myself about the ways participants responded to my questions, the possibilities of higher-level themes to explore later on, and the differences and connections between the women as a group.

Next I re-contacted four participants to conduct individual, follow-up interviews. I chose these 4 participants because they expressed a high interest in the project. They were also undergoing experimental medical treatments and surgeries, so I wanted to check-in with them during their healing process. The purpose of follow-up interviews was to achieve a more accurate analysis of the data. These interviews were more free-flowing than the first interviews, and most were conducted without an interview guide. I asked participants about their thoughts on various concepts I was writing about in my analysis. The purpose of group interviews—conducted in stage 2—was to present my analysis of individual interviews, discuss the findings as a group, and think of strategies to change the social problems confronting the participants as a group. These interviews lasted around three hours, and I went in with a summary of data that I had previously analyzed (Appendix E).

In the first group interview, participants wanted to address social problems confronting people with disabilities, specifically their experiences with negative or ignorant attitudes toward them. They concluded that public testimonials about their
experiences to able-bodied people would be the best strategy to confront these attitudes. I call this portion of the project the “public testimonials.” I offer an overview of the methodology behind this turn later in this Chapter. Stage 2 of the research also consisted of action interviews, linked to the public testimonials in classrooms at the university. The purpose of these interviews was to solicit input throughout each stage of the public testimonials, both before and after the group panel sessions. In these interviews, I asked participants questions like “How do you feel the class responded to your story?” “How did it feel speaking about this issue?” and “What would you like to improve for the next group panel session?” (for more examples, see Appendix C). Action interviews were usually conducted a few weeks after each group panel session, in a few cases immediately after (I was worried about fatigue; I did not want to exhaust participants). Some overlap existed between stage 1 and 2 of the project, since the second group interview continued the dialogue from the first group interview while also planning future panel discussions. Next, I will explain the development of my interview guide and theoretical stance.

Methodological Stance on Interviewing: A Three-Fold Approach

If sociology is the science whose purpose is to interpret the meaning of social interaction (Weber, 1978), then interviewing is one of the most powerful tools for such interpretation (Fontana & Frey, 2000). We live in what has been termed an “interview society” where the majority of what is known about human behavior comes from interviews (Fontana & Frey, 2000; Holstein & Gubrium, 1995). Conversations hold powerful keys to understanding our world. But the practice of “doing” an interview is not as simple as it appears, especially in a project that involves both social psychological and activist components. Often I wavered on what stance I should take in the interview:
should I approach it as search-and-discovery mission, or does discovery happen within the interview itself? Moreover, what was my role as the interviewee? Am I a reporter or a storyteller? Or a participant myself? In this section, I will explain my methodological decisions behind interviewing. Doing so is important because the stance I chose informed the data I produced. This project adopts a three-fold approach to interviewing, blending constructivist, feminist, and activist interviewing types throughout all stages of the research.

**Constructivist interviewing**

Constructivists view knowledge as “an attempt to impose meaning and significance on events and ideas” (Higgs, 2001). Usually this word is used interchangeably with “social constructionist,” a general perspective within sociology that examines the social and historical constructs of knowledge in terms of what knowledge is socially produced and what counts as knowledge (ibid). The constructivist paradigm assumes a relativist ontology (multiple realities), a subjectivist epistemology and a naturalistic set of methodological procedures (e.g. grounded theory methods) (Denzin & Lincoln, 2000). Generally speaking, constructivists desire that participants take an increasingly active role in nominating questions of interest for any inquiry (Lincoln & Guba, 2000).

Most of my introduction to the constructivist paradigm comes from Charmaz (2006), a student of Glaser and Strauss (1967), the founders of the “grounded theory” method of qualitative research. Glaser and Strauss invigorated qualitative methods by emphasizing its systematic quality at a time when methods in sociology in the 1960s were heavily quantitative. Qualitative research had small stature within the social sciences because it was seen as too subjective and “touchy-feely.” Glaser and Strauss
were able to keep qualitative methods “respectable” by situating it within a positivist framework. This means that they seek truth, but with a small “t” (Charmaz, 2003).

Tensions exist within the grounded theory, specifically regarding how interviews should be conducted. Grounded theory methods house both constructivist and positivist paradigms. For myself, I lean toward a constructivist paradigm, but I feel that this project combined both paradigms in the interviews. Most constructivists maintain that if a researcher does not interact with the data, the research site, and the interviewee, then they will not understand the context of the data. A researcher must intermingle with participants to make interaction a part of the data itself. Constructivist grounded theorists argue that interviewing should not “cloak raw experience and mute feelings” when these feelings are data in itself. The researcher’s “sustained involvement with research participants lessens these problems” (Charmaz, 2003, p. 275). Because this project contained an activist component, I actually became friends with a few of the participants, which likely changed the data that I received. Positivist grounded theory, meanwhile, maintains that it is the participant’s job to change the researcher’s mind about phenomena. Charmaz rejects this view and says that instead, we should look at the researcher as “standing within the process.” By “process,” I extend this to mean researcher’s sustained involvement with research participants. This is why constructivists usually recommend interviewing someone multiple times, because the construction of reality may change depending on time and context. For this reason, I chose to conduct multiple interviews since the project’s goals took shape over the course of data collection.
There was a time when I thought that all qualitative researchers used grounded theory. I did not understand how grounded theory related to constructivist perspectives. Now I know that adopting the constructivist perspective does not necessitate grounded theory methods; nor does grounded theory always imply anti-positivist qualitative research. Looking back on the entire two-year project, I would say that I “grounded” my theories in the data by interviewing participants multiple times to make sure that a concept made sense to them. Likewise, I wanted to make sure that the theories I applied from other research made sense to them as well. If I encountered an interesting concept in a book or journal article, I would read an excerpt and ask participants to respond. Furthermore, a shift in research priorities was another telling sign that I used grounded theory. At the beginning stages I asked participants how their disability informed their identity. Later, I moved away from a constructivist interview stance and focused more on political questions of access to care, transportation, and mobility since these issues appeared most pressing in participants’ lives. This did not mean I stopped analyzing the construction of identities; on the contrary, the project itself caused identities to shift as participants became public advocates for themselves and others.

Constructivist interviewing has inspired other forms of interviewing—feminist and active interviewing in particular. Yet, constructivist interviewing tends to focus more on ethnomethodological concerns of how meaning is produced, whereas active interviewing combines this approach with understanding “the ‘what’s’ of everyday life” or the conditions underlying interpretive practice (Holstein & Gubrium, 1995, p. 16).

**The active interview**

The “active” interview is an approach developed by Holstein and Gubrium (1995) to urge social researchers to recognize how that the interview is not an unbiased tool.
Throughout their work, Holstein and Gubrium parse through the role of interview, respondent, and researcher. By saying the interview should be seen as an “interpersonal drama with a developing plot,” the authors mean that interviews are dynamic and collaborative (p. 14). The researcher and respondent create meaning from their conversation—through improvisational, multi-vocal interaction. The respondent is the storyteller, the researcher is the navigator (or the roles may switch back and forth). And so an interview becomes a joint-biography, where two (or more) people actively construct a unique social situation.

The active interview aims for mutual disclosure—that is, gaining the confidence of the respondent. Holstein and Gubrium promote linkages—work satisfaction is implicated in geography, possessions, home life, or child care, for example—to make the interview fuller, richer, and substantive. The active interview exposes the multiple angles of a person’s life that surveys obfuscate. The angles emerge through “narrative production,” where the interview unfolds and cross-references itself. Sometimes the interview looks like a straightforward “story” on paper, but in the interview itself, the situation is much different. Underneath the surface of the conversation, the participant calls on situated knowledge—or “stocks of knowledge” (p. 30) depending on which experience or position is activated. One example of this practice is the saying: “Every time I tell this story, it changes.” Changing roles/shifting positions/emergent identities—all of these constructs explain why the story changes. Stories, imply the authors, never remain in the past. As long as the interviewee is telling them, they are active and present.

More so than feminist or constructivist interviewing, active interviewing makes the interview come alive. The richest interviews are those in which the respondent knows
how to access their own “stocks of knowledge.” Respondents work through their stocks on their own, often contradicting themselves in the course of sifting through this information, but creating a dynamic story in the process. The odd thing about active interviewing, then, is that if the respondents do not pick up on this practice, the interviewer must encourage them to have confidence in their own stocks of knowledge.

In this study, the active interviewing strategy was useful given how the passage of time is a unit of analysis when examining participant life histories. The more interesting interviews were those in which the participant examined *her own life* in the process of telling her story. When I spoke with a woman who had been bullied in school for her most of her childhood and teenage years, she recounted how her younger self felt about that experience, and why it was important to her at the time to continue to be around her tormentors.¹ This reasoning had changed now that she was older, recognizing that her life was richer because of her persistence, refusing the option to segregate herself to classrooms for people with disabilities. She was able to look back on that time as one where the bullies themselves were not empowered, but afraid of her differentness. The ability to shift between different meanings of one situation, creating a new definition-of-the-situation altogether, is one example of the active approach.

Moreover, using the active interviewing approach allows me to grasp two distinct and interconnected “knowledges”: first, the knowledge of embodiment and second, the process of consciousness raising. In the interview, I became attuned to the language of “milestones, turning points, and crises…to capture the flow of life” (p. 50). The group

¹ As she explained, the benefit of being around “regular people” in “mainstream” (non-disabled) classrooms offset the teasing and ridicule she endured. At the time she sensed that separate classrooms for disabled children would have marginalized her even more.
interviews were more closely related to the active interview style than the individual interviews. The reason for this is because at that point in data collection, I truly felt like the interview itself was collaborative. Meaning was created by us together, as a group. I facilitated the group interview by stressing social change. One question I asked was “Is there anything we can do as a group to address this problem?” At this point, I felt comfortable using the term “we,” at least temporarily in that setting, even though I was not a woman with a chronic illness or disability. What mattered was that we were women in a room, thinking of ways to challenge oppressive ideas. The group interviews were charged with meaning-making as we constructed new knowledge about social action together.

**Feminist interviewing**

Doing feminist interviewing is not a simple act of “interviewing women.” On the contrary, Hesse-Biber, Leavy, and Yaiser (2004) explain that feminist research does not have a codified “scientific method” or even a feminist “figurehead” who guides research agendas. Instead, the patriarchal bias in scientific thought necessitates feminist research. Hesse-Biber et al. show how positivism itself creates facts which cannot be disputed. This has a detrimental effect on women and minorities. Feminist researchers ask “who knows it,” “why is it considered correct or incorrect,” and “who benefits from that knowledge.” In other words, the common thread among feminist researchers is their understanding that research must include an analysis of power relationships within the data as well and the research community itself. This is why feminist methods and action research share similar methodological histories.

Hesse-Biber et al. suggest that feminist interviewing stresses the importance of “accessing different voices” (p. 12). How one accesses these voices does not
necessarily matter. What is important is that “partial truths” are heard and considered valid, rather than an all-encompassing “Truth.” Taking this idea even further, *standpoint feminism* stresses starting any research project from the standpoint of the oppressed (Harding, 2004). The result is “knowledge that is produced for marginalized groups, rather than about marginalized groups” (Hesse-Biber et al., p. 16, emphasis mine). Different strains of feminist research contain intra-debates over the feminist project within research, but most agree that an inherent goal of their project is social change.

It is easy to find philosophical reflections on feminist research, but harder to find examples of how this philosophy actually informs interviewing. I imagine that the reasons for this are that researchers are not interested in telling other feminists how to do their own research. Interviewing itself has facilitated feminist research because in this way “learning from women is an antidote to centuries of ignoring women’s ideas altogether or having men speak for women” (Reinharz, 1992, p. 12). Similar to active interviewing, the line between interviewer and interviewee is blurred in feminist interviews. Reinhartz notes that the feminist interviewer is always conscious of their position within the interview (and the entire study itself). The interviewer is also aware of how research can exploit participants.

She observes several loosely connected properties arise from this position. First, feminists must describe their relationship to the participant—are they friends, strangers, neither, or both? Second, feminists reject the tactic of using “instruments” to “get the truth out” of people. Instead, believing the interviewee is important to doing feminist research. Anderson notes that a “more appropriate research strategy is to look not for the falsehoods of their claims, but to the actual conditions of the women’s lives and the
way those conditions might generate the contentment women express” (Andersen, 1981). Third, if the interviewee is to be believed, this means that researchers become learners and listeners rather than “experts.” This does not mean, however, that nursing researchers, for instance, cannot adopt the role of patient advocates, or that the interviewee cannot become the researcher’s advocate (Webb, 1984). Finally, feminist interviewing encourages multiple interviews with the same interviewee. One advantage of this approach is to share the interview transcripts or notes with the interviewee, then invite their analysis. Another advantage is to see how thoughts are situated within particular circumstances. Feminists are cognizant of the need to portray research as a collaboration rather than a closed-door process. This is important because interviews that replicate dominant power structures (rather than question them) are antithetical to feminist research.

Like many qualitative approaches, feminist researchers view the interview as a conversation and emphasize how the interviewer and the participant are involved in a mutual construction of meaning. In contrast to positivist interview strategies, feminists recognize that eliciting women’s accounts of their lived experiences is not as simple as getting them to talk. More than this, researchers require acknowledgement of how traditional sociological concepts actually distort women’s experiences (Devault, 1990; D. E. Smith, 1987). At the same time, sociologists doing feminist interviewing often insist on accurate representations of women or minorities in their research. In this way, I observe that the emphasis on “lived experience” becomes a slightly positivist position. For instance, saying that multiple interviews make data more accurate implies that ascertaining “truth” is still important, but that this truth is not necessarily generalizable to
other people because of the tenets of difference feminism. A feminist social researcher would qualify that the interview itself is only once slice of this reality, but feminists are obligated to portray this reality as accurately as possible because each individual person’s experience is true to them. In this critical dismantling of the interview setting, validity has come to be less equated with a single truth and more associated with partial truths, reflexivity, difference, and standpoint (Olesen, 2000; D. E. Smith, 1987, 1990).

Creating the Interview Guides

I used sensitizing concepts as a general source of guidance to craft questions in the interview guide (Appendix B). Sensitizing concepts are theoretical tools created by other researchers to better situate a class of data (van den Hoonaard, 1997). In this case, the class of data involves the embodied experiences of young women with disabilities, chronic illnesses, and skin conditions. At the time when I created the guides, I borrowed sensitizing concepts like good days/bad days from Charmaz (1991), the embodied self from Goffman (1959) and Charmaz (1995), critical consciousness from Freire (1970), embodied marginalization from Gibson, Young, Upshur, & McKeever (2007), and the liminal space of young womanhood from Bettis & Adams (2008). Their contributions to this interview guide are evident in questions like “How would you describe what it’s like to live with this disability/difference on a day-to-day basis?” and “What was it like growing up as a young girl?”

Sensitizing concepts changed as themes changed throughout the data collection. I revised the original interview guide after pilot testing it on the first five interviews. After the five interviews were analyzed, I re-tooled the questions to gather richer data. For example, I began the interviews with the concept of attitudinal violence established by Whittington-Walsh (2002). She found that women with facial differences were subjected
to a double colonizing gaze from medical institutions and the general public. While attitudinal violence in medical and public encounters was one salient theme of conversation, it only applied to women with visible physical differences. As data collection proceeded, the very real repercussions of violent social attitudes became apparent, culminating in a particular type of social disadvantage. For this reason, I chose to use the concept of embodied marginalization to further explore the way in which participants were excluded from the privileges of able-bodied society. Hence, I began to ask more political questions like “What obstacles has society placed on people with (disability/illness/condition), “have you encountered any of these obstacles in your own life?” and “what does the future hold for you as a woman with a (disability/illness/condition)?” This new question produced an entirely new conversation about the history of social exclusion for people with disabilities and the potential for changing policies and social attitudes.

**Analysis of Interview Data**

I analyzed the data using a loose adaptation of grounded theory coding developed by Charmaz (2006). All data were analyzed using QSR nVivo 9, a software program specifically designed for managing qualitative data. Coding is the primary method for moving from concrete statements to analytical interpretations by creating and developing abstractions from the data (Morse & Richards, 2002). Qualitative codes take segments of data apart and name them according to a number of theoretical categories. Grounded theory coding consists of three main phases: 1) an initial phase, involving naming each word, line or segment of data followed by 2) a focused phased, using the most significant or frequent initial codes to sort, synthesize, integrate, and organize large amounts of data, and 3) a theoretical phase that determines how the
codes from phase two relate to one another using an established theoretical orientation (Charmaz, 2006, p. 46).

In the initial coding phase, my goal was to construct codes and develop them into categories that crystalized participants’ experience. At first, I coded line-by-line so as not to become so immersed in my respondent’s worldview that I failed to see the subtext (i.e. the meaning-making at work in their minds). Codes were given tentative labels that were as close to the participant’s words as possible, such as “giving up on a cure,” and “not rocking the boat.” As I noticed similar experiences and patterns in the data, codes became slightly more abstract. At this point, categories or a loose coding framework began to develop. As more data was produced, I used the constant comparative process (Glaser & Strauss, 1967) to compare incidents across several different platforms: incident with incident, category with incident, and category with category. Eventually, as I conducted multiple interviews, I compared data in earlier and later interviews of the same individuals.

The focused coding phase continued the process of creating abstract codes, only this time I made decisions about categorization. Focused coding means “using the most significant and/or frequent earlier codes to sift through large amounts of data” to determine the relevance of the codes (Charmaz, 2006, p. 57). Hence, “giving up on a cure” was determined to be a relevant code because most participants went through a stage where their medicines to treat or “cure” their most debilitating symptoms had failed. I also made a decision about the relationship of this code to other talk about healing; therefore, I situated this code under “narratives of healing,” which was housed under a larger category, “cures, treatments, and therapies.”
Finally, in the theoretical coding stage (developed by Glaser, 1978), I began to code according to a coherent, analytic story, loosely structured around the Chapters of the dissertation. Charmaz calls these “coding families,” (p. 63) and here I began to make note of the structural order of participant’s lives and discovered their strategies for dealing with them. I also identified theoretical contributions in the literature that advance the understanding of body trouble for young women and their dialogues resisting social barriers. As such, I began to make note of how the data fit with symbolic interactionist, phenomenological, and critical pedagogical perspectives. While these three steps were my general coding roadmap, I admit that the process did not occur in linear, distinct phases. Instead, “the picture slowly emerged as a patchwork mosaic” (Dey, 2003, p. 86).

**Overview of Public Testimonials**

Participants wanted to speak publicly about their lives; hence, I call this portion of the project “public testimonials.” The idea of public testimonials came out of the first group interview. Public testimonials are one form of action research that attempts to resist the patriarchal construction of reality. They were first evaluated by Angueira (1988) as a consciousness-raising tool against sexual assault in Puerto Rico:

Testimony, oral or written, requires intrinsic contact with a woman’s perception of her own reality. The collecting of raw evidence from the original source permits social actors to formulate categories that enable them to name and create symbolic representations from their own perspective, thus allowing outsiders to understand the construction of reality of those who experienced the event. Testimony provides women with a key that can unlock the heavy vault of silence that has so effectively smothered emotions ignited by the oppression of sexual politics (p. 69).

Their proximity to the experience allows individuals giving testimony to name the problem, control the discourse, and exercise their right to establish a dialogue with their
own reality. This process recuperates their voice and publicizes a perspective typically restricted to the private sphere. In other words, public testimonials make the personal the political. Chapter 7 details the findings from the group interviews. Public testimonials are but one method under the umbrella of action research.

The decision to use public testimonials changed the type of knowledge produced. The project moved from producing practical to emancipatory knowledge. These are two different forms of knowledge generation as defined by Habermas (1981). Table 4-3 distinguishes between the researcher’s interests, type of knowledge produced, and a corresponding research methodology. Practical interests will not incite “revolutionary” change for participants or society. Instead, such interests seek to understand the world through interpretation and generate knowledge that informs how people make judgments about the world. Emancipatory interests will not unreflectively reproduce current practices or traditions; instead, researchers problematize the traditions that make everyday oppression acceptable. The choice in study design assumes that participants have the potential to become empowered through the research—although I cannot say with certainty whether that actually happened. I can confidently state, however, that the intent of the research is both practical and emancipatory: practical in the sense that the primary focus is on the embodied experiences of young women, and emancipatory in the sense that the intended goal is liberation from those gendered, ableist meanings that silence “outsider” ways of living and knowing the body. This goal leads me to a discussion of one type of method to achieve this goal, what some call “participatory action research,” “cooperative inquiry,” or simply, “action research.”
Methodological Stance on Action Research

Since action research is relatively new to sociology, I feel the need to give an overview of the history of its development. Action research (AR) is inquiry that is done with insiders to a community. AR involves some action that community members have taken, are taking, or wish to take to address a particular problematic situation (Herr & Anderson, 2005). McTaggert (1997) identifies action research as a collaborative, reflexive method for emancipation. It aims to release people from the constraints embedded in the “social media” in which they interact—language, modes of work, social relationships of power, difference, inclusion, and exclusion. In AR, people deliberately set out to “contest and reconstitute irrational, unproductive, unjust, or alienating ways of describing their world” (p. 567). A variety of definitions of action research exist. Social psychologist Lewin (1946) coined the term “action research” as proceeding in a spiral of steps, moving from planning, acting, observing, and evaluating the results. A group decides to work together on a “thematic concern” (Kemmis & McTaggart, 1988) to make improvements in society. Some researchers take a more “personal is political” stance; Smith (1997) says that AR is about “personal and social transformation for liberation.” In this vein, scholars who use AR (Shrestha, 2003; Wallerstein & Bernstein, 1988) note the connection between Paulo Freire’s (1970) theory of pedagogical liberation that consists of “listening-dialogue-action” cycles to help members reveal their values, gain local insights, and develop leadership abilities. AR’s methodology follows the cycle of “analysis-action-reflection” (Purdey, Adhikari, Robinson, & Cox, 1994). Hence, AR purports that through reflection on their own lives, participants can decide on an action that they feel could bring about change.
AR also defers “control” of the research to the participants to create a partnership. Greenwood et al. (1993) remark on “expert research,” in which the former “authority and execution of research is controlled by the researcher.” In AR, though, authority over and execution of the research is highly collaborative between expert researchers and members of the community under study (p. 176). They see AR as comprised of three core tenets: collaboration, incorporation of local knowledge, and eclecticism and diversity. Scherer (1993) clarifies what AR is not: “it is not a heuristic approach or license for a ‘fishing expedition’” (p. 3). I take this to mean that AR is a structured research activity that allows participants to set their own goals, tell their own stories, and decide on their own course of action. AR also (potentially) reconciles the problematic nature of researcher and researched. Collet (2008) asserts the “democratization of knowledge” is an inherent component of AR, so that knowledge is not exclusively the domain of universities. He also remarks that AR “breaks down one of the most rigid factors separating communities from researchers, namely the perception and fear that the community will be (once again) ‘used’ for research purposes, without receiving any real or tangible benefit” (p. 9). For these reasons, AR has been best applied in the service of marginalized groups who are located in a hegemonic world that silences their voices.

The popularity of AR forces more precise definitions. McTaggart is careful to distinguish between “participation” and “involvement,” where the former must result in ownership over the project. She says that “mere involvement…creates the risk of co-option and exploitation of people in the realization of the plans of others” (p. 28). For this reason, researchers insist that AR is an unambiguous method. There is no “AR-lite.”
Qualitative researchers, especially mixed-methods folks, might question the reasons for such catholicism around particular method. Yet I understand the concern when methods themselves are given social meaning. That is, the methodological “turns” in social science and medicine are swinging toward AR as a “desirable” method for studying health in community contexts. Allowing loose attempts at this method can weaken its transformative power when conducted in its purest form.

McTaggert goes on to explain that community programs may “involve” participants, but they do not share the way research is conceptualized, practiced, and brought to bear on the life-world (p. 28). McTaggert’s definition of AR goes further than other definitions that I have seen. She says that AR is not about forcing dramatic social change through research—it is about “thinking globally and acting locally:”

Changing a whole society and culture is...beyond the reach of individuals; in [AR], groups work together to change their language, modes of action, and social relationships, thus, in their own ways, prefigure, foreshadow, and provoke changes in the broader fabric of interactions that characterize our society and culture. In other words, [AR] has individual and collective and local and extended aspects: individual action researchers change themselves, support others in their own efforts to change, and together work to change institutions and society (p. 34).

Social change through individual change is the goal here. For example, Cancian (1989) organized a group of ten academic women with children to discuss the problems of combining career and family and to consider solutions. She notes that while their meetings did not radically change the institutional culture in her department, they did foster a sense of personal change that spread through members of the group. The group’s “discussions of whether to take action revealed how internalized oppression works, i.e. how fear, self-blame, and an ideology of individual achievement maintain the status quo” (Reinharz, 1992).
Feminist research closely overlaps with AR. In the crudest sense, AR is feminist in that it is predicated on consciousness-raising. Olesen (2000) explains how action research looks when it involves women: “In activist studies, researchers and participants collaborate to enable women to do research for themselves and on topics of concern in their lives. In customary research the researcher frames interpretations; in action research, researchers and participants undertake this task” (p. 234). In feminist research, theory and method are constitutive of each other, meaning that feminist theory is embedded in research designs, interpretations, and uses of the research results (Dyck, 1993; Moss, 2006; Wolf, 1996). Denzin and Lincoln (2000) distinguish feminist research from other approaches by its theoretical concerns of lived experience, accountability, praxis, emotion, and standpoint. This leads to the essays, stories, experimental writing, and visual types of narration. AR encourages creative methods because its theoretical energy is heavily invested in personal location.

Any activist project that touts emancipation is not without ethical concerns. Danieli & Woodhams (2005) question the “emancipatory paradigm” in disability research. They worry that emancipatory research has become too hegemonic, where a small group of elite disability scholars stipulate how disability research must be conducted. In this way, they argue, emancipatory research is not a radical departure from positivism because it requires researchers to adopt theoretical lenses created by scholars (like the social model of disability). Similar to Oliver (1990, 1996a, 1996b), Danieli & Woodhams argue that research can only be judged “emancipatory” after the event. The “empowerment assumption” relates back to the concerns raised by Wendell (1996), in which feminist research must constantly position women as agents over their
own bodies. A valorization of resistance and empowerment—used simply to avoid seeing
women as victims—plays out in feminist research designs. I attempted to lessen this
tendency toward reductionism by recognizing that women’s lives are more dialectical
and contradictory than simple tales of resistance vs. oppression (which is why symbolic
interactionist theories are useful in AR).

**Defining the Community and Partnership**

An AR dissertation must describe the *community*. Who are they? How does a
community define itself? How did it form, who are its members, and what was their
involvement throughout the study? The community’s creation, membership, focus, and
involvement in an AR study is typically clear and precise, and its partnership with the
researcher and its influence on research design are observable. The community’s role
in defining itself and directing the research comprises the core of AR. I will attempt to
describe the qualities of the “community” and “partnership” involved in this study with
awareness that my research has limitations that prevent it from fully achieving the goals
the community defined.

I will address a few points about the creation of the research community that
steered the direction of this project. In selecting participants for this interview, I chose
those who had similar stories and struggles—and by “struggles” I mean social obstacles
in which the notion of “body trouble” was most endemic and socially regulated. This is
why I excluded women with skin conditions from this phase of the research—according
to their interviews, they were bullied less in childhood, their bodies were less intensely
monitored by authority figures, and their access to the community was not curtailed. For
these reasons I chose to include women with disabilities and chronic illnesses as
participants in the group interviews and public testimonials. Because they had been
pathologized so frequently in their lives, resisting mistaken ideas about disability required intervention.

I began to think of a community by identifying key individuals and relevant organizations that serve people with disabilities. I met with Lovetta Smith, a woman who worked for the Center for Independent Living of North Central Florida. She informed me about the diversity of community members that her organization serves, and that having a disability is not a requirement to use their services. She helped me with recruitment and offered her space at the Center for conducting the group interviews. Ms. Smith also expressed an interest in my study and encouraged me to pursue this research because the need for women to form community ties was important to their success in life. But a community group for young women with disabilities did not yet exist. Therefore, I had to create one. Unfortunately, this necessity created a power imbalance that strained my abilities to keep AR in the control of the community throughout all stages of the research.

With such diversity around disability and illness, I gambled that two identities—age and gender—combined with impairment, might unite the group into a mini-community inside the walls of the university. While I did not necessarily lack preexisting community ties (the interviews helped greatly in establishing them), I had to assert my privilege as a researcher to bring the women together. Hence, I began the first group interview with an icebreaker. I asked the four participants to bring a picture featuring them so that they could start the interview with a unique introduction to the group. This icebreaker was designed to bring everyone together on the “same page.” It was
inspiring to see how other participants commented on others’ pictures with verbal “high fives” and words of encouragement. I analyze this incident further in Chapter 7.

Another way that I directed the research was in the delivery of “my analysis” of findings from the interviews, after which I forced a question on them: “what do we do about all of this?” While the community was artificially created and its entry was limited to a select number of highly motivated participants, the use of testimonials was the first time I felt that the study was truly a collaborative effort. Before the group interviews, I felt that I could not relinquish control of the research because, who would I hand it to? No community existed to direct it. My dilemma of community formation is typical of most AR research dissertations, in which “doctoral students seldom have the time or money to make the dissertation a lifetime project” (Herr & Anderson, 2005, p. 111; Oliver, 1996b).

Despite the limited collaboration in methods throughout every stage, I noted evidence of a partnership even before the testimonials began. Mainly, the group interviews fostered collaboration by creating a “participatory structure,” in which the research was educative for all parties and stimulated a sharper analysis of phenomena going forward. In other words, the group interviews produced outcome validity. Rather than simply solving a problem, outcome validity forces the researcher to reframe the problem in a more complex way, often leading to a new set of questions or problems (Herr & Anderson, 2005). This reframing creates a “spiraling dynamic” (idib) of questions that lead to closer partnership ties. For example, when I reported findings in the group interview, participants provided contextual data to help explain the interview findings. Moreover, the questions related body image and stigma in the original
interview guides were not compelling modes of action for the participants; access to equal employment opportunities, community mobility services, and paternalism in medicine was more important to them.

**Researcher Positionality**

As Herr and Anderson (2005) observe, when discussing positionality, or the relationship of the researcher to the researched, “the notion of insider and outsider is often a matter of degree” (p. 38). The degrees are necessary to pinpoint since complete objectivism in research is an illusion (Habermas 1971). In this section I will briefly discuss how I think my position as a white, heterosexual, able-bodied woman, academic, and former care worker influenced the research process. After ten years as a student of sociology, I have learned how to reflect on my own privilege in necessary ways; however, I cannot reveal a complete picture of how all of these identities were continually negotiated as the research took shape. The writing on this subject is never “done.”

I began thinking about my own position as a researcher by tossing around words for “health.” I realized that we have many words for people who have been “marked” by illness: sick, diseased, unhealthy, malaise, cripple, invalid. But “healthy” is the singular word opposing the rest. We are more apt to talk about the mediators (e.g. lifestyle, risk factors) than to deconstruct the meaning of “health” or create synonyms for it. Because it is so hidden yet so overt in our culture, health is a word laden with hegemony. Mortality confirms that “health” is fragile and illusory throughout our lives, yet for many able-bodied people, “healthy” operates like a master status in their minds. Perhaps I could say that I do not meet the inclusion criteria for my own study? However, this rather procedural point reveals nothing about my own experiences with my body that
might, in some small way, connect me to my participants. Moreover, some chronically ill people are “healthy” by managing their illness, some people are cured of their ailments, and concerns for health are irrelevant for many disabilities. My body fits into a simplified category of “able-bodied,” or “not-ill,” but I also firmly believe that these states are culturally maintained and temporary.

Consequently, the first identity I must explore is my own able-bodiedness. I knew from the beginning of the research that I would be tackling this topic as an outsider. This identity created a distance between me and the participants (which was not unexpected). Participants never asked me if I was disabled or had a chronic illness, probably because it was fairly obvious they were talking to an able-bodied person. After the interviews were over, however, I confirmed their suspicions, and told my story of how I came to be interested in this topic. As I began to gain participant trust after the group and follow-up interviews, they stressed that no amount of research would lead to a fuller understanding of “what it’s like” for them. For example, Saundra and I formed a bond that extended beyond the normal participant-interviewer relationship. I visited her apartment where she showed me her ROTC memorabilia. Afterward, we had lunch together, and I transported her to the grocery store. At one point during the process of getting to know one another, Saundra said to me: “You will never experience what I experience…You will never know what it’s like for Darcy or Ericka. You will never have [cerebral palsy].” It was such a simple statement, but its truth made me re-think my assumptions. I learned in my studies that disability was a minority group that everyone will join at some point in their lives (Shapiro, 1993). Yet despite my eventual disablement, Saundra and I were separated by body and time. Most certainly I would
never know what it was like to be a *young woman* with a disability, in addition to a young girl. Saundra had lived with her disability since birth, just like the other women she had named. By the time I will experience disablement, I will be filtering it through my lens as an older person *who was once able-bodied*. Indeed, no amount of research could capture participant experiences as “truth.” This project, therefore, comes with a disclaimer: even if I attempt to get as close to their truth as possible (even if I am an empathetic, reflexive researcher) my interpretations flow from an able-bodied, outsider perspective.

In writing my analysis I worried that my outsider status may have caused me to slip into cultural assumptions about disability. In deciding what theory to advance, I forced myself to recognize that “body trouble” may seem like I am framing disability as something sad, lacking, tragic, or undesirable. Rather than saying that the body *is* troubled, however, I mean to say that culture forces the disabled body into a deviant position, and this *deviancy* is what is troubling. Moreover, able-bodied people are troubled as well: troubled by the state’s control over women’s bodies, troubled by the violence inflicted on bodies that do not conform to gender or sexual norms, and troubled by the constant need to slavishly discipline the fat body. Hence, much like Judith Butler’s *Gender Trouble* (1990), body trouble comes from the constructs of normality and the constraints on what is “not normal.” Disability activist Mia Mingus (2010) identifies this strategy as necessary for moving disability politics into the twenty-first century:

As organizers, we need to think of access with an understanding of disability justice, moving away from an equality-based model of sameness and “we are just like you” to a model of disability that embraces difference, confronts privilege and challenges what is considered “normal” on every
We don’t want to simply join the ranks of the privileged; we want to dismantle those ranks and the systems that maintain them.

For this reason, Danieli and Woodhams urge disability researchers to conduct research that emancipates both disabled and able-bodied. We need a theory of disability for “the liberation of both disabled and able-bodied people, since the theory of disability is also the theory of the oppression of the body by a society and its culture” (Wendell, 1989, p. 104). The present research challenges the able/disabled dualism by interviewing women with a variety of frames for contesting body oppression. This is why I believe my own outsider status is sometimes useful. With it I can explore the contours of ableism and act as an able-bodied ally.

Because it shifted frequently, my insider status is much more complex than my outsider status. All of us were young, white, heterosexual, college-educated women. These became points of connection that allowed us to understand one another in small ways: the eyes that rolled whenever we talked about bad boyfriends, the difficulties of a stressful study week, and the blessings of parents who loved us unconditionally. Our identities as women were also sources for connection. In the future, however, I intend to open up this group to more diversity to include older folks, men, people of color, and queer people as well.

I consider my two-year job as a personal assistant for a woman with Duchenne muscular dystrophy a status with multiple positions, both insider and outsider. I was a personal assistant for “Babette” during the time I was conducting this research.2 In that capacity, I was an insider in terms of the daily life of a working disabled woman. I was involved in “body work,” which Twigg (2000) defines as direct, hands-on activities,

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2 Babette is a pseudonym
handling, assessing, and manipulating bodies. I worked alongside her at her job, preparing her lunch, shifting her body in her wheelchair, making her tea, helping her take her medicine, and adjusting her clothing. "Meggan is my hands and feet," she would say. I was tickled to think of myself as an assistive device: my body was part of her body. We were connected in such a way that I was her autonomy. Babette’s workplace paid for a personal assistant, which lessened the distress of asking for help all the time. Galvin (2004) shows how relying on the goodwill of others places people with disabilities in a state of constant gratitude. As her paid assistant, gratitude did not figure oppressively in our relationship.

Though this experience was overwhelmingly positive, I do not mean to romanticize our relationship and deny the politics therein. I was part of a paid, formal care arrangement—an advantage that is denied to most people with disabilities who rely on informal family care networks. As her “research assistant” and sometimes her “personal care assistant at work,” I was embroiled in the politics of care work, but less so than if I were helping her bathe or dress. In comparison to other personal assistants, I consider myself an outsider to their particular brand of at-home care work. Most body work for people with disabilities is “ambivalently positioned in relation to power, caught in dynamics that can tip either way” (Twigg, Wolkowitz, Cohen, & Nettleton, 2011, p. 4). Furthermore, as her hands and feet, I was a social marker, positioned at the boundary between independent adulthood and the way that children are “helped.” But my experience as Babette’s personal assistant does not make me a complete insider into the world of disability: if anything, it makes the positionality more complex. Since we had different levels of connection (mentor/mentee, friend/friend, research assistant/boss,
care worker/person being cared for), our relationship defies the easy dichotomy of insider/outsider.

A researcher herself, Babette was my mentor and inspiration throughout this project. She let me peak into her library filled with wondrous books on disability. One book that galvanized my thinking was Living in the State of Stuck (Scherer, 2005), a research study on the experiences of people with spinal cord injuries. I made a mental note that people with spinal cord injuries (whom I had interviewed prior to this project) rejected the wheelchair and desperately wanted to return to their “walking selves.” I became fascinated with the idea that bodies could become known to us in radically different ways depending on the time of disability. I mentally compared this experience to Babette, who has never walked. While she happily well-adjusted, she confronted obstacles: the good/bad days of her health, managing a full-time job, caring for ailing parents with their own disabilities, confronting discrimination in her early years of college, and being used as a political token for interest groups. I wanted to know more about the experiences of both people—women like Babette, and people with spinal cord injuries—especially those who were my age (under 30).

Eventually I observed how women like Babette were absent from my feminist education. I wondered why feminism had not included her perspective, and if it did, why it was usually framed in a medical context. Gill (1997) calls women with disabilities “the last sisters.” By using the word “last,” does this mean they are the most remote from common understandings of life? That they are last to be researched, and the last to gain full civil rights? Does “last sisters” also imply that they have been left out of social movements that aim to end oppression in all people’s lives? I interpret that “last”
to mean that women with disabilities are rarely thought about. I certainly did not study them in any of my sociology or women’s studies classes. Even the phrase “women with disabilities” was new to my lexicon—I had assumed that “disabled women” would suffice. But after much self-education, and entering disability studies without much guidance, I can confidently say that the gaps in my knowledge are not a fault of my own. They are a fault of an education that did not prepare me to include “disability” as a socio-relational category of oppression. These gaps are also the fault of a society that assumes disabled women are a minority and hence best forgotten. This dissertation is an attempt to understand why women with disabilities and chronic illnesses are neglected, to document the consequences for that neglect, and to somehow rectify the (for lack of a better term) “blind spots” in this important cultural understanding of the body.
Table 4-1. Description of participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Condition</th>
<th>Major/Occupation</th>
<th>Race</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angelique</td>
<td>20</td>
<td>Acne</td>
<td>physiology major</td>
<td>Black</td>
<td>Haitian</td>
</tr>
<tr>
<td>Josephine</td>
<td>19</td>
<td>Vitiligo</td>
<td>exercise</td>
<td>Other</td>
<td>Palestinian</td>
</tr>
<tr>
<td>Kirsty</td>
<td>23</td>
<td>port wine stain</td>
<td>English</td>
<td>White</td>
<td>N/A</td>
</tr>
<tr>
<td>Leslie</td>
<td>19</td>
<td>Mole</td>
<td>business major</td>
<td>White</td>
<td>N/A</td>
</tr>
<tr>
<td>Kokoro</td>
<td>19</td>
<td>Acne</td>
<td>art major</td>
<td>Other</td>
<td>Caucasian/</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Japanese</td>
</tr>
<tr>
<td>Nela</td>
<td>22</td>
<td>Acne</td>
<td>journalism major</td>
<td>White</td>
<td>N/A</td>
</tr>
<tr>
<td>Sylvie</td>
<td>20</td>
<td>nose infection</td>
<td>psychology major</td>
<td>Black</td>
<td>Haitian</td>
</tr>
<tr>
<td>Alissa</td>
<td>20</td>
<td>missing bones</td>
<td>film/media major</td>
<td>White</td>
<td>N/A</td>
</tr>
<tr>
<td>Tammy</td>
<td>21</td>
<td>spina bifida occulta; gait disorder; cerebral palsy</td>
<td>criminology major</td>
<td>White</td>
<td>N/A</td>
</tr>
<tr>
<td>Paula</td>
<td>G,M,P</td>
<td>19</td>
<td>paroxymal dyskinesia</td>
<td>physiology major</td>
<td>White</td>
</tr>
<tr>
<td>Ericka</td>
<td>G,M,P</td>
<td>29</td>
<td>Ataxia</td>
<td>sociology major</td>
<td>White</td>
</tr>
<tr>
<td>Julianne</td>
<td>M</td>
<td>crohn's disease; ulcerative colitis</td>
<td>criminal justice major</td>
<td>White</td>
<td>N/A</td>
</tr>
<tr>
<td>Saundra</td>
<td>G,P</td>
<td>25</td>
<td>ataxia/cerebral palsy</td>
<td>English</td>
<td>White</td>
</tr>
<tr>
<td>Carmella</td>
<td>19</td>
<td>undiagnosed, seizure-like condition</td>
<td>nursing major</td>
<td>White</td>
<td>N/A</td>
</tr>
<tr>
<td>Darcy</td>
<td>G</td>
<td>spina bifida; hydrocephalus</td>
<td>business</td>
<td>White</td>
<td>N/A</td>
</tr>
<tr>
<td>Emelia</td>
<td>M,P</td>
<td>21</td>
<td>congenital hand</td>
<td>physiology major</td>
<td>Asian</td>
</tr>
<tr>
<td>Brinn</td>
<td></td>
<td>Lupus</td>
<td>history major</td>
<td>White</td>
<td>Cuban</td>
</tr>
<tr>
<td>Myra</td>
<td>28</td>
<td>mobius syndrome</td>
<td>nurse's assistant</td>
<td>White</td>
<td>N/A</td>
</tr>
<tr>
<td>Janet</td>
<td>18</td>
<td>cerebral palsy</td>
<td>High school student</td>
<td>White</td>
<td>N/A</td>
</tr>
<tr>
<td>Kim</td>
<td>29</td>
<td>Fibromyalgia</td>
<td>education major/waitress</td>
<td>White</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Note: “G” participated in group interview(s), “M” participated in more than one individual interview, “P” participated in public testimonials

Table 4-2. Stages of data collection and interview types

<table>
<thead>
<tr>
<th>Stage</th>
<th>Interview Type</th>
<th>Purpose</th>
<th>Follow-Up</th>
<th>Group</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Individual</td>
<td>Exploratory: To explore major issues and priorities; to determine best sample for group interview</td>
<td>To confirm theoretical development of concepts with individual participants; to follow-up with them after surgery or treatments</td>
<td>Consciousness raising: To report findings from group interviews; discuss findings, and strategize plan of action for solving common issues</td>
<td>Survey and strategy: To solicit feedback on success or failure after each public testimony and to plan strategies for next session</td>
</tr>
<tr>
<td>2</td>
<td>Group</td>
<td>Members of group interview</td>
<td>Members of individual interviews</td>
<td>Members of individual interviews</td>
<td>Members of group interview</td>
</tr>
</tbody>
</table>

Recruitment Method: Flyers or other participants

Formal Interview Guide? Yes

Time: 1-2 hours
Table 4-2. Continued

<table>
<thead>
<tr>
<th>Stage</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview Type</td>
<td>Individual</td>
<td>Follow-Up</td>
</tr>
<tr>
<td>Number of Interviews</td>
<td>20 interviews</td>
<td>4 interviews</td>
</tr>
<tr>
<td>Total Number of Interviews Analyzed</td>
<td>28</td>
<td></td>
</tr>
<tr>
<td>Total Number of Participants</td>
<td>20</td>
<td></td>
</tr>
</tbody>
</table>

Table 4-3. Continuum of intentionality based on Habermas’ knowledge interests

<table>
<thead>
<tr>
<th>Knowledge Interest</th>
<th>Research Aims</th>
<th>Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practical/communicative</td>
<td>Illumination of understandings of participants</td>
<td>Textual, conversation, discourse analysis</td>
</tr>
<tr>
<td>Emancipatory</td>
<td>Critical reflection–how understandings are constrained or distorted by power relations</td>
<td>Any method that forms part of a cycle of ongoing critical reflection</td>
</tr>
</tbody>
</table>

Note: Table adapted from Herr and Anderson, 2005
CHAPTER 5
CREATING BODY TROUBLE: DIFFERENCE AND DISABLEMENT

Michael Oliver, proponent of the social model of disability, argues that “disability is wholly and exclusively social…disablement is nothing to do with the body” (1996b, p. 41-42). To add depth to his argument, I orient this Chapter around a question: how is disability lodged in society and not within us? By attending to the ways in which young women interact with medical and social institutions, I aim to reveal how culture assigns social significance to bodies by elevating their differences. First I tackle the medical system, which occupies a central position in the lives of the participants as an arbiter of status, legitimacy, moral responsibility, and illness identity. Here I show how the body becomes socially significant as the medical model classifies human conditions, experiences, and diseases. Participants often depended on the medical model for interpretations of their own bodies. This finding had two consequences: biomedicine helped manage the uncertainty of the condition or worked to downplay a layman’s knowledge of the body.

From a discussion on the medical system I move on to other systems of control, namely, education and workplace institutions. Participant narratives cannot definitely document all aspects of stigma and marginality maintenance in these institutions (an ethnography would be better suited for that). However, the structures that the participants live under are seen through their eyes. Education, social networks, employment, and everyday conversation created barriers between people, furthering the marginal status of those who lack power to organize through a minority status. I examine how this marginality impacts young women’s sense of self and visions for their
future. I conclude with a discussion on how difference is created under the social model and how it affected the women in this study.

Creating Difference through Medical Power

This section is a meditation on medical power in the lives of young women. First I highlight data that revealed stories of “first contact” with the medical world: the diagnosis (or lack thereof). Data suggest that diagnosis is a particularly critical turning point for participants confronting illnesses in young adulthood. Next, I discuss participants beliefs about their own medical expertise and values of self-care. Following that I discuss the difficulties of translation; namely, how participants struggled to convey their suffering to doctors and others. Finally, participants reveal how their lives are affected by state and corporate policies that have real consequences for the quality of medical care they receive. I situate these narratives within a balance of power that is shifting away from professionals and tilting toward the “consumers” of care (Turner, 1987).

Interviewing a diverse group of women creates a thorny problem when trying to cohesively discuss their medical encounters. No two participants shared the same experience with doctors, treatments, therapies, medical products, diagnoses; nor did they share the same attitudes about these experiences. The differences in experiences and attitudes can be partially explained by age at which the condition developed. Some participants had experienced bodily disruption as children, so that by the time I interviewed them they were confident enough in medical settings to be their own patient-advocates. Darcy, for example, frequently visited her doctors to monitor her spina bifida (which was discovered at an early age) and reflected positively about her care. Others, such as women with chronic illnesses, struggled with the moral management of their illnesses or their sick role status. A big theme in Carmella and
Julianne’s interviews was their frustration with diagnoses and a paternalistic tone that doctors assumed when discussing their health behavior. Medical encounters were minimally important for women with skin conditions. Parents tended to play a larger role in monitoring their daughter’s skin than dermatologists. Despite these variations, all participants spoke of at least one medical encounter concerning their conditions. I took this as evidence that they (or their parents) required some type of regulatory guide, expert wisdom, or official affirmation that their illness or condition could be calmed and controlled by science.

**Diagnosis Troubles and Biomedicalization**

Data suggests that medical diagnosis is a political process in which patient and doctor attempt to come to a common understanding about the causes, or etiology, of illness. To talk about the infinite ways that doctors and patients can be in conflict, Turner offers a continuum. On one side is the patient’s attempt to get “better” before the doctor is adequately convinced that health has been restored. On the other side sits a situation in which the patient stays “sick” but the doctor believes a new drug or therapy might help manage the illness (p. 47). Because they lived with various incurable conditions, participants with disabilities or illnesses spoke of conflicts that involved the latter point on the continuum.

Paula and Carmella, both of whom had faced chronic illness recently in their lives, experienced the greatest conflict with their doctors over a diagnosis. Both women describe doctors who were baffled by their illnesses that involved violent muscle spasms without a perceivable organic cause. The number of referrals kept piling up as they were transferred from one neurologist to the next. Carmella understood why doctors did not want to take her as their patient. She was marked as “abnormal” not
because she was ill, but because she presented an illness when her body appeared normal under the scrutiny of internal medical testing:

I don’t have a diagnosis…I mean I can say it’s a seizure, I can say it’s a migraine variant, because I get migraine headaches sometimes. The thing that makes it different than which I had trouble understanding at first is that there is no electrical EEG activity in my brain, it’s abnormal, so it’s obviously not a seizure. If it’s a migraine it has to be on one side as the definition. It’s on both sides for me. So I was discounted, and I was told I had psychological problems. That I need to see a psychiatrist, because clearly because we can’t test for it, it has to be fake, so you know it was like, maybe it was a conversion disorder or something.

At one point Carmella was “tested” using a very nontraditional method. One doctor purposefully upset her to see if she would present the seizure-like symptoms. She interpreted this tactic in a positive way:

They had to make me upset and cry. They had to see if it was psychological, because they didn’t know what it is. So I mean they had to, that’s their job. Because sometimes they induce an episode themselves because they’re upset. They were trying to see if they could get me upset enough if an episode could occur. And I understand it now. It was important. If they didn’t do that, they wouldn’t be doing their full job as a doctor.

At first she was shocked at the possibility that it was “all in her head.” Eventually, she normalized experiences like the one above as part of her diagnosis process. Carmella gradually learned to incorporate the possibilities of a psychological cause for her seizure-like symptoms. The suggestion that Carmella’s illness was the result of “psychological problems” relates to Western medicine’s privileging a mind/body dualism over the holistic, lived body. That is, if the body shows no signs of illness, then the cause must be non-physical and psychological. A middle ground between the two—psychosomatic illnesses—was not explored by doctors.

My own observations during one particular seizure-like episode helped me understand how Camella’s life was affected by her symptoms (no matter their origins).
As her professor I witnessed her “jerking” episodes in my class. She needed to lie down as I held her head to prevent it from hitting the concrete floor. Carmella was clearly suffering from the trauma of her jerking symptoms, its unknown causes, and doctors who could only talk to her in physical/psychological dualisms. Undiagnosed and undercut, she fought for recognition and entry into the sick role:

[For] people who are undiagnosed it’s more of a struggle because you’re just discounted so much and you just have so many people telling you you’re wrong, you don’t know what you’re talking about. And just completely just discounting anything you say that’s not happening, this is happening, you’re confused. It is really annoying. And I don’t get that so much now because I’m clearly awake and it won’t be so much of a struggle for them to believe me but it’s like, you’re pushed down so much when you’re sick, so it’s like you need therapy for the doctors alone.

She preferred doctors who admit that they “don’t know everything.” I assume that she appreciates this gesture because it transfers the burden of proof away from her and back to the doctors, who must do the complicated guesswork of diagnosis. Even if they do not arrive at one, doctors who are willing to admit error and ignorance in good faith are preferred. Most importantly she wanted a doctor who believes that her pain and discomfort are “real.”

At the time of our interview, Carmella had come to peace with this “non-diagnosis.” She said that a diagnosis did not matter so much after doctors reassured her that her illness was not life threatening. Carmella chose to “let go” of the need for a name and title for her condition: “You don’t have to identify it because it’s probably unidentifiable,” she said, “it doesn’t even matter at this point if [the illness is] psychological or not.” Exhausted from the repetition of trying to convince others that her illness was real, Carmella downplayed the importance of diagnosis and preferred techniques to help her manage the illness in her daily life.
Like Carmella, Paula encountered difficulties in the beginning stages of her care. She also had an illness that was difficult to diagnose. She described her symptoms as muscle spasms in her shoulders and arms that lasted for hours, leaving her exhausted afterward. Eventually, Paula reached a diagnosis, but the story of its discovery is interesting:

I was in an [Advanced Placement Biology] class and one of our projects was to write a ten page paper on something…and I kind of went through and tried to diagnose myself with all my symptoms. So, I came up with, like the full diagnosis. Paroxysmal dyskinesia with Dystonia, dystonic and chorathitonic symptoms.

Frustrated that her doctors could not figure out what was going on, Paula showed her research to her doctor, who confirmed her diagnosis. I asked Paula how she felt now that she finally had a name for her illness. She replied that she “really didn’t feel much of anything” because the diagnosis, for her, did not open the way for a cure. “Doctors still don’t know what to do with it,” she remarked. More than anything, she hoped for relief from the strength of the painful spasms that impacted her sleeping.

I asked Paula a follow-up question about the relationship between doctor and patient. I wanted to know what type of doctor-patient relationship she preferred in light of the uncertainty and rarity of her neurological disorder. Her thoughts were similar to Carmella’s point about doctors’ humility:

The [doctors] that I really like are the ones that are honest and they’re willing to let down their ego basically, and say “I don’t know what you have, but I’m willing to work with it.” But then you get the doctors who always have to be right and always have to say something and it doesn’t work, which has happened. They put me on a medication, which wasn’t for what I had but they just wanted to say something…Because the problem with some of these neurologists is that they don’t admit that they don’t know. So they try to make something up.
She said she thinks this “ego” did lead to a “bit of misdiagnosis” in the beginning of her visits. To counter this atmosphere she had her parents in the room during doctor’s visits. Doctor “ego” frequently emerged in participant narratives. Participants appreciated it when doctors experimented with different treatments and medications with them as a partner, but finding such a doctor was not easy. The distance between Paula and her first handful of doctors was stark: the first five neurologists that she visited gave their assessments without examining her. She said she still visits her childhood pediatrician because this doctor has disabilities of her own. Paula appreciated this characteristic. Her doctor could empathize because “she’s been there,” and “she knows me inside and out.” Three out of the 20 women stayed with pediatricians or family doctors as their primary care providers, suggesting that intimate physician familiarity was important to them.

For Julianne, an early diagnosis—a combination of Crohn’s disease and ulcerative colitis with various complications from both since childhood—did not necessarily make the classification more certain. When she was 8 years old she was diagnosed with ulcerative colitis. Twenty years later doctors changed the diagnosis to Crohn’s disease after she had her colon removed. At that point she took a blood test which found that she had 90% of the antibodies for Crohn’s and 80% of the antibodies for colitis. Her current gastroenterologist insisted on the Crohn’s diagnosis, but Julianne disagreed with him and chose to see herself as having both conditions. She spoke about this conflict as a negotiation of boundaries between the doctor’s knowledge and her own:

He’s been around a long time and he knows what’s going on. So I can understand the attitude that he has when he has a little 28 year old girl come in and say, hey, I know you’re my doctor and everything, but I’m going to tell you what I need because that’s how I do it. I’ll go into the
doctor’s office, because I’ve been doing this for twenty years myself, so I know my own body. Maybe I didn’t go to medical school, but I’ve experienced it so much that maybe I should. It’s funny because we may both have conflicting opinions and we’re both pretty head strong. But it’s good because opens up discussion.

Julianne respected these discussions because the doctors’ expertise did not override her own. She was allowed to keep her version of her diagnosis, which did not necessarily interfere with her treatment.

Paula, Carmella, and Julianne’s troublesome diagnosis process showcased a biomedical illness identity that alternated between certainty and uncertainty. The three women were not passive participants in their own diagnosis, as illustrated by Paula’s self-diagnosis, Carmella’s coping, and Julianne’s chosen diagnosis. The conflicts they confronted in the diagnosis process follows Sulik’s (2009) observation that many conditions do not fit well within the biomedical framework, creating uncertainty about how to prevent, diagnose, and treat illness. Moreover, because they do not fit, more vigilance toward “risk factors” and “experimental treatments” was required. Ironically, increased technological advancement, such as Julianne’s drug test to verify her condition and Carmella’s psychological tests, created even more uncertainty as they weighed two competing diagnoses against each other. These cases follow Parsons’ (1951) prediction that increased technology to understand the body would lead to increased biomedicalization, creating more uncertainty about the future because of endless risks to the body’s systems.

Biomedicalization is a type of medicalization in which the domains of life previously outside the jurisdiction of medicine come to be constructed as medical problems with the aid of technologies like genomization, gene testing, and biotechnology (Clarke, Shim, Mamo, Fosket, & Fishman, 2003). Consequently, Sulik
observes how new relationships between the body and self are formed out of biomedicalization. Sometimes a person identifies so strongly with the certainty of diagnosis that they integrate the classification into their identity. This process occurred most often for half of the sample—namely, the women who received a firm diagnosis in childhood (i.e. women like Tammy, Ericka, Saundra, and Darcy). The other half of the sample searched for new knowledge in order to augment an unstable illness or an uncertain diagnosis. Julianne and Paula were constantly researching their conditions and collecting expert knowledge. This process created a semi-professional identity that could be deployed whenever doctors challenged the validity of patient complaints. In both cases, whether identities are shaped around the diagnosis itself or the accumulation of expert knowledge, an ill or disabled person learns to think of themselves in biomedical terms. This fact was observed in women like Julianne and Paula, who used medical vocabulary to explain their experiences to others.

I observe a paradox in this trend toward biomedicalization in the diagnosis process. Whenever participants actively involved themselves in their own diagnosis, human agency was asserted and medical power challenged. At the same time, however, technical selves are formed, as people desire to think and speak in medical terms in order to stress their humanity as patients. The result is a person who becomes an active participant in their own biomedicalization. Sulik hails this development as a way for patients to own a small piece of medical authority and make smarter medical decisions. Yet I share Sulik’s worry that the allure of biomedicalization will discourage people from questioning its underlying assumptions and lead to pathologies that may
not exist or may be shaped by cultural factors instead of biomedical ones. In this way I foresee the body becoming more “troubled” through these new diagnostic techniques.

**Moral Responsibility for Health and Patient Expertise**

In this study, participants positioned themselves as responsible partners in the doctor-patient relationship. Those who had been visiting doctors since a very early age insisted that they possessed enhanced knowledge of their own bodies. They argued that this knowledge gave them just as much expertise as doctors in some cases. They ruminated on the ways that good skin, health, and bodies could be achieved in their lives, expressing optimism about the ability to live as responsible managers of illness. Unlike the stories of participants who blamed the medical system for their inability to diagnose them, participants with a clear diagnosis sometimes blamed themselves if their condition exacerbated. Hence, they appeared to be more ambivalent about their new role as a patient. For women who internalized the specific notions of health and “goodness,” their moral narratives revealed the allocation of blame.

Skin conditions like acne contain conflicting moral codes about patient responsibility. Society judges people with acne if they do not take advantage of the tools to manage it, even though it is an incurable condition. As a primary indicator of social worth in interpersonal settings, the face “is a visible symbol of not only one’s morality and ethics but also what makes us human and gives us our identity” (Landau, 1989; Macgregor, 1974; in Whittington-Walsh, 2004, p. 7). Kokoro described how skin becomes an indicator of health and self-care. I asked her if acne was comparable to obesity, in which patients are viewed as personally responsible for controlling their weight. She responded,
No, not really. Because I feel like the way you view weight versus the way you view skin is kind of different, like you view weight as something more in your control, as someone who has a skin problem it's like, oh you need to go to the doctor and take creams, but like other than that you can't really do anything about it. There is always more of a focus on weight cause I feel like that applies to a lot more people than like skin problems. Skin problems like oh I have one zit, oh go to the market and get facial wash and Clearasil, you're good, like, there's a one-size-fits-all solution whereas weight there's so many things you can do.

Though Kokoro claimed that her acne is outside of her control because of its limited routes for treatment, she explained how she believes lifestyle can regulate it. The management of acne involved a hidden language about moral status where the social pressures for controlling the condition are internalized:

I think a lot of acne is done by lifestyle because your body, your skin is like…when you detox like the skin is one of the first things your body uses to detox your body. So in forms of acne, and some of it could be purely hormonal, but I think a lot of it is what you eat, how you sleep, how much water you take, like what it is that you’re eating, how you’re eating, are you eating really fast, it’s just you have to…it’s just a lifestyle change. And then like if you change your lifestyle and your thinking it changes how your body functions in a way. My acne isn’t hormonal. I went to the doctor and they checked my hormone levels and it’s not hormonal. It’s not like I could go on birth control. So it’s just a lifestyle. And I think it’s true with most people with acne.

Birth control is often prescribed if acne has a hormonal cause—one way that responsibility for the condition is excused. But in Kokoro’s case she asserted that her power to control her health rested on her daily routines and activities. She linked poor health behaviors with poor skin:

Your skin is like the first thing you see, like you can tell someone’s health by like their hair, their skin. If someone has like very pale like, like there’s a way that their skin looks is normally a sign of like, how their body is. I mean that’s like with anything, the way your body looks is the equivalent of how you take care of yourself.

Kokoro was not the first to claim that skin acts like a window into health. Of course, acne is rarely an indicator for a larger illness (Kokoro is incorrect here), but it does
culturally symbolize disruption or uncleanliness. Kokoro, like the other women with acne that I interviewed, felt that they knew what foods to avoid to make their acne worse (for Kokoro it was potato chips, for Nela it was white chocolate). What is most frustrating about acne, however, its precise causes are unknown, and is sometimes unrelated to an underlying medical condition (Meisler, 2003).

Sylvie was an interesting case study in the moral responsibility of illness. She suffered from an infection on her face in childhood that caused her face to swell so much she could not open her eyes. Living apart from her parents who were in Haiti at the time, she blamed herself for allowing the infection to grow without alerting grown-ups to the problem. She said that she “didn’t take care of it” and “let it get so bad” that she had to be taken in to surgery. This surgery left her with a scar on her nose. She described herself as a “good patient,” (not crying from the pain and submitting to the doctors) but that her behavior leading up to her hospital stay was a “lesson” for her. When people asked her about her scar, she said “I kind of feel somewhat embarrassed about it because it’s like an infection, and I didn’t take care of it, and I feel like I was small then and didn’t know better, but I know better [now]. I can’t say that that’s my favorite topic. People just don’t like to hear about puss.” When she returned home to Haiti her parents chided her for underestimating the seriousness of her condition: “it was like part of their discipline for me. They said that I should have treated from the beginning or it wouldn’t have happened to me.” Sylvie’s story is an example of how the process of scanning for problems in the body is not inherent in children; it is taught.

Carmella was a late adolescent when she had to learn the process of listening to her body. She described her new-found identity as a mental state requiring practice:
I think now I’m starting to be able to do that. And I’ve had to learn to adjust. I was one of those people that would block out any kind of uncomfortable sensation in my body, “Oh it will go away.” So it was really hard at first to have to listen to my body to what it was telling me. Now every little thing is just like, “What is that, what is that?” I immediately feel it and try to figure out what it is. Do I need to eat, do I need a pill, am I sleepy?

In rare cases, the “good patient” has clearly defined roles about what activities are permitted and allowed. Saundra’s renal failure and subsequent kidney transplant left her with some control over how long her kidneys would last. Saundra’s mother donated her kidney to her. Saundra said that with “my mother’s kidney is as old as she is…they wear out. And it depends on the individual, what you do to it, how good or bad you treat it. I don’t smoke, drink, or do any drugs.” As long as she was a “good patient and a good girl” (her words), she felt that she could have some modicum of control over her illness.

Life-long illness, in which patients tend to become their own experts, evinces complex ideas about patient responsibility. For the women with disabilities, listening to the body as an adult was like tuning into a familiar radio station. They know what type of music is played but they cannot predict the order of the songs. Unlike Carmella and Paula, whose symptoms developed in their first year of college, participants like Julianne have been living with their conditions since childhood. Living with a complex mix of chronic illnesses and their secondary conditions often required explicit attention to the body’s rhythms. No doubt medical advances helped patients understand their own bodies in new ways. But much of the work of understanding takes practice, involving years of trial and error, diagnosis and treatment. This practice resulted in accumulated knowledge for women like Julianne. Some sociologists attest that the doctor-patient relationship can be regarded as a “meeting of experts” (Tuckett, Bolton, Olson, & Williams, 1985). In Julianne’s case, the complexity of her multiple conditions
required that she sift through competing claims, interpretations, and hypotheses. She called this process “being a responsible patient,” which in her words means:

You shouldn’t be dependent solely on the doctor. I mean that’s not appropriate, because everybody is different, you have to be accountable for your own body. Maybe you don’t understand it, but the doctor is there to understand what’s going on. He shouldn’t have to tell you every little thing and exactly how you have to live your life to be a certain way, healthy.

Research on doctor-patient relationships typically focuses on doctors’ behavior, but Julianne asserted that patient behavior should also be scrutinized. She appreciated that her doctor gave her “all the options” so she could make her own medical decisions. She claimed that this relationship works well because one of her doctors also has Crohn’s and can empathize with her daily management of the illness.

Life-long illness also shapes self-images of people in such a way that expert knowledge about the body leads to the construction of what I call the politics of specialty care. This phrase refers to participants who expected a higher standard of specialist care because their illness demanded extra attention or resources that an able-bodied patient would find stifling. Hence, Julianne related a story of one of the few “bad visits” to the hospital, in which she distinguished two types of people: the temporarily ill and the permanently ill. In her mind, permanently ill people should receive care that is distinct from the care received for temporary illness. The formation of this belief became apparent when she entered the emergency room (ER) and was moved to the “chest pain ward,” which housed people with acute symptoms. She presented with migraine pain, the cause of which was a pseudo tumor cerebriae (diagnosed in a previous spate of hospital visits). The nurse on that particular floor saw her diagnosis on the chart and insisted that the fluid in her head needed to be drained immediately through a lumbar puncture. Julianne did not feel comfortable permitting the staff in this particular ward to
allow them to do the procedure. Her reasoning for this was that every lumbar puncture she had received in the past was done in radiology, and she felt uneasy going through with the procedure without a doctor present. She eventually declined service and left the ER untreated. Describing the situation as a “bad visit,” Julianne reveals why she walked away upset:

I’m used to a very particular behavior. I’m a high risk, so I’m usually treated as a high risk and that’s usually because of my history. I’ve got crazy rare disorders that nobody knows anything about. So, usually, I see a doctor and I see some specialist, they admit me and treat me for a while until they figure out what’s going on. It was different to kind of have everyone gloss over all these things and treat it like it was…like people next to me were there for a sprained my ankle…I’m just use to having specialists. And so it was just weird, nobody seemed as alarmed as I was.

Eventually she made an appointment with her neurologist, whom she trusted more to conduct the procedure in an outpatient capacity. No other participant expressed Julianne’s particular frustration with hospital staff who did not meet the expectations for specialty care.

**Trouble in Translation: The Limited Vocabulary of Suffering**

Western culture has a limited toolset for conveying bodily experiences and suffering. Wendell observes how biomedicine interferes, rather than supports, our abilities to communicate the phenomenology of pain. The language structures, syntax, and vocabulary of Western medicine shape how people experience their bodies. Following this, doctors who use “different conceptual schemes” (such as “alternative” medicine) may have patients who articulate suffering differently. This language barrier has implications for exacerbating the doctor-patient divide:

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3 Saundra shared Julianne’s concerns about medical encounters where she has had to help medical students draw her own blood.
Medical practitioners tend to measure their success by the “objective” state of the patient’s body and to regard death as their greatest failure. Patients, on the other hand, are more likely to measure a healer’s success by the quality of their subjective experiences, and to consider medicine’s greatest failures to be cases of unrecognized, unsupported, meaningless, or hopeless suffering (Wendell, 1996, p. 138).

Frank calls this “medical colonialization,” in which medicine claims the body of its patient as “its territory…The pressures on clinical practice, including the costs of physicians’ time and ever greater use of technologies mean less time for patients to speak” (p. 151).

I came across these ideas late in my research, but not late enough to ask Julianne if it was relevant to her experience. She immediately understood Wendell’s point, relating the limited vocabulary of suffering to the typical 0-10 pain scales that doctors use in diagnostic tests, calling them “ridiculous” but the “only thing they can use.” She noted that they have the effect of choosing sensations and states for people rather than using the words by patients to describe themselves. The pain scales have embedded themselves into the way she talked about her body; throughout her interview she described her pain in numerical ways (“I entered the hospital at a 6…”).

The lack of words to describe bodily fluids was another way that the depth of the illness experience became lost in translation from patient to doctor. Since Crohn’s disease is an autoimmune disorder that affects the intestines, Julianne was asked to describe the consistency of her poop. She used food analogies like “pudding” or “soupy” to describe it, remarking that it “takes a special doctor” (or a specialist like a gastroenterologist) who can understand what she is describing and filter that description through their specialized knowledge. This specialized knowledge is no substitute for
first-hand experience, however. Julianne explained her frustration with a doctor who had trouble understanding the sensation of pain medications:

When I was in the hospital after my surgery, I was trying to explain why I prefer to be on Cebutex [non-opiate pain medication] or something instead of an Oxycodone [opiate pain medication] and I’m like, “You know how you feel after you’ve been on pain medicine?” [The doctor] has never been on pain medicine before, and he’s a pain doctor, that’s one of the things that he specializes in. So it’s hard to relate to people that haven’t experienced something that you have. I mean you try to put it into words that they can understand, but sometimes it’s just completely unrelatable to another person. It’s hard to tell a person who doesn’t have Crohn’s or a pseudo tumor exactly how those things make you feel.

I read Julianne an excerpt from Wendell’s book on the limited vocabulary of suffering. She responded,

Just like that woman [Wendell] is trying to explain how Chronic Fatigue Syndrome feels to someone who doesn’t have it, well you can only use things that that person has experienced. So like her, I’ve always had that problem trying to come up with analogies…metaphors…to convey exactly how I’m feeling or what the situation is.

In the quotes above, Julianne fleshed out Wendell’s theory by uncovering gaps or “blind spots” in knowledge between doctor and patient. She hoped to fix this gap through language, but she admitted that lacks words to convey her experiences to others. The experiential deficit embedded in Western medicine is another way in which bodies become “troubled.”

The public testimonials, discussed in more detail in Chapter 7, were formed to remedy this frustration. Participants wanted to convey the experience of their illness or disability to medical students. The limited vocabulary of disease—not just suffering—could be expanded when using a wider lens focused on the human management of illness. How people understand their illness, how it impacts their life, what it means to their
sense of self, and how it shapes their interaction with others is just as valuable as, for instance, learning the mechanics of the body at the cellular level.

The repercussions of this limited vocabulary could mean that suffering is accepted and normalized. After years of multiple surgeries and procedures to resolve torn muscles and ligaments, Julianne learned an important lesson: that pain does not need to visit her constantly. “Pain is pain. You’re going to have it,” she said, but “I’m also happy that I don’t have to accept it.” She described herself as “complacent” when it came to pain, believing that it was a natural part of her life. The only pain management she knew was prescription medication. More recently, however, she had been introduced to deep tissue massage, which she said greatly reduced the pain around her surgery scars. Julianne wondered if her pain would have decreased if she had gotten this massage after each surgery, instead of medicating with opiates. She felt empowered by this choice—one that doctors could have suggested to her from the beginning. No doubt Julianne would benefit from a focus on pain as a condition itself, with accompanying vocabulary, treatment options, and metaphors to ask, insist, and act on pain treatment.

**Bodies Meet Bureaucracy**

In the United States, the state and corporations are ever-present in people’s lives, and increasingly so in the management of their health. Weber’s theory of bureaucratization describes the changes undergoing medicine today. McKinlay & Stoeckle (1988) argue that bureaucratization in medical practice leaves physicians subordinated to the requirements of highly profitable production of medical care and state regulatory agencies (p. 180). Hence, I call this section “bodies meet bureaucracy” because “patients are technically clients whom physicians share with other specialists”
Just as social workers have a “case load,” physicians have “case bodies." In this study, participants expressed frustration when dealing with Western medicine’s bureaucratic rules regarding health insurance and patient record sharing. Two participants, Julianne and Saundra, alleged that medical bureaucracies created unnecessary obstacles to their care. They also described how it limited knowledge and options—for them and their doctors—when making decisions about their bodies.

Julianne believed that her medical care suffered from federal rules regarding patient privacy. In 1996, sweeping legislation under the Health Insurance Portability and Accountability Act (HIPAA) mandated national standards “to protect the security and privacy of individually identifiable health information transmitted in any form” (Kumekawa, 2001). HIPAA changed the way that hospitals, researchers, practitioners, and health insurance agencies communicated with patients, their families, and with each other. Patient confidentiality, the benchmark for securing a sacred trust between doctor and patient, has a downside, said Julianne. Based on her extensive interactions with hospitals, she argued that HIPAA is “good for the wrong reasons” because free information sharing between her multiple doctors is very difficult:

I am a huge fan of doctor’s sharing records. If nothing else, we need a more comprehensive approach where doctors are able to communicate with everyone who is taking care of a patient. But now, these doctors aren’t sharing information, so the compartmentalization of it is a paranoia thing that has been just engendered with HIPAA records, people are afraid to share. They’ve gotten to the point where they don’t want anybody to have anything. And that’s not going to help you.

She proposed an alternative so that information sharing was the law’s default condition:

I think there should be a backwards HIPAA. I don’t want my records to stay private. I want my doctors to be able to get my stuff. I want everybody to know about this so that in case somebody else has an idea of what’s going on they can do something about it and they can get to me immediately.
Proclaiming that “knowledge is power for everyone,” Julianne would like HIPAA to have less constricting influence on her life. This would mean a less burdensome struggle to disseminate her records to the multitude of specialists she had to visit. “When you’re sick,” she said, arriving at the hospital to pick up paper copies of medical records is “the last thing in the world you’re worried about doing.”

A reformed medical system would also mean doctors communicating between each other. The complexity of this “compartmentalization,” as Julianne called it, emerges as she described her recent surgery to repair a fistula:

If you’re not fostering an information-sharing type of culture, as a medical professional, then you’re doing it wrong. With your surgeon, you’ve got at least two or three other doctors on the surgical team. You’ve got your primary care physician, you’ve got a gastroenterologist, you’ve got a rheumatologist, and then you’ve got your gynecologist who needs to be there. So the gynecologist had to be in on everything, and like everybody else, they knew nothing about the gastroenterology and gastroenterologist knew nothing about gynecology. And then I had to have the plastic surgeon there [too].

Julianne said that she would love to have a team of doctors who communicated with each other instead of individually reviewing her case based on their own specialization.

Other women sharply observed how health care bureaucracies shaped their lives and bodies. The U.S. has no single health care system; instead, it is provided through a multi-mix of private and public schemes (Fry, Light, Rodnick, & Orton, 1997). Like most people in America, Sandra's care was paid for by a mix of private (received through her parents) and public health insurance (Medicaid). She voiced complaints about the health insurance structure in America–namely, its reliance on insurance companies who can deny benefits based on “preexisting conditions” and the high cost of individual insurance plans. These barriers prevented her from getting access to care that she needed to manage her conditions:
Like if I decided that I wanted to open my own business, how would I get access to health care? I would have to go and find a private insurance company. You find that people that don’t have insurance so they don’t go to the doctor often, they won’t go to the dentist, they won’t take care of their medical needs. And for some people with disabilities, that could mean the difference between life or death. I need Medicaid so that I would at least have access to primary care and the prescriptions. That way I’m not in the hospital all the time.

Saundra framed health care as an economic problem that has more detrimental effects for persons with disabilities. She was also aware that finding a private insurance company to insure her would be impossible since she has many preexisting conditions. Moreover, at 24, she lived dangerously close to the age at which insurance companies stop covering dependent children (26). For both these reasons, Saundra worried that she would no longer be able to receive health coverage because of her “uninsurability.” Her only option would be to find employment with health benefits—yet this was not an easy thing to do (employment is discussed in more detail in Chapter 7).

For these reasons, she welcomed the 2010 Affordable Care Act, the centerpiece of President Obama’s health care reform efforts. When the act passed, Saundra rejoiced over two central reforms: dependent coverage up to age 26, and the elimination of denying coverage based on preexisting conditions. These changes gave her enough time to stay on her parent’s insurance for one more year. They were not air-tight solutions, however. She anticipated a bleak time in the future when she would have to find her own insurance on the open market: “It’s making me a little nervous because am I going to have to fight these insurance companies.” The preexisting law in the Affordable Care act, in light of Saundra’s experience, made her eligible to battle it out with insurance companies—just like everyone else.
Saundra also revealed how the old preexisting condition rules in the health insurance industry shaped her life. A preexisting condition is defined as “medical condition that occurred before a program of health benefits went into effect” (University of Pittsburgh Medical Center, Medical Terminology). In order to meet these criteria, Saundra recounted how her parents were “constantly trying to find a cure” for her cerebral palsy when she was younger. She endured experimental treatments that attempted to eliminate her palsy, without success. “They weren’t trying to fix me” temporarily, she says, “they were trying to cure me.”

I brought up the fact that under most insurance policies, even the presence of a past condition would probably deny her coverage anyway. She concurred, stating that she would still be vulnerable to the whims of the insurance industry. People with serious health conditions are subjected to discriminatory practices like preexisting conditions, benefit limits, exclusions, higher premiums, and rate increases. The preexisting condition rule, in particular, requires that bodies be normalized before policies are signed, leaving people with disabilities in the high risk pools of underfunded social programs. Such a rule unintentionally aides the biomedical search for a cure, which developed as modernity increasingly medicalized and rationalized the body in the nineteenth and twentieth centuries (Thomson, 1997). Now that the rule has been outlawed, perhaps we will see fewer obsessions with unnecessary medical cures that are based on fears of health insurance discrimination.

**Creating Difference through Social Exclusion**

Divisive social policies and spaces greatly affected women with illnesses and disabilities and systematically worked to exclude them from normal social life. Body trouble in this section occurs when bodies are ranked through social practices. I discuss
how difference and ranking manifest in the politics of space and deprivation, or what French sociologists call “social exclusion” (Paugam, 1993). America has a long history of systematic social exclusion: W.E.B. Du Bois describes Black isolation in city wards, social exclusion persists in educational institutions, and America suffers from unequal access to basic necessities in health, housing, and food. Room (1995) argues that poverty entails *distributional* issues (lack of resources) while social exclusion involves *relational* issues (the lack of social ties to family, friends, local community, state services). My analysis suggests that distributional and relational issues are entwined for the women interviewed. In this section I illustrate how frayed relational issues diminish social capital and keep people with disabilities and illnesses in a perpetual state of poverty. Social exclusion manifested in four areas: education, social networks, the workplace, and public encounters. Before I discuss these, however, I would like to talk about how the participants viewed exclusionary policies more generally.

The practice of socially excluding people like themselves from “mainstream society” was a heated topic of discussion in both the group and individual interviews. The women with disabilities were keenly aware of their own marginalization; moreover, they recounted the history of social exclusion for people with disabilities. Saundra and Darcy illustrated their awareness in the following exchange:

Darcy: I heard that in certain parts of the country you weren’t allowed to mingle with society just because you had a disability.

Sandra: Exactly, or you weren’t institutionalized.

Darcy: Or they arrested you because you were trying to mingle with society.

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4 Walker (1997) also defines social exclusion as the “dynamic process of being shut out, fully or partially, from any of the social, economic, and cultural systems which determine the social integration of a person in society. Social exclusion may, therefore be seen as the denial (or non-realization) of the civil, political, and social rights of citizenship” (p. 8).
Sandra: And this wasn't that long ago.

Their tone evoked a looming fear that they were facing the same discrimination as their predecessors. Because they struggled to find gainful employment, women with physical disabilities were skeptical that this type of social exclusion would be fully eradicated in their lifetime.

In the same interview, Sandra and Darcy discussed “making it” as a person with a disability living on public assistance in America. I found this conversation fascinating for its analysis of problems in the “helping systems.” The participants struggled with these systems as the state engaged in a morality play where citizens were judged more or less “deserving” of help. Sandra and Darcy, both receiving public assistance, spoke from experience about Supplemental Security Income (SSI), which pays benefits to low income disabled adults while subtracting a predetermined amount from employment income. The women framed this calculation as a confusing dance of subtraction/addition, resulting in a catch-22 that kept them poor:

Sandra: They say they’re being generous. They go, Okay for every two dollars that you earn, we’ll only take one dollar away. But immediately one of those two dollars is going to go back to refill what they took away, so you’re earning half of what you earned in the first place!

Interviewer: Punishing you for doing something that is trying to better yourself? Is that the limitation of welfare?

Darcy: Right, you’re only allowed to have like two grand [$2,000] to your name.

Sandra: Which is a higher amount than they used to have…but that’s extremely below poverty level.

Interviewer: So to get help, you have to look poor?

Darcy, Saundra (together): Yeah.

Sandra: Actually I think it’s more not even poor---more like destitution. Really, no I’m serious!
This last statement provoked nervous laughter around the room. I think we laughed because of our collective realization at that moment: these policies are like a slapstick comedy played with real people’s lives. People must “perform” disability to convince state agencies that they are “unworthy” citizens but “worthy” of benefits. Consequently, these fights over “table scraps” created hierarchies between people with disabilities that serve no one.

Similarly, my comment about looking poor enough to deserve help comes from insights I gained while watching the 1992 film *When Billy Broke His Head*. In that film, Billy, a brain injury survivor attempting to earn an income as a writer, confronts a social worker about his depreciating monthly benefits. As he struggled to comprehend the complex mathematical formulas used by the Social Security Administration to calculate his “spend down” (the procedure by which the government decides how much earned money should be deducted from his benefits) Billy reflects on the absurdity of a situation that “felt like punishment.” Billy, like Saundra, could only respond with sardonic humor to policies that, to them, make no sense whatsoever.

After a time, we discussed how this “forced destitution” related to social exclusion and the lack of public investment in caring for the disabled. Sandra and Darcy again took charge of mapping out this relationship:

Darcy: People with disabilities are treated differently.

Sandra: Exactly, they’re really discluded [sic] from society. So I think we’re really lucky considering how far we’ve come in America as far as disability rights. I think we still have a way to go…

Interviewer: For an affluent society we should be better I think.

Saundra: Yes, but to get cost of living assistance, the taxes have to go up. And right now in this political situations that is not going to happen. No way in heck! …Most Americans aren’t willing to pay for other people’s expenses.
Darcy: I was really upset when I found out through Facebook that a lot of funding is getting cut for this developmental disabilities population APD, which is the Agency for Persons with Disabilities, I've been on their fucking waiting list for three years, going on four, and I have received zilch. And all these services, VR [Vocational Rehabilitation], and CIL [Center for Independent Living], they receive all this funding from the state, so if the state goes bankrupt and the government takes funding away from the agencies that are supposed to be helping us, it doesn't help us.

Sandra: Yeah but here’s my advocate question, *are they really helping us?* [emphasis mine] Because they make it look like they’re the benevolent people giving assistance.

The women offered two different critiques of the dilemmas in the American welfare system. Thinking cynically for a moment, I believe Sandra’s pointed question about the “real help” in the helping systems can be interpreted as a subterfuge: a calculated maneuver by the state to feign concern for its marginalized members. More optimistically, the worry about cuts to state services for people with disabilities indicated how important these state services were to the participants (even if the system itself is maligned for lacking sincerity). Indeed, I think the group receiving the most scorn by Darcy and Saundra was the public, who lacked conviction in holding governments accountable to fund even the most basic of social services.

**In Education**

Women with disabilities (not so much for women in other groups) had much to say about the act of navigating educational institutions. Here, the practice of social exclusion appeared to mirror welfare policies for the disabled. Well-meaning attempts to address inequalities—when applied too bureaucratically—isolated, divided, and differentiated people based on bodily ability. Interviews from three women—Darcy, Saundra, and Janet—spoke to this observation. They reported how their experiences in
higher education lacked support for people with disabilities. Moreover, in high school, support existed but it was not the kind that they desired.

Darcy’s narrative, for example, read like a travelogue—only one in which the traveler has no control over their destination. From elementary to high school, she bounced around public, private, “mainstream,” and Exceptional Student Education (ESE) classrooms and schools. She said she never seemed to fit because the ESE classes distanced her from mainstream (she means able-bodied) students, but encountered relentless bullying in the “mainstream” classes for her slow speech and gait. The advocates she truly valued were her teachers who sheltered her from the worst of the bullying. She was touched by their gestures of protection, remarking: “It drove me crazy because [the mainstream students] were so mean. If I hadn’t had the teachers that I had, [high school] would have been hell.”

I discuss bullying more generally later in this Chapter, but I briefly want to touch on its psychological and social effects. I asked Darcy if the bullying shut her down and stopped her from speaking in classrooms. In other words, I wanted (needed) to know if it changed her behavior and core self in any way. She replied that she was always a quiet person, but that she felt more comfortable with the “ESE kids” because they were all different or unique like her. With the “regular kids,” who all shared largely the same traits, she noted how there was a built-in division between her and the rest of the students: “It was clear, just this whole social distance, this wall [emphasis mine]”. Her choice in metaphor begs the question: What makes up this wall? How is it created?
One “wall building technique” was the politics of accommodation. Darcy observed that, in the process accommodating differences in ability, the education system lumps children with disabilities into one group, assuming that they all need the same help:

A lot of people think that by accommodating somebody you’re giving them an advantage over somebody else. Not the case. People can’t see their own advantages when they’re able-bodied. I see giving somebody five minutes more on a test as leveling the playing field. And so you’re making things equal, you're equalizing things. I definitely think that people who are able-bodied see people with disabilities not being able to do every day things, so they take things for granted. They assume that they need help, and what I try to get teachers to understand is that I am not the same person as Johnny over there. Johnny may need more of your attention than I do…We have a lot of kids with disabilities who in high school were in self-contained classrooms, or were separate and didn’t really mingle with the rest of the school. And it’s like, how are you supposed to get people to interact with each other if you separate them?

Darcy observed that the education system does not conceptualize differences in abilities among people very well. She saw herself as a student who needed extra time on tests, but not much beyond that. This simple accommodation, however, pushed her into ESE and away from mainstream classes. In other words, the wall becomes an overreaction–a metaphor for the inability to see the diversity in bodies and abilities. Her modest accommodations were interpreted as dire deficiencies, and so the wall became a stigmatizing device. While she felt more comfortable in the ESE classes, Darcy concluded that they offer limited social benefits to her in the long run because of their excessive social exclusion.

This wall metaphor jumped out to me when coding Darcy’s interview, so in subsequent interviews I began to ask participants about instances of social exclusion through education. Since most of the women were enrolled in an educational institution, stories flowed like water. Saundra used a similar architectural metaphor for her experience, only this time she referred to the experience of disability as a “buffer, but
bigger…more like a moat." When she transitioned from the shelter of high school to the wider world of college, she felt like she was “dropped into an ocean and had to swim to the shore.” She was glad to have unmitigated contact with mainstream society, but adjustment to this new life was difficult—I assume because of her previous social exclusion in high school.

At age 18 and still in high school herself, Janet was my youngest participant. While Darcy, 25, and Saundra, 26, merely reflected on high school, Janet was currently experiencing it. Her story was less about ESE instruction and more about navigating status in everyday interactions. For example, she talked about how her uneven gait made rushing between classes while carrying a heavy book bag a concern for the school. Janet, however, was wary of the help from teachers and principals, as explained in this passage:

The teachers were trying to make all these accommodations for me, trying to get me out of class early to walk to classes, when I was only two minutes away from my class. I’m like “no.” And they got mad at me, and I was like, I don’t care. They wanted me to have the principal carry my bags around for me. Are you kidding, do you want me to get killed? To have the principal come in to every single one of my classes? That’s not cool. Some teachers realized that I can do this on my own, but then some people were like “let me do everything for you.” And I’m like, leave me alone. I’m strong enough to carry my own backpack, you don’t have to do it for me.

To grasp the full effect of this story, picture Janet’s exaggerated eye-rolling as she told it. She flaunted authority while mocking the meager understanding of the power dynamics behind this accommodation. Interestingly, Saundra encountered the same treatment—an aide was assigned to walk around school with her; however, she said this was not out of concern for her welfare but the school’s. The school board told her they were afraid she would sue if she fell down. Like Janet, Saundra reacted brusquely to the accommodation, stating that she falls all the time anyway, and that the aide only served
the school’s needs. Indeed, the simple act of walking to class—what so many able-bodied students take for granted—was a minefield of body trouble for participants, exacerbated by failure to ponder their potential.

**In Social Networks**

All participants had social support networks—such as boyfriends, parents, and neighbors—that they could turn to when needed. The largest networks (not necessarily the strongest) were those like Brinn’s, made up of many college friends who supported her through her lupus diagnosis, and Paula, who found support networks in Christian groups on campus. All women had parents or siblings on whom they could rely unconditionally. Participants in their late 20s, like Ericka, were in the process of assuming caregiver roles for their aging parents. As I inquired about how participants formed friendship networks, other women painted pictures of fragmentation—caused, I believe, by the construction of difference and the hidden underworld of illness.

Ericka saw a dramatic change in her social support system that she had built since high school. The cause was not necessarily her worsening ataxia, but a misunderstanding about her abilities. She experienced frustrations with friends who, in her view, abandoned her for inexplicable reasons:

> I’ve always been Miss Popular, you know like I’m a people person. I’ve had a group of girlfriends since sixth grade and we were tighter than tight. Even as we all got to like [age] 30, even though we all lived miles away, we all came together. My best friend—we grew up next to each other—was getting married, and didn’t want me at the bachelorette party.

> And not that my disease had progressed, but they were afraid that because they were all going to be drinking that it would be too difficult to help me go to like the bathroom and that kind of thing. And I’m like, I can get a room with rails, I’ll be fine. But no. And so my friendship ended with like nine of my closest friends, and so now I am finding it very difficult to come out of and submerge myself back in the group.
Ericka asked her best friend to come to her defense, but her friend did not and held the bachelorette party without her. How to understand this story, which is perhaps the most lucid example of the personal consequences of a rigid construction of difference? I can only speculate, but I see how body trouble is created when disability is viewed an inconvenience to able-bodied people. Ericka’s friends appeared uncomfortable with her needs and did not want to be responsible for her. Maybe from their perspectives they thought her exclusion was in her “best interests,” but this concern (either for her safety or for their own selfish desires) would have been built on paternalism. Ericka’s feelings of betrayal and loss were poignant because for many years, her friends seemed to love and accept her for who she was until this incident.

Saundra, Ericka, and Darcy said that college did not expand their social networks. They agreed that the wild “college life,” was not something they were interested in, welcomed into, or wanted to maintain into adulthood:

Ericka: I don’t know if it is because of my disability or because I am older than ninety-five percent of the students on campus, but I did not have one new friend at school. Not one. I have friends, but they’re from like elementary school or like when I went to other places…And it’s really hard, especially here on campus because everyone is like younger than me and into partying and going out, and I’m like, I’ve already done that.

Darcy: In college I wasn’t into the whole partying thing. Everybody was like let’s go, and I’m like nuh uh. Nope.

Saundra: I went clubbing like once or twice. It was the most boring thing in the world to me.

In some ways, the three women had much in common with non-traditional students like Veterans, who do not enter college to socialize and make friends. Instead, they see college as another job, unlike some traditional college students who see it as a resort vacation. How the exclusion of people with disabilities in wider society impacts their
social bonds in college is a question beyond the scope of this dissertation. The mere presence of people with disabilities on college campuses, however, is not strong enough to eliminate the stigma or hidden underworld in which they were relegated.

Carmella’s illness became a litmus test for what she defined as “true friendship.” Explaining that she had always been “popular with hundreds of friends,” her spate of hospital stays challenged that identity:

> It’s difficult to find people who understand. So I got really sick and I was in the hospital and I’m like, where are my friends, why aren’t they answering their phone or email? I realized these people don’t even give a crap that I was sick. Some people like told me oh what are you going to do about school, you’re going to be behind. Seriously? I just assumed that people would do things that I would do for them.

Carmella was offended by those whose only expression of concern was falling behind in school, not surviving her illness. She goes on to explain how people who do care are those who have had experience with illness—unlike her friends who did not want to understand it:

> It’s really hard to find the type of person [who cares], and I think it has to be someone that’s maybe has experience with that type of thing. Maybe a parent I found that has already been through this illness and it’s a maturity thing. I’m not really sure what it is, it has to be somebody that’s more caring, not self-absorbed in themselves…I could easily realize what type of people they were after that and see what type of people I should see associating myself with.

She was not alone during the roughest times of her illness, however. Older adults like friends’ parents, doctors, and nurses, gave her support that she needed (cards, flowers, or a hug). Most of these people were doctors and nurses who worked with her father (a physician himself). At the time of our interview, Carmella also had a boyfriend who gave her needed support as well.
For some people, disability and illness can give a person’s life a renewed meaning and purpose, but only in tandem with their full integration society. The loss of friends in young adulthood, however temporary, is a product of the negative representation of illness and disability gaining purchase in everyday relationships. People already have an expectation that ill people are socially isolated individuals who cower from the public eye. So when confronted with illness close to home, they flee. Even though the majority of participants did not have experiences like Ericka and Carmella (the more extreme examples), social isolation has emerged as a theme in art by people with disabilities. Take Anne Macfarlane’s (1995) poem “Loss” for example,

I expose a stormy outburst of emotion
Marking almost half a century
Of anger
For the loss of relationships.
Are they something experienced only
By non-disabled people?
Belonging, being welcome as
Part of family, community, society?
Let me give expression to
Almost a lifespan
Of isolation, of painful separations.

If ill people are socially isolated, they will be politically isolated as well. If they cannot form solid, dependable friendships, they cannot be expected to organize for their interests.

In the Workplace

Understandably, participants living with disability and chronic illness were extremely attentive to their exclusion from the working world. A majority of the sample was highly educated and the women had hopes that their education would buffer them from poverty. I interviewed them on the cusp of their prime working years, so uncertainty about the future may explain these anxieties. Grievances included their own
disappointing experiences with the job market and personal experience with employment discrimination. Participants claimed they had to work harder to manage employers’ expectations of them.

For the most part, participants articulated principles of the social model that blame work structures, not individuals, for diminished employment prospects. Ericka noted how some professions exhibited short-sightedness in imagining what she could do. She defined herself as someone who was born to care for others, so she decided to go to school for a career in nursing. Eventually she dropped out, not because she believed she could not handle the demands of the job, but that nursing as a profession could not handle her:

I went through nursing school, gosh dang it, I have the ability to draw blood or you know, help with the pap, or doing any of that. But because I’m in a wheelchair people think “Oh none of that can happen, she can’t do any of it.” I’m worth the [paycheck], I went to school, so I have the ability.

Ericka remarked that no one told explicitly told her she was not capable at nursing. Yet she noted subtle negative attitudes from patients, whom she said could not conceive of a person with a disability caring for them. She believed that compassion, her greatest asset, was overlooked in addition to her ability to do basic helping tasks. She thought that fields like nursing would benefit from those who have personal experiences with illness and disability.

Saundra also encountered employers who had a limited vision of her skills. At the time of our interview, she was relentlessly searching for work because she had recently finished her bachelor’s degree. Her dream was to join the military, but she had come to accept the military enlistment rules on disability. Nevertheless, she was persistent in finding a job in security at the federal level:
I go every semester to the career fair to do networking. I went to the Navy table and asked if they had any civil service positions available. I was sitting in my wheelchair and the man came up to me and asked, “Well, ma’am why are you in a wheelchair?” and I told him that I have cerebral palsy. “Well you can’t be an officer,” he said. And I said “That’s why I asked about civilian positions!” The commander was looking at him like, “come here, I’ll deal with her.” I’ve had some really insulting stuff happening to me, which has been from the guys, and I just smile politely and go, “okay.” Asshole.

Like Ericka, recruiters made their conclusions about Saundra based on her wheelchair. I imagine that recruiters do not tell able-bodied people what they “cannot do” as a point of introduction at career fairs. All that was needed was some sensitivity in this matter, and Saundra would not have felt stigmatized. She managed the insults with a mix of sarcasm and grace:

Of course what I find funny is when I’m in a wheel chair and the guy is standing up at an average height of about six feet, I am right below to just go, BAM! [She punches out her fist as if punching him in the balls]. “Oh sorry, I just had a spastic urge!” But then again that wouldn’t be considered polite especially since I’m looking for a job. Yes, I let it roll off my back.

With a simple joke, Saundra inverted the recruiter’s belief that her wheelchair was a hindrance. She turned it into an asset that enabled her to lash out and reclaim power.

Unlike Ericka or Saundra whose disabilities were visible, Julianne’s illness was hidden. This fact led to a greater consideration about whether to hide or disclose her illness. Julianne discussed the hiring process at her job in the medical research field, revealing her concern with managing perceptions about her abilities and competence. Before her interview, she had to weigh which strategy would secure her chances to win the job: would she openly admit to her chronic illness, wait to tell them about it after being hired, or not tell them at all? She chose the first option, admitting that it was highly
risky. She knew that the employer could have refused to hire her during the interview “for whatever reason and get away with it,” but she explained her choice this way:

I did it actually because I didn’t want them to hire me and then I would be sick and out of work all the time, and then have to explain myself further and justify things. I think it’s important to be up front. I know this isn’t a decision many people would go with, and maybe it’s just the way that I am. I am far more consumed with what others think about me then what I think about them.

She said that interviewing for an employer who conducts medical research assuaged her fears that they would react negatively to her. Her assumption proved right, and she got the job. Her belabored thought process indicates the effects of a workplace organized around an idealized norm.

During her job she used up many sick days for hospital stays. Her boss was fine with this, as long as she got her work done, which she did. After about a year, at least one of her coworkers noted her tendency to work from home and made a complaint to human resources. An agent from human resources asked her if she wanted to make working from home a “semi-permanent thing,” meaning she would declare her illness as “accredited” (her employer was large enough to offer this option). She refused the option for the following reason:

I don’t want to do that. I hope to be back to work, I hope to be back in the office. And so when she said, hey do you want to make this permanent. I was just like, no, I don’t want you to see me as a person that needs help [emphasis mine], but I mean obviously, that’s how they see me as a person that’s going to need an exception. I don’t even want to know who it was that complained; I think it would hurt my feelings.

She still wanted to come into work occasionally and to make face-time and socialize. This decision was based on the crucial importance of making connections and gaining

5 That is, discriminate against her without getting blamed for it
social capital in the workplace. I take the italicized words to mean that even though computer technology and a supportive boss have enabled her to work from home, this flexibility can also be seen as exclusionary social-wise, effectively distancing her from her co-workers. Like Darcy’s complicated attitude toward her exceptional student classes, Julianne worried about the stigma of being labeled as “different” (or in this case a person who needs “special treatment”).

**In Everyday Conversation**

Women from all groups received comments on their physical body from friends, strangers, classmates, children, and adults. This commentary ranged from curious questions to intentional bullying. I interpret the remarks as the fourth way in which bodies were marked for social exclusion, although there are exceptions to this practice. The data cannot reveal if these remarks were one, intended to exclude, and two, if they had enough power on their own to create systematic segregation.

Out of all the women, the group with skin conditions appeared to receive more “casual” remarks about their bodies from strangers in public. Remarks were usually made in passing curiosity, but incorrect assumptions irritated the participants. Josephine’s vitiligo formed in white spots around her eyes and on her knees and was more noticeable because of her dark skin. She received what she called “random comments” about the spots, like the following:

I was at the grocery store and I didn’t really put a lot of make up on, not around my eyes. If I don’t wear any make up, it looks like I have really bad raccoon eyes. And that people are like, so you’ve been out in the sun today, huh? I’ll be “no actually I haven’t” and then I make them feel really bad. But I’m like I didn’t mean to make you feel bad, I just wanted to let you know that…or if I’m nice I say “actually I have a loss of pigment,” and they’re like “oh I’m so sorry” and I’m like no really I’m not worried about it.
Even though comments like these were part of her daily life, Josephine preferred comments over people who simply stared in what she called “quiet judgment.”

Kirsty received similar remarks about the port wine stain above her eyebrow, but usually on the days when she did not wear make-up. She explained to people that it was a birth mark. Sometimes people responded by showing her their birth marks. I asked her if she felt a commonality with this folks. “When someone has a brown spot on their leg, no,” she said, “I don’t feel like that person has ever been teased about their mark. When I was a child, I was teased about it. That’s why I started covering it up, so I wouldn’t feel insecure if I had a spot on my leg.” Instead seeing it a common shared experience—“everyone has birth marks!”—Kirsty makes a point about privilege.

Women with disabilities had the most to say about the experience of teasing and bullying. Seven out of the ten women with disability/illness had been bullied at least once in their lives. I asked Tammy why she thought the bullying occurs:

I think they just realize the people being teased won’t do anything. If you’re different, if you’re a loner, if you’re just weird, then you are more of an easy target for people that are more popular. You’re either in or you’re out. You’re the target or you’re the one being the bully.

Darcy explained bullying as a tactic that developed as children grew into adolescence. In her experience the teasing only got worse as she got older:

When I was in elementary school I was doing little speeches with my class, trying to describe spina bifida. And when you are at that age, they don’t really care. Kids don’t understand so they don’t care, and they’re not going to sit there and tease you. But when I got older, I was teased and bullied to no end. I had the good student reputation and so my teachers kind of protected me, more or less and so they looked out for me and so the bullying was not as severe as it could have been.
Darcy described this experience as being less severe than it could have been because she maintained a good student reputation. Hence, the teachers protected her. She remarked on the psychological effects of the practice, pondering:

I wondered “Am I going to be able to amount to something or am I going to be living at home with my parents for the rest of my life?” I saw these people being able to do things that I couldn’t do. I was not allowed to go out for sports, I was not able to just come and go as I pleased. I was more strictly books and go to school and go to class, go home, instead of being more social.

Social exclusion acted cyclically, shuffling Darcy into different activities than her peers. Bullying enforced this exclusion and pressured the bullied to internalize and accept their subordinate position. The meanness Darcy encountered in mainstream classes in high school affected her self-esteem and access to normal activities outside of school.

**Conclusions**

In this Chapter I offer a concrete view of the impact of medical institutions and ideologies on women living with illness, disability, and skin conditions. Participants described a frustrating diagnosis process, defined their own ideas about responsibilities and obligations in this system, struggled to convey their sensations to doctors, and guarded themselves against the vagaries of health insurance rules. In their narratives, medical power did not resemble a supreme control center for disciplining bodies to fit a cultural mainstream. Instead, participants directly engaged biomedicine’s neglect of their personhood, empowerment, and voice. Similarly, in institutional spaces outside of medicine—from everyday encounters in public to the educational system—difference was communicated to them. Barriers between people created ideas about disability, and this is why this Chapter explores Oliver’s concept of disability as a societal feature, rather than a physical one.
Moreover, participants lived under social constraints that shaped the experience and definition of their disability, illness, or skin condition. These practices in medicine, social networks, employment, and everyday conversation form the material of the cultural fabric of the body—similar to what we see in other constructs like race, gender, and sexuality. The narratives suggest how discourses that locate, define, and maintain the very idea of disability and illness as different, subordinate, and even subversive.

Behind assertions of difference rests standards that construct people with disabilities as a subordinate class. Of course, I am speaking broadly when referring to “people with disabilities,” since impairment in the human body is a very common phenomenon. Impairment is present in almost every facet of social life—yet as these narratives suggest, we do not yet know how to respond to it. Participants were confronted with situations in which they had to assert their validity as people worthy of functioning in mainstream, able-bodied society. As Garland-Thomson (2003) explains, this knowledge is best expressed in the language of critical theory:

Difference is constructed relationally. In other words, my body, my “congenital disability,” becomes different, abnormal, disabled, only in comparison to the socially established bodily standards and expectations that interpret it so within a social context. Being stared at is one of the social practices that creates my disability, my sense of myself as different from what I should be (p. 471).

For women like Garland-Thomson and those whom I interviewed, difficulties and disadvantages are not produced entirely by impairments. This fact establishes distinctions between disability and impairment made by Oliver, who claims that disabled people have been controlled through exclusion and the medicalizing of disability. These two elements constitute disability as hegemony, historically constructed by dominant groups in capitalist societies to divide “productive” from “non-productive” workers. I offer
evidence that these two forms of control persist in the present in a post-ADA world. This context is important to my arguments going forward, as I continue to discuss disability—the social phenomenon—and its corollary, impairment. In the Chapter 6, I interrogate impairment more fully in order to remind us that the body is not simply constructed but experienced.
CHAPTER 6
MANAGING BODY TROUBLE: IMPAIRMENT AND SELFHOOD

As the field of disability studies matures, Carol Thomas (2002) observes that “the body question will not go away” (p. 70). Opinions vary about impairment and its role in the disability rights movement. They cluster around a central question: to what degree does the body prevent one from living a rich, full life? Some scholars argue that the human body has limitless adaptive potential (Oliver, 1996). In this view, disability oppression and disablism—that is, social limitations and attitudes, not biophysical limitations—hamper an individual’s quality of life. Others insist that this stance ignores the tactile experiences of the body and relegates impairment to the clinical gaze (Crow, 1996; Morris, 1996; Wendell, 2001). Bafflingly, scholars tend to take an either/or stance in this debate. In this Chapter, I attempt to see the world through young women’s experience to illuminate the meaning and management of bodily impairment, difference, and identity. I believe these embodied meanings offer fruitful knowledge without disrupting the cause to eliminate disability oppression.

In Chapter 5, I examined the creation of barriers between people based on regimes of bodily control. Here I introduce a physical component, exploring what Morris (1991) calls “real bodies:” bodies that experience pain, nausea, fatigue, and weakness. While I do not fully abandon the constructivist orientation that views bodies as representations (since participants discussed women’s bodies in media), I elevate the body’s materiality as Thomas (1999) and Wendell (1996) advocate. I believe materiality is an important point because differences between bodies are not arbitrarily created. As

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1 I explore these two stances further in Chapter 8. As an aside, Oliver (1996)–fierce advocate of the social model–argues that any attempt to locate disability inside the body is “politically dangerous” because it could “divert attention away from the main goal: challenging the socio-structural social barriers ‘out there.’” (in Thomas 1999, 2006).
I will show, bodies are *lived*, not merely represented. Impairment was a salient fact of this lived experience for the participants. The women managed the meaning of impairment through intersecting realms of gender, sexual relationships, motherhood, appearance, physical sensations, emotions, and self-presentation. Overall, I discern that *corporeal* bodies and the public *reaction* to bodies were difficult to manage and control. Selves, however, were infinitely malleable.

**Physical Realities**

Women with more significant physical impairments (spina bifida, cerebral palsy, ataxia) and disabling chronic illnesses (lupus, Crohn’s) shed light on day-to-day experiences of embodiment. Women like Alissa, Tammy, Paula, Ericka, Julianne, Saundra, Darcy, Brinn, and Janet talked about managing movement; that is, doing the daily work of being a person “present in the world” with their body. I organize this section according to four concepts: the body in pain, the falling body, the uncontrollable body, and the moving body in space. All participants told strikingly similar stories on bodily fluids, body parts, pain, fatigue, and drug side effects. They also related similar experiences with unpredictable organs and limbs. Despite these similarities, the narratives were personalized, unique meditations on the body’s rhythms and how “real” they become to people.

**Pain and Fatigue**

I asked the participants “What is it like living in your body on most days?” Pain and fatigue became immediate themes in the answers of women with chronic illness and physical disability. The results also varied depending on type, severity, and length of time living with the condition. To make sense of this variation, it might be best to think of the storyteller’s body as a character in the story itself. Not only did I want to explore
what pain *felt like* for the women, I also wanted to understand what pain *meant* to them, especially when it acts like a visitor or constant companion. Hence, pain was often anthropomorphized by participants as a tactic to examine its role in their lives.

I will begin with Paula, since her condition, paroxysmal dyskinesia, was one that was the most unfamiliar to me. I asked her describe the spasmodic sensations she felt in her arms:

It’s like a sharp pain, usually at night after an episode, and my muscles become sore afterward. The force of the spasms makes them sore, because when it does spasm and sometimes my wrist will cringe and it tries to hyperextend and it’s really painful... It sort of shoots all the way down my arm. The muscles in my shoulder seem to be tighter, because all of your nerves come through underneath your arm pit and down your arm and so like all around there where it’s really tight and that’s compressing the nerve there and that’s what causes the spasms throughout the arm.

Pain and fatigue were inseparable for Paula. She described muscles working so furiously during these spasms that afterward her body felt like it had gone through a grueling work out. Her spasms usually happened in the evenings, so she would spend the next day groggy, without a full night’s sleep. At the time of our interview, she had just begun experimental botox treatments, which seemed to lessen the severity of her spasms. Paula also considered her condition more of an illness and less of a disability because she had to contend with chronic pain on a daily basis.

Some medications and treatments doubled the original pain and fatigue. Carmella experienced fatigue from migraines and “seizures,” but this was secondary to the overwhelming exhaustion she felt from the drugs and devices designed to help her adapt to the illness:

I never really thought about it until I experienced how sedating and tiring and exhausting the medicine is in itself. I mean just the medicine is disabling. I have side effects from medicines that disable—like my eyes, I never had to wear glasses until now. [The drugs] make my vision fuzzy.
And then some other medicine I was taking made my eyes dry, so I take medicine for my dry eyes…and I have special prism lenses but I get a headache from wearing them.

Carmella understood the social mediation of fatigue, and how its origins were external to her anatomy. Using medications to treat the side effects of other medications is a familiar story to ill people. The narrative of the “trade off” becomes a way to make sense of this conundrum. Carmella treated one disability but received another.

As a person with Crohn’s disease, Julianne experienced constant pain throughout most of her life; consequently, her thoughts on it were complex and introspective. She called her physical sensations “flare ups,” or a burning irritation in her stomach. “I still have these weird flare ups that we really don’t know where they’re coming from, because it’s constant,” she stated, “it’s almost like a constant state of flare. I have to be on antibiotics almost constantly.” Interestingly, she felt the same pain after her colectomy as she did before the surgery. It was almost as if nothing had changed in her body. This fact surprised her because the colon’s removal meant there was no physical organ present to become irritated. She tried to make sense of this oddity in a fascinating way:

I don’t know where the pain is. After you’ve had your colon removed, things, like nerves, things get shifted around. So maybe the pain that I’m feeling, I think that it’s coming from here, but it’s actually coming from [somewhere else]. It’s like phantom pain, because, they put everything back in as best as they could, but it’s not the same. Plus I’m missing six feet [of large intestine]. You know my body may think it’s still there. Maybe its phantom intestine pain and my body doesn’t realize that it’s not there, or maybe something is irritating those nerves.

Here pain is not a precise property–its exact cause and location for Julianne is unknown. She also characterized her body as having its own consciousness (albeit an ignorant one), producing pain without purpose. She also used singular and plural
pronouns interchangeably throughout her interview, switching from “I just deal with the pain,” to “we just don’t know.” The “we,” I think, refers to both her and her doctors collectively scrutinizing her body’s mysteries. Moreover, the bizarre experience of phantom bowel/intestine pain is a phenomenon that cannot be explained with a purely social constructivist approach, exposing the theory’s limitations.

Pain is so much more than a simple, personalized sensation in the body. It has ideological significance. Julianne was recovering from surgery to repair a hernia and fistula during our second interview. After surgery she felt two types of pain: one a “constant pain,” and the other an “intermittent” that felt like a “sharp, can’t move, ‘your-breath-is-stuck’ kind of pain.” These sensations worried her so much that she returned to the emergency room, fearing that she had torn her sutures or herniated more tissue. The doctors probed her stomach and bowels for the cause, but found nothing. Eventually it dawned on her to go to a physical therapist who massaged her scar tissue and eliminated the pain altogether. Julianne had pointed remarks about this revelation:

In twenty years [of surgery] nobody suggested physical therapy. I know that wouldn’t have solved any of my actual Crohn’s problems. But somebody could have told me about [physical therapy] ten years ago after I had my first surgery and maybe I wouldn’t have had so many problems, maybe I wouldn’t have had to have second, third surgeries. Maybe all I would have needed was the physical therapy after the first couple. And they wouldn’t have had to go in, re-cut and re-scar everything.

Pain had been something she thought she had to “work through” on her own. The physical therapists helped her realize that pain did not need to also mean submissiveness. Julianne began to politicize pain, to find its social origins, and to disassociate it from her identity.
The Falling Body

Three women—Tammy, Ericka, and Saundra—frequently experienced falls. Falls were a fact of everyday life for them, so they tended to downplay any problems it posed to their functioning. Falls had occurred so frequently throughout their lives that they became normal, unremarkable events. At the time of the interview, Tammy walked with the aid of a guide dog, Ericka used a wheelchair, and Saundra used a variety of devices (wheelchair, cane, crutches). The women addressed five fall-related issues: falling as an “art,” pain from hurting themselves during a fall, building inaccessibility, fear of lawsuits, and other people’s reaction to falling in public.

In the first case, participants found ways to manipulate their bodies to lessen injury to themselves and others. Ericka and Saundra bonded over their mastery of the “art” of falling:

Ericka: I fall two or three times a week at least. And typically I know how to fall.

Saundra: I’ve developed it into an art basically.

Ericka: When you falling you just know where to place things so you don’t get hurt. But if you’re not thinking, then you’re going to get hurt. I’ll tell plenty of people like if I’m going to fall in a crowd of people, I have to figure out my surroundings.

Saundra: Like I lay more on my ass.

Ericka: Yeah you try and go for your butt.

Saundra: For me, it’s like one minute I’m in the air and the next minute I know I’m falling, and then I’m on the ground. And sometimes it’s even I’m in the air, I’m on the ground, I don’t know how I fell, and I’m like great I have to get back up.

Falling expertise did not mean that the women moved around without injuries, however. Tammy illustrated how falling is not just an act of tripping over one’s feet while walking—it can even happen lying down. "My balance is very bad," she says, and “recently my
back has been killing me because I had an accident, fell off my bed in my dorm room...so that’s been hurting." Ericka remarked that her disability (Frederick's ataxia) was not a source of pain—it was more so the accidents she had accumulated over the years:

I guess I do have lack of feeling in my lower extremities. I don't have any pain due to the [ataxia]. I have other things that have happened, like my broken foot that I have pain from, or a broken arm. I broke my arm a few years ago and I have pain from that occasionally. But the [ataxia] doesn't cause any pain.

She noted that her accidents caused bruising, and that this was painful to her. However, it was not unimaginable pain; Tammy and Ericka both stressed their high pain tolerance and that they did not hurt themselves every time they fell.

Ericka and Saundra’s conversations also revealed how problematic public spaces can become for people who are prone to falls. Public restrooms posed difficulties for Ericka when she was recuperating from arm surgery:

I have to hold myself on the rail to be able to stand, and with my arm, I’ve fallen in public restrooms like three times. The first two weeks [after surgery] it was really bad. I’ve never fallen in a public restroom, and I couldn’t get up, it was concrete. I can’t get on my knees on the concrete and get back up on my chair. I’ve had to ask people to come in and help me up. Once I was in the mall and a lady had to crawl under the stall to help me out. That was really embarrassing.

Ericka hinted that these kinds of falls—the ones where she is unable to get back in her chair—come from a combination of poorly built environments and her own upper-limb impairment. Similarly, Saundra suggested that falls were products of a fast-paced world and an inability to match its pace:

One problem I have with falling is my nerves. I walked [from the bus stop to the cafeteria in the student union] and I froze because there was this big crowd of people heading toward me. And I’m like oh crap, I forgot about that. And my feet don’t move as fast as my brain does if I’m thinking about it
really seriously. And that's what got me, I kind of froze and then kind stumbled over the wall.

People in the crowd helped her, but I sensed from the interview that she did not want their help. The fact that she *almost* made it to her destination fall-free seemed to trouble her. Up to that point, she had been concentrating on walking, but the crowd broke that concentration. To me, this incident revealed the way in which able-bodied people are not aware that walking in large groups is a benefit they enjoy. Saundra, however, wanted to be as unobtrusive as possible. She said she felt bad because her helpers were busy: “they're taking time out of their schedule to help me and I'm going 'I know I'm making you late!'”

Oftentimes able-bodied people are oblivious to their upright posture and ability to move freely over ground. This creates a culture in which they define falls as exceptional, worrisome events. For people like Tammy, Saundra, and Ericka, however, falls were mundane. Workman’s compensation rules exemplify this conflict and the two different worlds the groups inhabit. Saundra admitted that her workplace was an especially tricky place to fall: “It scares the shit out of everybody at work. [They ask] ‘are you okay? Do we have to fill out another accident report?’ I’m like no, I fall every single day. What’s your damn problem?” Saundra questioned a system in which she had to constantly fill out official forms for events that were as natural to her as breathing.

 Whereas the women assured me that most people expressed well-meaning concern and offered assistance, a few people did not. I had to ask the women about any bizarre reactions people have had to their falls. Saundra responded immediately with one of the most ironic and hilarious stories thus far in our conversation:

One time somebody thought I was drunk and threatened to call the police on me. I was a freshman [in college] and I had decided to go on a walk. I
was living on frat row and I fell on an incline, so I fell down into the gutter right behind one of the frat houses. This one guy decides to fish me out and–I’m so ignorant–his parents were there and his mother took one look at me and she goes “Are you drunk? Are you on drugs?” And I’m like, “No ma’am, I’ve got something called cerebral palsy, and I’m perfectly fine.”

In the interview we had a good laugh about this woman’s overreaction, and how she could only think of Saundra’s fall as drug-induced. This illustrated a fact about living America today: being disabled or ill in public is still inconceivable to many people. Public displays of disability, like falling down, caused people to make strange conclusions about the way bodies should and should not behave.

The Grotesque Body

Researchers have documented that experiencing uncertainty is a persistent characteristic of persons with illness and disability (Mishel, 1988, 1999). People who are ill worry about remissions, recurrences, setbacks, exacerbations, and destabilization of health, which prevents them from planning day-to-day events and setting long-term goals. More viscerally, the experience of disability and illness is shaped—and some say defined by—the inability to control muscles, movements, or fluids. Descriptions of the body in this section may seem gross or crude, but that is exactly the point–too often this fact of life is glossed over by heroic stories of overcoming the body’s limits. Crude narratives were most prominent among women diagnosed with chronic illness. Carmella, Brinn, Julianne, Paula talked about their bodies acting erratically and discussed how it felt physically and psychologically to live in a body with a mind of its own.

I interviewed Brinn a few months after her first serious hospital stay that culminated in a lupus diagnosis. Steroids caused her body to swell to the point where
she did not recognize herself in the mirror. This was distressing because of the speed at which she gained the weight. She did not have time to adjust, stating that,

I went from being too little, too skinny, to being overweight, and I've never had that overweight feeling in my life before, so it was one of the hardest parts of this...not being to do anything about it. Knowing that I wasn't like that, knowing that I could push on my skin and see it going in, you know what I mean. I just felt like it wasn't really my body. It was really surreal. Like an out of body experience. You feel like it's you, but it's not.

Brinn struggled to recognize herself inside her own body. As a person who had newly entered the world of illness, this confusion was common. Weight fluctuations were familiar to participants with autoimmune disorders. During the first episodes of illness, one’s self-image cannot catch up with the body’s rapid changes.

Adaptation to an illness did not necessarily lessen the likelihood of an out-of-body experience. Juliane recounted a harrowing year of her life when she had to wear a colostomy bag. A colostomy bag is a pouch that sits outside the body and connects to the large intestine. The intestine comes out in a suture at the abdomen. Juliane described the reality of wearing her insides on the outside for an extended period of time:

It was beyond surreal. I really did live as if my life was completely on hold. I did not try to go on with normal things. I just let that happen and I just let my body heal and go through the process. And let the insides, my internal organs, heal up so that I could get the [bag] removed, so that I wouldn’t have to deal with the bag because it was like living in a dream. I basically had to stay outside of myself because if I went in, it was just so depressing and awful to see your body in such a terrible shape.

She then described what made her body so unsettling:

Basically you see your intestines looking out of a little hole in your stomach and that is a terrifying, terrifying thing. And when you see it, that’s what horror movies have, the disemboweling. Jason with his mask and he’s disemboweling somebody, you know. Oh God, that looks like me.
Like Brinn, Julianne separated herself from her body to cope with the gruesomeness of the ordeal. She did not go out in public, staying in bed for a year. She only got up to go to the bathroom and shower. These tasks posed different problems. Showering was a mess because water would loosen the adhesive around the bag, and poop leaked out on its own. While poop was easier to clean up in the shower, emptying the bag—what normal folks would call going to the bathroom—was even messier:

You can’t sit down and empty [the bag], I don’t care what the people tell you, you cannot sit down and empty it. The nurses tell you to empty it, sit down and empty it between your legs. And it’s not going to happen, it doesn’t work, it splashes. You can turn the bag a lot of the times and kind of aim it that way, but it’s a very large hole, the bag has at the end. So it’s going to get either on you, on your clothes, it’s going to splash. It’s gross.

Public restrooms were exceptionally difficult places to empty the bag because she did not want to touch the floor. Her arthritis (a common secondary condition among people with Crohn’s) posed even more challenges:

Imagine trying to maneuver, kneel down in front of a public toilet, trying to kneel down, basically facing it…I wouldn’t touch the ground, and can you imagine having joint problems, trying to maneuver yourself into a position where you’re trying to empty this thing, it’s…it’s very difficult.

Of course, such stories of filth and revulsion are never broadcast in public discourses about disability. Shrouded in shame, they are intimately private accounts; if I had not been a friend of Julianne’s prior to the interview, I might not have been privy to them. Other participants did not open up to me as much as she did. But the difficulties Julianne experienced convey the body’s unpredictability and the physical reality of illness in important ways. Exposed guts, cracked skin, spilled poop and dirty floors are glimpses of people’s daily degradations. In Chapter 8, I will explore the political nature of these degradations, drawing parallels to other oppressions thrust upon immigrants and people of color.
Surveying Space, Managing Movement

People with impairments must cope with a material and social world that is hostile and frequently disordered (Kelly, 2001). More precisely, navigating inaccessible spaces with an unpredictable body is a common anxiety for people with disabilities. Participants with chronic illness and disability reported similar anxieties. As a response to a body that she could not control, Ericka created an orderly sanctum out of her house:

I like to have everything in its place, you know. I like to have to have my clothes laid out before school. I’m just very much organized. I’ve said this to other people and they look at me like I’m crazy, I don’t have control over my physical body, so I have control over my space. Like the [Frederick’s ataxia], I can’t really like control at all…but I can say well that needs to go there, I need to have all my school done by 11:15 at night, you know, I have control over those things.

Having interviewed Ericka in her home, I can attest to her orderly household. She had me fetch a wheelchair for her in the back of her closet, and it was exactly where she said it was, neatly tucked away. Ericka lived alone independently in an accessible apartment. The control she was able to exert over her personal space contrasts with the authoritative spaces of institutions. It is important to note, though, that domestic spaces were not always so benign, stable, and cozy; in the Victorian era, many households quickly ejected their disabled members without sentimentality (Gleeson, 1998).

When most able-bodied people think of “accessibility” for the disabled community, they think of typical modifications like wheelchair ramps or audio signals at crosswalks. Few people think of the implications of clean, proximal bathrooms. This was Julianne’s concern since she had frequent, unpredictable bathroom urges. We visited a flea market together the weekend of our interview, and I asked her how her body responded in a space like that:
When we went to the flea market, I was very nervous about their bathroom situation because it was outdoors and it was not very clean. So the anxiety or worrying, that becomes an issue as well, that almost becomes physical crippling because you can’t move, you are so scared, so nervous about what happens if you can’t get to the bathroom, am I going to be able to hold it, am I going to be able to go somewhere else, and that becomes nerve wracking because of the social stigma of potty training.

The social anxiety she developed about bathrooms and toileting was a social disablement on top of her physical impairment. As a result, Julianne had to strategically plan her daily outings and long-term trips. I asked her about her process of daily and long term planning and how it affected her life growing up. In both cases, she felt limited by her body and the environment. As for her daily outings in the community, she explained how she made mental maps of surrounding bathrooms:

Rather than always suffering through all that kind of stuff, either I would have some sort of elaborate plan, like I’d know where a secret bathroom was or something like that or I just wouldn’t do stuff because it did, it really did…I wouldn’t go to the mall, or I wouldn’t go out to eat, or I wouldn’t go, to skate night or something like that, you know. I was definitely missing out on things.

Planning for a long trip was even more disconcerting. Julianne described how she missed out connecting with family members because of the difficulties that trips posed to her body:

The idea of traveling and having to use restrooms, on the Interstate, gas stations or whatever, that’s just so uhhhh! - nerve racking and anxiety inducing. It’s hard to tell my parents that I’m not coming home for Christmas. I don’t want to drive the five hours and then feel like shit while I’m there the entire time. A five hour drive will do that to me, it’s exhausting.

Having to think all the time about her body was another exhausting feature of travel.

She detailed why she needed a bathroom close by, even if she did not eat or drink:

I don’t have the muscular control that use to, and so I mean just a slight movement or something could set me off in the wrong direction, and I mean it’s not like my body doesn’t distinguish between gas and actual bowel
movements anymore. It’s the same, not like fart silently, I have to find a bathroom, I just have to.

Julianne’s case related to the interaction between a disabling physical and social environment (Albrecht & Devlieger, 1999). She sought spaces that could accommodate her needs, but her body’s mixed signals frustrated these spaces, even when they were available. It is important to note that Julianne was very “in touch” with her body; in her case, illness was a job where she marshaled her resources to succeed by attending to her body’s needs above everything else—even ties to the community.

**Working on the Self through the Body**

This section relates to laboring or working on the body as a technique to modify, understand, or cope with a person’s self-image. The technique is highly relational, as people who work on their body draw from myths and images in our culture about what a “sick person” looks like, how they should behave, and what makes them different from others. Therefore, in this section I actually use the different groups I interviewed as a basis for comparison— but only as a way to understand how body work differs across conditions (not to claim that one is better/worse, or more/less difficult). I also discuss ways in which participants sought to repair their bodies through medications, cures, treatments, and therapies.

**Comparisons to Other Women**

The women made simple social comparisons to others (usually to other women) in their interviews. Comparisons are part of the human tendency to negotiate one’s own moral standing as a “good person” (Charmaz, 1999; Noam, 1993). For women, much of their “goodness” is related to their appearance. Kokoro and Nela, two women with acne, expressed dismay at these unfair social judgments, but also could not resist making
comparisons themselves. Kokoro offered insight into the way that women judge each other—and in turn judge themselves: “Women definitely judge each other on their looks. Like I always judge my sister. I say ‘oh she’s so much prettier than me.’ My sister has always been ‘the pretty girl,’ even when she didn’t try to be.” I asked Kokoro what she meant by “pretty” since it’s a highly subjective description. She ventured:

[My sister] has a really pretty face is what I’m getting at. It’s everything. She has perfect teeth. She has perfect skin. She has a perfect face. She has unmanageable hair but she knows how to manage it. She knows how to like dress, she has a really nice body. She has good materials and she knows how to work it.

Kokoro described herself and her older sister as “complete opposites” in terms of appearance. Curious if these comparisons caused any tension in the family, I asked if the two had any discussions about their differences in appearance. “No, not in depth,” she responded, “because I know what my sister would say. ‘Kokoro, no matter what anyone says, you are pretty. Don’t ever say that [you’re not]!’” Kokoro described herself as “scared” of her sister when she made these forceful statements. In Kokoro’s mind, skin became the main conduit for sizing up the differences between them:

[My sister] has never had any skin problems. She could eat a greasy cheese pizza, and maybe get a little fat, but she won’t break out, and then she’ll be fine. But I could eat the same greasy cheese pizza the next day I’ll have like a cyst on my nose. When I see people eat like whatever they wanna eat and they don’t break out it’s just like, kind of frustrating. Like man I wanna do that, screw you.

Kokoro described acne in a similar fashion to those illnesses that require meticulous daily management to avoid a flare up or remission. She worked on her self-image through the body by expressing unfairness about pleasures that she cannot enjoy without consequences, like everyone else.
Women like Nela were also trying to sort out their own possibilities for self-presentation by comparing themselves to other women. Though Nela had acne off and on for most of her life, she insisted that presently, weight was more of a concern than skin. In a confessional tone, she described how she made comparisons between women and herself, yet also felt guilty about this process:

If I find a girl who is actually wearing shorts, but I will watch them. I will compare her body to mine. Because I'll actually see some girls who are bigger than me who will wear shorts, but they actually look good in them. So I'm constantly trying to figure out why is it that there are some girls who are a little bit heavier who can't get away with certain clothes, and there are others who can. And they actually make it work. I've just noticed that. So I'm always wondering myself why is it that some people, clearly they're not the ideal image but they can do it. And they have confidence about themselves. But other people on the street can't do it. Why can that person do it and not that person? And then then I think of myself thinner “She can do it, but could I do it?” I think about it for me, could I do it too? That kind of thing. And I feel like such a creep.

This “creep” feeling Nela mentioned is an expression of shame about the act of dazing up women's bodies. She does not describe it as an act of sexual attraction; instead, Nela felt disturbed because it could be misunderstood as one. How women closely examine each other’s bodies and clothing is rarely discussed openly among women. Yet, Nela revealed the back stage work to create a front stage persona—or, at the very least the possibility of a persona that she hoped to develop in the future. The end goal of this comparative work was, essentially, to feel good about oneself. Kokoro explained that comparisons are not acts of meanness or spite—instead, they are moral boosts to one’s self-esteem: “You'll say 'I look better than her!' and that makes you feel good, because compared to everyone else you look nicer. But it's not this negative ‘I look better than you, and you should feel bad!’ It's more like ‘I look better than that girl, so I feel good today.’” This statement typifies beauty hierarchies that shape women’s
relationship to their bodies. Normative femininity becomes oppressive to women when
the basis for self-worth is a yardstick.

Face Work

Goffman (1967) recognizes how the face acts as a template to invoke, process,
and manage emotions. Similarly, in her ethnography on facial disfigurement, Talley
(2008) observes that the face is a “social technology through which people are labeled,
differentiated, and potentially devalued” (p. 12). Indeed, within dramaturgical studies on
the body and feminist studies on body work, the face is a salient object of sociological
inquiry.

In my research I found that women with acne or obvious birth marks did not
experience the same type of body trouble as women with illness or disability. Unlike the
latter group, women with skin conditions appeared to be more invested in female body
projects like obtaining flawless skin, losing weight (especially in the face), and
experimenting with make-up. Participants in this group tended to view their own faces
as doorways to project embodied selves. They were also more likely to believe that
changing their bodies and/or faces was possible and/or necessary, and that this change
could be achieved temporarily (like make-up or creams) or permanently (like laser-
treatments or cosmetic surgeries). Unlike women with illness in this study, women with
skin conditions expressed a heightened interest in competent appearances and
feminine gender codes. Of course, they processed these concerns through their
interactions with their friends and consumer culture.

Kirsty had a pink port wine stain above her eyebrow that she often hid with
foundation. Perhaps this mark caused her to read other people’s faces in a nuanced
way: “I saw a girl who had a brown mark that would have taken a lot more effort to hide
[than mine], and I was like, that really sucks. That’s what I thought in my head, ‘I shouldn’t be thinking that, I have one too and I wouldn’t feel good if someone was thinking that about me.’” Kirsty engaged in what interactionist scholars call “alignment,” or the work done to mend or “save face” in joint actions with others (Stokes and Hewitt, 1976). Kirsty mentally checked herself, applying effort toward policing her negative thoughts. For Kirsty, alignment was the end stage of tiny units of unspoken actions: looking at a face, comparing it to one’s own, processing differences, reacting negatively, and correcting that negativity with a positive, more empathetic view.

Nela described the mental work-out she exerted when comparing her own face to the “perfect” faces in advertisements. Commenting on what most bothered her about her own face, she said:

It would definitely be all the [acne] scarring. You can’t get rid of it. It stays with me. I look at all these girls, they have clear skin. I see them on TV—I try not to use TV as my model but sometimes it’s kind of hard. It sinks in. I’m a communications major and I’m studying it, and I know clearly this is ridiculous. I know this, but it’s like in my brain, I fight it.

Nela illustrated her struggle to resist irrational thoughts about the impossibility of a “perfect face.” She was fully aware of the camera’s tricks to create unblemished images, but this knowledge did not assuage her uneasy relationship with her own acne scars. Shifting the conversation to the subject of the ads—make-up—Nela opened up about her own use of the product. I asked her how, why, and when she applies make-up:

The only make-up I use is foundation. When I use it I feel like I am more confident. I use it as a cover up for my job, to look more presentable. I felt like I was hiding myself…but I did it because I didn’t want my customers to see me in that way. And I was like “oh my goodness!” My eyes opened. I was like “I’m wearing make-up on my face!” I was a senior in high school when I did this, it was so bizarre, like whoa!
She then explained the progression of her make-up use. Foundation, more so than any other make-up tool, changed her self-image in a drastic, yet positive, way:

In the beginning, I was like “this is unnatural.” And I just kept doing it. Just the foundation. But it took me a while to get any farther than that. Occasional lipstick, no big deal though that doesn’t count. I don’t count lipstick as make-up. Anybody can do that. But foundation was…I did feel like I had a new persona…like I was a new person.

Gentina, Palan, & Fosse-Gomez (2012) found that first-time make-up use represents a rite of passage laden with emotional symbolism for teenage girls. Indeed, Nela gradually found pleasure in her first experiment with make-up as a tool for self-expression. The new persona cosmetics seemed to offer her was alluring, not just giving her a new look but a new outlook on life.

How does this positivity toward cosmetics fit with Nela’s negativity toward airbrushed faces in advertisements? Nela is not a “cultural dupe,” (Dellinger & Williams, 1997, p. 175): she expressed doubt (“this is unnatural,” “I felt like I was hiding myself”), distinguished between different types of make-up (“I don’t count lipstick as make-up”), and acknowledged the odd sensation (“it was so bizarre”). Jeffries, however, argues that the individual “choice” and “freedom” of cosmetics are not made in a political vacuum: wearing make-up is empowering but also debilitating, as women are caught between a beauty practice that makes them feel simultaneously confident and self-conscious. The “foundation” of face work, in this case, is a familiar beauty contradiction. In sum, for women with skin conditions, face work demanded more effort on the part of the participants; they must deflect threats to their self-presentation while consciously using cosmetic technologies to do so.
Repairing the Self

This section explores participant narratives on cures, coping techniques, and discursive strategies to “heal” the self. Disability and illness, especially when experienced suddenly, can present what Morse (1997) calls “threats to the integrity of the self,” meaning that an injury disrupts a person’s life so violently that their core identity is compromised or altered in some essential way. Becker (1997) also notes that efforts to reorder the world after a disruption begin with the body, since life revolves around what the body can do. Hence, people attempt to reorder life, create order out of chaos, establish continuity, or integrate past and present lives (ibid). In this study, participants engaged in these strategies for preserving their moral identities and maintaining a sense of control over their uncontrollable bodies. Throughout the analysis, I describe how participants imagined futures in which bodies/selves might be improved and renewed. Scarier futures, full of constant pain and uncertainty, were also on participant’s minds. By organizing this section temporally, I convey one of the themes of this Chapter–working on the self through the body–by detailing specific types of body trouble and corresponding repairs to it for past, present, and future selves.

Present repair

Some participants were willing to examine their lives at the moment of the interview, assessing their identities as “a person with an illness” and how their bodies impacted those identities. Julianne, for instance, saw herself as a “person with Chron’s,” and this disturbed her somewhat:

It really has become who I am, and it’s sad, I don’t want to be who I am. I really don’t. I mean I wake up in the morning, or sometimes in the middle of night, and I can’t move because I’m so stiff from the arthritis, and I’ve got to wait until I can move. And so I’m gradually able to move around. Everything that I do outside of the house revolves around where bathrooms
are at all times. It also revolves around how much walking we’re going to be doing. Is it going to be fast paced, is it going to be slow paced? Is it going to be a stressful situation where I’m just going to be drenched in sweat, like out of nowhere? I can’t go to work, I mean I can’t go into the office very often because I’m constantly like, everybody always has maneuver around me.

Julianne did not want the illness to dictate her identity. The need to structure her life around it, however, gave her few outlets to try on a new persona. Instead she focused on meaningful identities beyond her illness like the work she produced at her job and her relationship with her fiancée. “A few things that I can still do is be with [my fiancée] and work,” she said, adding “these are two things that I’m good at and that I enjoy.”

If her body interfered with those two accomplishments, she foresaw a distressing future in which she would have to be “taken care of” by her parents. She had a taste of this loss of independence during her recovery from fistula surgery. She reflected on how difficult it was to be known as nothing but a sick person whose body had failed. At the time of our interview she was independent from the sickbed and her parent’s house. Working and being in a relationship gave her life continuity and purpose beyond her body’s dictates.

**Past repair**

Most of the participants with chronic illness remembered how the illness had forced them to reorient their lives around it, either gradually or suddenly. Narratively, they chose to discuss how their bodies broke down during key moments (most often while attempting to complete college or high school). Two participants, Carmella and Julianne, dealt with the memory of body difficulties in two very different ways. Carmella chose to forget, while Julianne chose to remember. The former says of her sickest days: “I just don’t linger on it, I don’t think about how horrible it was.” As an alternative, she
shifted her mind to the advancements she had made to heal. She reorganized her life to avoid triggering the seizure-like episodes or migraines. Carmella also had difficulties remembering the worst days, when she felt “out of control;” she speculates that the memory loss made it easier to avoid dwelling on the past.

Julianne decided to actively enshrine the memory of her colon removal by half-mourning, half-celebrating it. To remember the event, she hosted a “Colon Going away Party” the day before her surgery. Her friends created a “Colon No More” banner, and she ate lots of spicy food. “It was a giant change,” she said, likening it to an amputation—except that she had no idea how much work her colon did for her body. “You don’t realize how much your intestines mean to you until they’re gone” she exclaimed. An interesting fact about Julianne’s colon is that it was, as her doctor’s described it, “lymphatic,” and “pre-cancerous.” Julianne just called it “icky.” Once removed, she asked her doctor if she could keep it. She paraphrased the doctor’s answer: “’No you can’t have it, we have to send it to nephrology. We’ve never seen anything like it. I think we’re going to write a paper.’” I laughed at this, and then asked Julianne, “So your colon is probably in a textbook somewhere?” She believed it was, perhaps used as a case study for gastroenterology students. Talking about her lost body part as if it had “moved on” to a new life without her helped Julianne make sense of a major life change.

**Future repair**

Every participant had hopes for the future that varied from finding a job after graduation to finding relief from chronic pain. The body was always implicated in these hopes as participants insisted on a new future *with* or *without* a corresponding transformation in their bodies. The women with skin conditions were more likely to hope for a cure for their condition and actively search for one without dire consequences to
their health. Women with chronic illness hoped for the ability to maintain the strict
tightrope they needed to walk in order to keep their conditions under control. They
spoke about a cure as if it resided in their own will-power. For the most part, women
with physical disabilities rejected searching for a cure (a decision they did not have the
luxury to make as children), reasoning that the search was medically intrusive, painful,
and unrewarding. Instead, they used their imaginations to think about how technology
could change their bodily experiences.

Like most of the women with skin conditions, Josephine wanted a future in which
she did not have to rely on make-up to feel good about herself. At the time of our
interview, she was using creams that she claimed faded her vitiligo. She sought a cure
because she thought an even skin tone would make her feel better about her body:

I’m excited that maybe one day I won’t have to put on make-up every day. Also I guess it’s that self-image kind of thing where you’re kind of like, if I don’t have it, it would be so much less of a hassle, I won’t have to answer questions anymore, I won’t have to worry about walking out of the house in shorts, and people staring at my knees or my eyes.

“A hassle” was the way that many of the participants described their skin conditions.
Their own acne, moles, birth marks, etc. were not something they thought about often.
Only when people made pointed comments about their skin did it become something
the participants had to “deal with” and explain.

Brinn knew that her illness was very precarious, and that much of it depended on
how well she took care of her body. She had a lot of moral responsibility placed on her
shoulders to achieve her hopes for the future. More than anything, she wanted to
become a person who could smoothly manage the interplay between her emotional and
physical health:
I do get really anxious, but I don’t want it to be one of those things where I take like Adavan or Xanex and not talk to somebody about it. So I would like to get better at maybe with the way I deal with things like stress. With lupus, you can have flairs from stress. I have anxiety and I don’t want that to happen to me. I want to be good in all aspects. When something traumatic does happen to me…I want to be able to handle it in the right way.

Brinn could not specify the “traumatic” event, she just knew that her response to it would matter more than the event itself. Like most people with chronic illness, she was confronted with what she described as “fear of the unknown, fear of now knowing what’s going to happen to you.” Managing this anxiety was a layer of mental work that only emerged among participants with chronic illness. This finding suggests that young women newly diagnosed with chronic illness may need special care and concern for their emotional well-being.

The participants with physical disabilities had given up on finding a cure for their conditions. I did not press them on this point, aware that that “curing” disabilities suggests eugenic-thinking—an offensive concept to some in the disability activist community. Ericka and Saundra, whose parents had sent them to doctors throughout their childhood in search of a cure, appeared to process self-repair by coming to terms with their bodies’ limitations. They refused to volunteer for involved, life-long medical experimentation. Moreover, since the majority of the participants were born with their disability, they expressed fewer ruptures between their bodies and selves.

A certain identity was nonetheless evident in our conversations about technologies to improve the body. In a group interview, Saundra and Ericka discussed the science fiction/fantasy movie *Avatar*, in which a man with a spinal cord injury regains a newer, better body. Saundra explains her reaction to the film:
The moment he gets transferred from that coffin thing into the blue people body, I started to think “wow,” and it was something that he hadn’t been able to do. I would take them up on it in a heartbeat because that’s what it’s like. I don’t really think of it as, “You don’t know what I go through.” It’s more like, I would like one morning not to wake up stiff and cramped and knowing that sometimes I have to crawl to the bathroom.

*Avatar* captured Saundra’s imagination because she wanted a relief from embodied distress. She wanted the convenience of moving around freely. Ericka agreed, offering a similar view:

**Ericka:** I told my mom and dad for years that if we had the technology, I’d like amputate my legs and put fake legs on them. If that means I would be able to walk and to do all the things an able-bodied person does. Don’t feel like that now because I love my tattoo.

**Interviewer:** Are you saying want a new body?

**Ericka:** Not necessarily, it would just be nice to have the mobility, if that makes any sense. Like you [referring to interviewer] can stand up and play in the rain, I can’t stand up and play in the rain. Even dance, I grew up dancing, I was in toe shoes for God sakes. I can’t do that anymore. I would give my right arm to be able to stand up and dance.

When Ericka said this to me, I felt a gulf open between us. She directly named the experiences that she cannot enjoy and ones that I took for granted. These experiences could not be bought since they were not based on material luxuries or class privileges. They were embodied differences that separated her from a common, everyday activity. The type of self-repair she engaged in (imagining new legs, finding pleasure in her tattoo) differed from the repair work of women with skin conditions or chronic illnesses. This type of repair work involved imagining living a world without inequalities in sensation, mobility, and movement.

**Understanding Difference**

One theme that surfaced across the interviews was the diversity in how the participants understood that they were different. While everyone had a unique rationale.
for explaining their differences from other people, everyone spoke about how they looked, acted, felt, moved, walked, or thought differently than others. They also had precise memories about the first time they realized this difference. Those who had a positive outlook toward difference (seeming “at peace” with it) had usually lived with it for a long time. Those who were new to difference felt like they were thrust into a confusing world where people’s responses to them made little sense. How people understand difference is another facet to working on the self through the body in order to manage a morally threatening body trouble.

Emelia was born with a congenital condition that stunted finger development in her left hand. Since she was born with this disability, she had many years to think about it. She reflected on a time in middle school when she always wore long sleeved shirts so that no one would see her hand. She said she wanted to hide herself because she felt strange and different. Looking back, however, she realized that this was an unsustainable way to live: “It was one of the silliest things I’ve ever done. And I don’t know if that’s what made me who I am, because now I’m not too extroverted, but I think I’m ok with that.” Emelia and other participants born with disabilities wondered how much growing up “different” shaped their personalities. Of course, such questions were difficult to answer.

Tammy was born with spina bifida and walked with a gait disorder. She recalled the first time she knew that she was different from other people. Like Emelia, she wanted to hide from public view:

This must have been like 6 or younger than 10, I know it was before my surgery. I remember being young and shopping with my mom and I saw a boy. I remember saying, oh he’s cute. I would purposely try to not walk by him because I didn’t want him looking at me. I was ashamed when I was
younger of being different. I didn’t want to be different or want to be seen as different. Especially when I was younger, like if I fell, I didn’t want people to go “Oh my gosh, let me help her.” I didn’t want that.

As a young girl with a physical disability, Tammy was taught to be afraid of difference and normalize herself at all costs. People making “a fuss” over her was undesirable because other kids did not have the same kind of attention forced on them. As she aged, Tammy began to realize that difference was within her power to manipulate:

Sometimes I downplay my disability, where I’ll totally be independent, I’ll deny help. But other times, it depends on the day, the mood, I’ll be like you know what, I’ll let you carry my tray for me or I’ll let you open the door for me, things like that.

Tammy then explained how she is no longer constantly reminded that she is different because she has been able to blend in with able-bodied society. When I asked her if she feels like her disability is a part of her identity, she stated,

It depends, I think yes, my disability is part of my identity, I don’t ignore that, but sometimes it can slip my mind, I forget. Like if I’m sitting in class, people don’t realize, they don’t know anything like they just meet me while sitting.

Like any other identity bound by social structures, disability has different meanings depending on the time and the place.

Saundra and Ericka echoed Tammy’s thoughts about perceiving oneself as not different. This finding reminds able-bodied people that Saundra, Ericka, and Tammy do not think about their disability all the time. Nor did they choose to forever identify themselves as a “person with a disability.” Ericka said “I see myself as able-bodied, just like you do.” Saundra, who wrote fiction, agreed, stating that “when I’m writing my characters they are kind of based on me and they walk around like able-bodied people.” She continued, speaking for herself and Ericka: “We really don’t think of ourselves as disabled, and I really thank our families for that because they didn’t just dump us on the
curb.” Saundra appreciated how her parents gave her a normal upbringing so that she knew how to think, act, and envision herself as part of the able-bodied world. “My dad was constantly saying, you don’t have a disability, he was always so funny about it. He still does that, which gives me great confidence, but at the same time growing up wasn’t easy.” Recognizing this, Saundra’s parents prepared her for a point when she would eventually encounter discrimination. This perplexed her because she did not consider herself a minority at risk for discrimination. Her dad handed her an ADA pamphlet during her senior year in high school. “I’m like ‘what’s this?’” she said, “I didn’t know I had any rights. I figured I was like everybody else.”

Truly, Saundra had the most in-depth examples for ways that she understood difference and sameness. She was constantly challenged to think of herself as different and not different. I think this is because she desired to enter society’s most ableist institution: the military. She recounted:

I took martial arts when I was in high school. My sensei kind of broke it down for me real plainly. He was like “Look you’re not going to be able to get in, because it’s going to take a lot of people to help you out of the field because you can’t run as fast.” Of course, I was in high school, I was cocky, I thought I was at the top of my game! But when I got to college in the ROTC [Reserve Officer’s Training Corps], I finally realized what he was talking about, because technically it takes four people to carry one injured person out of the field.

During her time in the ROTC Saundra focused on what she could do well, and did not dwell on those things she could not (like marching). Her difference from other ROTC members was an unavoidable fact (being ineligible to join the military as an officer), but this was not at the forefront of her mind. She enjoyed the program for the camaraderie and fellowship she found with like-minded individuals.
Women like Carmella who had recently acquired an illness had greater difficulties adapting to the way others responded to them. Whenever she sensed one of her episodes coming on, she had to lie down on her back, no matter where she was at the time. This created an interesting exercise in breaking a social norm (unintentionally, of course):

I’ve had some staring, usually people look at you funny and walk off just whatever and some people are occasionally concerned. It’s hard for me to convince them not to call 9-11, that’s very difficult. Because I don’t really need paramedics unless I hurt myself.

She understood her own difference by the lack of a wheelchair—a visible symbol that clearly translated the help required:

I don’t know if they think that I’m trying to take a nap or something. I know someone in a wheelchair, and if she falls out she has people come and help her get up. But with me, nothing is obvious, they think I’m drunk or on drugs or something. I’m not sure what’s going through their brains. It’s very foreign to me because I don’t understand. It gets to the point where I’m jerking and as part of my brain is like, where is everybody, why aren’t people coming to help me?

Lying down in the middle of campus provoked a mix of behaviors from people that Carmella struggled to understand. Maybe one day she could manage their responses with practice, but difference was not a tool she felt like she could control like Tammy or Saundra did. At that point in her life, there was no way for Carmella to insist that she was not different whenever she had an episode in public.

**Having a Disability “Sometimes”**

Peters (1993) inspired the title of this section. She writes about individuals who “sometimes” lack consistency in the appearance of their disability, although their disability in reality remains with them (p. 26). Dichotomizing disability into “invisible,” and “visible,” ignores how it is often experienced as a changing state of being. Having a
disability “sometimes,” says Peters, is a unique identity that is defined by inconsistent and perplexing responses of others. Hence, individuals must work harder to project images of themselves as legitimately excused from normal social behavior. Participants with “intermittent” medical conditions, like lupus, Crohn’s, paroxysmal dyskinesia, and undiagnosed disorders managed their bodies in addition to managing other people’s expectations.

Carmella wondered if having a visible disability might make people’s responses to her more sympathetic and less skeptical. She explained how she strived to assert herself as someone who qualified as disabled:

To some extent this is my life. I tell somebody I’m disabled, and they’re like “What are you talking about?” It’s a big hassle. I think maybe it would almost be easier if they could physically see that I was, because the fact that I don’t look physically disabled is like, “How do you want me to react, I don’t understand.”

Carmella explained her undiagnosed condition in the simplest way possible–she tells them it is “like a seizure or a migraine.” Carmella welcomed any definitions of disability beyond the stereotypical image of a person in a wheelchair. She would benefit from more social awareness and understanding of people like her who have a disability “sometimes.”

When disability or illness lacks easily interpretable symbols like a gait disorder or assistive device, people must exert more effort to remain in good standing with others. Schneider (1985) shows how people with epilepsy represent a moral view of illness, distinct from deviance or stigma. Physically ill people may not be blamed or devalued for their condition, but “their illness can become the basis for others having to do more ‘work’ and take on more and sometimes heavy responsibilities. . . They become ‘risks,’ liabilities,’ and ‘worries’ in others’ eyes” (p. 119). Julianne did not want to trouble others
with her chronic pain and discomfort. At the same time, she wanted to make them aware that her behavior was a response to discomfort—not a symptom of a poor work ethic or disgruntled mood:

I'm sick, I don't necessarily look sick, and so it’s hard to tell my boss I feel bad. I feel uncomfortable doing that. I would rather go to work and be sick than make someone think that I'm trying to get out of work. That is my greatest fear, is that people think I’m lazy. Or that people think that I’m doing something because I either don't like them or don't want to. The thing is, if I can't do something, it’s because something on the inside is going wrong. I'm not going to sit down with [my boss] and be like, “Hey my labia is hurting,” or “I'm bleeding on the inside,” because that's going to freak her out.

She was concerned about how her behavior looked to her co-workers when she got up to go to the bathroom or left work early. “I feel like I have to apologize for that,” she said, fearing they would notice her special treatment without understanding her body’s limitations. Moreover, the good days when she felt well and everything seemed normal on the outside confused people even more. Indeed, being disabled “sometimes,” embodied in the good/bad days, ups and downs of illness, is a complex state for healthy people to grasp. Julianne believed she needed to compensate for her lack of visible disability and seemingly erratic behavior by working harder or keeping her pain to herself. People like Julianne and Carmella who have a disability sometimes must spend more time and energy managing impressions and avoiding threats to the self.

**Gendering Body Trouble**

Because women’s bodies form the central axis of power relationships between genders (Weitz, 1998) and because youth are especially susceptible to extreme manifestations of body-hatred under Western capitalism (Frost, 2001), the landscape of young womanhood demands closer scrutiny. For this section I wish to focus on the unique experiences of being a young woman with a chronic illness, disability, or skin
condition. Up to this point in the dissertation, gender has lingered in the background, but now I will bring it to the forefront of my analysis. The sample confronted a host of issues that able-bodied women took for granted. Data suggest that these power relationships are more palpable for women burdened with societal judgments about their health and appearance. Participants confronted gendered dynamics embedded the issues of sexual relationships, fertility and motherhood, and media representations of women’s bodies. Hence, by eliciting the experiences of young women outside the hegemonic standard of an “able body,” I explore the broader political and moral constructions of health, fitness, and gender within a rigid surveillance culture.

**Sex and Dating**

Young women in America grow up around contradictory expectations about sexuality: that they will be “nice” and “good” in addition to “attractive” and “sexy,” that they will be defined by their sexuality but denied any pleasure from it, and that they will have sexual power over men without positive feelings about their bodies (Frost, 2001). Women and girls with disabilities encounter all of these contradictions through the discourse of asexuality. Disabled girls approaching adolescence lack “sex access” (Shuttleworth & Mona, 2002), meaning they are excluded from normal sexually coded spaces like dances, dating, leisure, and sports. Moreover, Erevelles & Mutua (2005) found that school special education programs do not support a well-rounded sense of sexuality because public discourse defines their students as asexual children (Milligan & Neufeldt, 2001). This discourse is so strong that sexy women with disabilities are welcomed in the media without a corresponding “girlpower!” model of sexual pleasure and independence.
I discussed this “asexual/sexy” conundrum with the women in the first group interview. “I’m going to get personal,” said Ericka, not shy about broaching the subject of sex and dating issues. She wanted to see if the other women had difficulties in relationships with men. Ericka thought that men she dated found it difficult to value her for anything other than sex:

Ericka: Guys will always go after the booty first. Plain and simple. They don’t want a relationship. You’re a booty call.

Interviewer: You’re a booty call, but do you see that as progress for women with disabilities to even be sexually desired…?

Saundra: To a certain extent.

Ericka: Yeah, to a certain extent.

Saundra: But you also want to feel treasured, you want to feel protected.

Ericka: Yeah, instead of [just being] friends with benefits…[Guys] don’t know how to see you as a person because whatever is physically wrong with you is like more overpowering.

Ericka claimed that the men she dates do not see her as a full person because of her physical disability. At the same time, in both Ericka and Saundra’s view, men only valued them for sex. Either way, the body was the primary factor in determining the shape and contour of their sexual relations: when physical impairment disqualified them from relationships, sexual objectification took precedence. For women like Ericka and Saundra, asexuality was not as much of a problem as the assumption that they were not marriageable.

Saundra and Ericka continued to discuss the idea that a physical disability precluded them from full relationship or life partner “material.” They worried that men preferred to seriously date women who did not have a physical disability:
Ericka: When I go out with someone, like and I’m very extremely self-confident. But when I’m out with a guy and I see like a bunch of hot chicks, you know and they walk in and they have long blond hair, I’m just like...[exasperated sigh]

Saundra: Exactly, and they have on those high heels and the short mini-skirts, and they have perfect legs. And I’m thinking, “Oh god if I wore those I would break both my ankles.” There is always that thought that there is somebody else out there who—I know this is going to sound debilitating—who can walk. It’s as simple as that. Someone who can walk, someone who can you know, think straight half the time.

They reasoned that men would always desire someone able-bodied. Here the participants observed how femininity is an able-bodied gender performance, expressed through typically feminine gestures that involve walking not just in upright posture, but in “high heel” posture. Saundra continued, noting an additional feminine performance that went beyond physical impairment: flirting. She recognized its importance but resented its necessity:

I don’t know how to fucking flirt. I really don’t. I’m very direct. I’ll just go up to a guy and say hey, I like your shirt. I remember asking a classmate of mine who I didn’t really like—I was that desperate—“what’s flirting, will you teach me?” And she goes, “It’s not something you teach!” although she promised she would but she never did. Which you know is fine with me because I feel more comfortable in my own shoes, and I don’t want to have to be coy and flirtatious. It’s a subtle social skill, like playing politics.

Even though Ericka and Saundra were both in committed relationships at the time of this interview, doubts surfaced in their minds about their feminine competence. They worried that their boyfriends would desire a partner who looked and acted like a typical able-bodied woman. Embodied difference impacted their sense of worth in relationships, producing feelings of inferiority. In short, they felt disrupted in their trajectory toward adult/womanhood.

Women with physical disabilities were not the only ones in the sample to ponder how their differences impacted their sexual relationships. During her lupus flare up,
Brinn broke out into hives. “I was so self-conscious with guys,” she recalled, “because I would get it on my hips and legs, and you don’t feel sexy when you’re breaking out in hives.” She was committed to returning to her former self, a woman who was extremely confident around men and in control of her body/sexuality. Brinn believed the key to future dating success depended on how well she obeyed her doctors and stayed “healthy.” Josephine, meanwhile, wondered out loud why she had not dated anyone yet at age 19: “I’ve never really dated, but sometimes I wonder if I didn’t have vitiligo…? Maybe it’s just me. It’s something that you think about, especially being a girl, like ‘what’s wrong with me?’” She immediately dismissed this reasoning as unfounded: “it’s probably not [the vitiligo] at all.” Difference had an acute impact on how women judged themselves as “worthy” of relationships with men. Similar anxieties among all the three groups of women illustrated the pervasive concern for being seen as sexually desirable. Dating and relationship success was an important facet of their identities as young women who were viewed as “different” from the norm.

**Fear of Caregiver Burden**

Launching new relationships was a concern among the participants; extending relationships across a lifetime of illness was another. What I can only describe as fear of “caregiver burden” dramatically affected one participant’s outlook on relationships. Saundra encountered severe discriminatory attitudes from her boyfriend’s parents. Their first meeting was the only time Saundra said she felt like an “imperfect person.” Let me briefly summarize what happened at this meeting. Saundra said that she made three bad impressions on his family: the first was falling out of the car as soon as they arrived in the drive way, the second was irritating his family because she put hand prints on their walls (she used them for balance), and the third was angering the father when she
snuggled with her boyfriend (clothed, she added) in their house. All of these were minor upsets, however, compared to the root of this hostility: the fear of Saundra being dependable, needy, and economically costly to their son.

His dad said [to my boyfriend] "If we ever get married, if you get sick, you’re going to have to take care of her." I’m like “Who the hell is he to tell you that?” His dad was a nurse, his step mom was a nurse, I would think they would have understood. My mother described it as “They’re going to think like parents, they’re not going to think like nurses.”

I told Saundra that able-bodied people do not encounter questions about their fitness or financial burden in these situations. She agreed:

No, they don’t have to deal with it. It’s made me kind of fearful, because even if my boyfriend and I, we’ve been together for five years, but that doesn’t guarantee that we’re going to stay together forever. I know this is only one example of what’s happened, but is this going to happen to every other set of parents that I may have to meet over time?

Truly, Saundra was appalled that her loving relationship was defined in such base economic terms. Her boyfriend’s father placed a price on her head and decided that she was a financial drain. Thankfully, Saundra’s boyfriend stuck by her during this tense time.

Saundra described the entire experience as an exercise in disability consciousness. For the first time, she had hit a wall in her ability to control how other people viewed her:

I really struggled with that for a number of years, to tell you the truth, and that was really when it hit me. I may never reach level where I’m same as everybody else. I will constantly be a second class citizen. They really do think of us as second class.

Gill (1996) claims that people (especially women) with disabilities encounter strong social messages that they are not suitable romantic partners. Often their relationships are assumed to be untenable or doomed from the start. A partial explanation for this
reaction is fear—or, more precisely, a misunderstanding about how intimate relationships among people with disabilities actually work. The financial penalties of disability are systemic: a combined family income under marriage can cut off government funding for health care, equipment, and personal assistance services. This injustice offered no solace to Saundra, however, who simply wanted to feel welcomed in the home of her boyfriend’s parents. She used the word “us” to collectively identify as a class oppressed by a separate, privileged class. More disconcertingly, she had her first brush with discrimination in a place that affected matters of the heart: an intimate relationship.

The Politics of (a Future) Motherhood

Political controversies swirl around concepts of disability and motherhood. Women with health conditions who want to become pregnant must navigate a minefield of “risk” discourse with its “unspoken evaluative assumptions,” e.g. mothers are blamed first for any genetic mutations in children (Thomas, 1997, p. 640). Hence, disabled women’s reproductive journeys are marked by attitudinal, ideological, and material barriers (ibid). Thomas documented this phenomenon fifteen years ago; interview data suggest that little has changed for today’s generation of women with medical conditions pondering motherhood.

Women in this study grappled with three issues related to motherhood and reproduction. The first was other people’s insensitivity toward their limited reproductive choices. Darcy’s own family had difficulties understanding how a pregnancy would stretch her body to its limits. She recounted how her sisters were not aware of the difficulties of pregnancy for women with spina bifida:

[My sisters have] had a little bit easier time with the whole dating thing. The one that’s 23 is starting to talk about weddings, you know, like her dream wedding and how many kids she wants. And one day out of the blue she
came to me and said, “So how many kids do you think you’ll have?” And I’m going, first of all, I don’t even know if I’m able to have kids, like if my body would allow me to do that and...also I think if having a child is their number one priority, then it would happen in the way that they choose. I would hope that someone loved me for me, whether or not I’m able to have kids.

Darcy was angered by her sister’s question because she “did not consider the fact that [I’m] physically disabled” and that children would be very stressful on her body. Darcy alludes to the fact that reproduction is an unequally accessed institution. Her sister assumed Darcy would take the same life path as the rest of the women in the family. In this discourse, fertility and able-bodied privilege were invisible. Darcy clearly saw their contours, however. Forced social linkages between women and pregnancy gloss over how reproduction is an “ability” shaped by the body’s limitations. Consequently, motherhood was assumed to be within Darcy’s future because she was a woman, and all women are inevitable child bearers. Of course, this assumption is a classic myth that feminists have debunked for years.

Participants like Saundra and Brinn met a second challenge to reproduction: the question of medications and risk of birth defects. Since they were both in their mid-20’s, doctors informed them of serious ethical dilemmas they would need to resolve if they wanted to have children. Brinn wanted children in the future; Saundra was more ambivalent about it. The former worried about how the drug she takes for lupus (cytoxin) might affect her fertility:

It’s kind expected as a woman, like that’s the main thing is to have kids. it really worries me about that because I don’t know if I’ll be able to, but if I can’t, I’ll adopt. I had always planned to adopt, but in a way, you want to have your own child that’s from you to continue on the family and stuff like that. It’s a part of my identity, you know having, wanting to have children. It’s a lot of guilt that you put on yourself, you know, like not only why did this have to happen to me, but feeling bad...like what if my future kids have
this? It makes me feel more guilty, puts more stress on me, gives me more anxiety, because what is my husband going to have to put up with?

In contrast to Darcy and Saundra, Brinn lived her entire life as a woman without impairment. She integrated motherhood into her identity, believing, like Darcy’s sister, that pregnancy is a woman’s goal in life. Brinn, however, had to find her footing in a new world where illness disrupts biological motherhood. Saundra, meanwhile, had concerns about the medications she took for her kidney transplant and concluded, after discussions with her boyfriend, that she did not want to risk birth defects for her child. The challenges confronting women with disabilities are daunting, but birth defects are but one discourse among many other practical problems, such as the lack of social support for parents and difficulties winning funded resources (Prilleltensky, 2003).

The third concern involved the functional limitations of caring for kids. Saundra engaged in numerous discussions with her boyfriend about children. Her decisions evolved over time. She reached the following conclusion in their first discussion:

I do know my limits. My boyfriend goes yes, I could see you having an infant, but could you carry yourself through a pregnancy? It’s true, I’ve always had this fear or falling on a little kid because of my ataxia and my spasticity. I don’t want to crush a 2 year old. But I just sat there and thought about my boyfriend’s [question], because he sees it a little bit more realistically. I’m just like, yes, let’s do this. I made the decision.

At that time, she thought her body could handle the rigors of childbirth and care. She had second thoughts, however, after her niece had a child.

I noticed the way she carried it, I was like, I can’t do that. I saw the limitation right in front of my face. I’ve had no experience with kids, so for me, now it’s just like a fleeting fantasy. My boyfriend asked me how I felt about it and I said “oh shoot, now I feel like I can’t obliged my biological purpose!” But there’s more ways to get over that.

As I looked deeper into research on childcare among mothers with disabilities, I found heartbreaking examples of systemic inequality. But the picture was not entire bleak.
Programs can distribute adaptive equipment and facilitate early infant adaptations (Kirshbaum, 1996). Formal supports like paid nurturing assistants can help new mothers interpret the new “language” of childcare, while parent-directed childcare assistance can fill in when a mother’s energy level is low (Prilleltensky, 2003). Children of parents with disabilities can gain positive enrichment as they learn about disability and difference (Kirshbaum & Olkin, 2002), and impressive family cohesion does exist when mothers are chronically ill (Backman, Smith, Smith, Montie, & Suto, 2007; Whitley, Beck, & Rutowski, 1999). I include this literature not to paint a rosy picture, but to highlight how the participants in this study framed motherhood itself as another disability, or something they could not do. They reached this conclusion by attempting to plan families around their bodies. Yet the anxious narratives about motherhood suggested that they also internalized the pathological discourse about disabled mothers in our culture.

**Complicated Relationships with Femininity**

Gender scholars note how subversive gender performances simultaneously identify with femininity while resisting patriarchal notions of feminine inferiority. Unlike women in goth (Wilkins, 2004), punk (Leblanc, 1999), and femme (Ryan, 2009) subcultures, my participants did not actively challenge normative femininity by subverting it. Instead, they destabilized femininity by the simple fact of inhabiting a body that was “unladylike.” Participants disidentified with femininity defined by popular media, but were persistently aware of the “tyranny of slenderness” (Chernin, 1981) and the “tyranny of perfection” (Glassner, 1992). They fully recognized the flaws of a patriarchal femininity that dictated impossible appearances and submissive behavior but
they lacked a subversive subculture and ideology to make sense of patriarchy’s contradictory imperatives.

Much of women’s anxiety about the body originates in a complicated relationship with patriarchal femininity and the heightened awareness that one’s body does not conform to hegemonic cultural ideals (Kwan, 2010). Likewise, living within and internalizing cultural notions of femininity, many women with disabilities often feel themselves ambiguously positioned both within and outside of the category of “woman” (Garland-Thomson, 2002; Zitzelsberger, 2005). Participants illustrated this theory when their impairments clashed with “ladylike” or “cute” gender performances. Consider Julianne, for example. Her digestive disorder illuminated the tightrope she must walk when “doing femininity” means “doing perfection:”

Going to the bathroom at all is not very feminine. Girls don’t fart, they pee very rarely and they only pee. They don’t have anything else coming out of their bodies, except for me apparently. I always felt like it’s such a strange like cultural thing, I mean it’s so normal to eat, but for some reason it’s not normal to evacuate. It’s such a bizarre mindset. Sure it’s gross, it’s not pleasant, but I mean it happens, everybody does it.

Jillianne, among other participants, pushed the limits of a narrowly constructed femininity to challenge notions of neatness, cleanliness, and orderliness. Indeed, the discussion of physical realities explored at the beginning of this Chapter conveys how medically ill or physically disabled bodies “do gender” (West & Zimmerman, 1987) in atypical ways.

Though they scoffed at some of femininity’s absurd demands, women wished that they could partake in some of its simple joys. Julianne questioned the feminine standards for perfection, but feelings of uncleanliness troubled her. About the ordeal of using public restrooms, she said, “I always felt embarrassed and just kind of
inappropriate. I felt wrong, like it wasn’t right for me to go to the bathroom…I mean you can hear the noises, you can hear the smells, and it was always a very touchy and embarrassing thing.” She revealed how rigid self-surveillance works in one of the few public, women-only spaces (the bathroom).

Missing femur bones in her leg required Alissa to wear specialty-made, heel-adjusted shoes. She explained the implications of her impairment for the feminine-coded practice of shoe shopping:

I can’t wear a lot of like types of sandals or I can’t wear like heals at all. I love shoes and I think it’s always been like a really sensitive issue for me. It’s been really hard. Especially with things like prom and homecoming dances, I couldn’t really wear like short dresses. I had to find long dresses and then I had to spend more money to get a longer dress, and I couldn’t have nice shoes. And like whenever it comes to some instance where I need to dress up, it’s really like, upsetting, because I can’t wear the typical things that a girl would wear. While my friends could go out and maybe just find like a cheap dress and like shoes in like an hour.

Alissa’s story exposed the economic and social benefits of able-bodied femininity. For women, shoes are a big part of “dressing up” and “looking cute.” People who need more practical shoes (Darcy and Tammy reported similar shoe requirements) are positioned on the outside of femininity even as they try to gain access to it in other areas (like wearing long dresses). In comparison, a few participants saw femininity as a tool to simplify public images of themselves. Ericka used femininity to position herself as an intelligent, competent person:

I’m one of the girliest girls you’ll ever meet in your entire life, make-up all that. But sometimes I feel like need to overcompensate. Like sometimes I slur my speech and people look at me like I’m mentally retarded or something or half-crocked. I’m like No! I’m a person! I can’t walk but I’m still here.

Ericka illustrated how she used feminine gender’s more recognizable “short-cuts” to smooth over the more complicated work of deciphering disability.
I was thrilled to interview Janet because of her insider view into the world of gender in a high school setting. She described a cut-throat world that, to me, sounded like the teen movie *Mean Girls.*

“I had a lot of problems with girls,” Janet complained, because the male classmates treated her like “one of the guys.” She claimed that the women were jealous of her, so to make friends she tried to please them. Eventually she realized this was a losing battle because she was not making herself happy in the process. She got to the point where she made a conscious choice to ignore the accusations that she was “mean” or “stealing their boyfriends:"

Before I kind of cared what people thought about me...I had to have everyone like me, I had to, because I was different. I had to have everything perfect the way I wanted to have it. And so I finally got to the point, my sophomore year in high school where I was like, this is stupid, I’m not going to worry, I’m not going to let them bug me. I was trying to please people.

At times I wondered if I was interviewing a “young woman with cerebral palsy” or a “young woman in high school.” The distinctions between the two were not always clear.

For example, in one particular incident Janet described how she punched a female classmate in the nose. Janet claimed that the classmate was verbally harassing her out of jealousy over a boyfriend. I had trouble determining if Janet was fighting bullies for being bullies or fighting women over other men. The former would have much more resistive potential, but the latter is not unexpected for high school behavior. Either way, Janet’s assumed weakness saved her from retribution: “She tried to press charges on me, and the cop told her it wasn’t a smart idea. He said she would have lost because there’s no way a judge is going to believe that I severely injured her.” Like Ericka, Janet conveyed how she used femininity to her advantage to upset people’s expectations of

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2 A successor to *Heathers* and *Clueless,* both classic cinematic explorations of high school girl cliques.
her. “I’m happy all the time. It’s just that me being happy all the time is dangerous for some people because they never know when I’m irritated or I don’t show it [my emphasis].” This was subtle emotion work; Janet used a “nice” feminine demeanor as a subterfuge to obscure her true feelings. Whereas before she was managing other people’s emotions by trying to please them, she realized that she could gain power by being feared instead.

The women discussed body image, media’s role in it, and satisfaction with one’s own body. Leslie, one of my participants with a large birth mark on her face, believed that appearance was so malleable that no woman should ever be dissatisfied with herself. “We may not always try to reach the same ideal as all the women in fashion magazines, she insisted, “but we have to create our own ideal of what we want to look like,” adding, “you don’t need to look like everybody else.” In this view, unique femininity was something to be “found” through experimentation. Leslie suggested that Youtube videos made unique self-expressions accessible by teaching make-up or hair-dye techniques. These comments made me wonder how much “resisting sameness” relied on beauty/makeover industry to help women “love themselves.” Solutions to social problem of body hatred are typically individualistic, demanding that women change their attitudes by changing their bodies. Comedian and writer Caitlin Moran remarks that media imagines women as “massive makeover projects” (Bernstein, 2012). Marwick (2010) identifies these projects as moral self-regulating procedures that promise women access to their “true selves” through self-improvement. Some participants (moreso those with skin conditions) were apt to discuss “the body image problem” in this individualized language.
Opposing individual solutions, the fat acceptance movement maintains the importance of processing negative feelings of body hatred (Johnston & Taylor, 2008). I find value in negative feelings for women who must contend with difference on a daily basis. Body hatred validates the silent workings of beauty hierarchies (silent because popular media is always reifying them and simultaneously denying their existence). Josephine wished that she did not have such thoughts, but social interactions with other women who were oblivious to vitiligo fueled her negativity:

When you’re around girls that are skinnier than you or they don’t have skin problems like yours, everything builds up. Then there are points where you have your breaking moments where you’re like “I just want to be normal and look like [them].” Then you bring yourself back to reality, you are who you are and you’re fine…I guess there’s a little bit of jealousy too. I try not to be, but I mean there is moment where I’m kind of like, man I wish I just had that body…

Wavering back and forth between despair and satisfaction was a typical way to talk about the subject. Julianne said that the scarring from her numerous surgeries, portacath under her skin, and colostomy bag were parts of herself that she wanted to hide. At the same time, they did not worry her to the point of incapacitation: “It’s not going to make me curl up and cry. But I don’t want this purple thing sticking out of my chest or all these scars on my neck and collarbone.” She would rather cover up and avoid bathing suits than have to explain her scars. Covering up a colostomy bag, however, was much more difficult. “If it’s full,” she remarked, “you’re going to be able to

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3 Johnston & Taylor summarize their position as follows: “To compensate for the hierarchical nature of beauty ideals, the ideology of beauty suggests that every woman can, and should, feel beautiful, presenting beauty as a democratic gender good, akin to life, liberty, and the pursuit of happiness…Women’s acceptance of their bodies as beautiful is demanded, rather than recognized as inherently complex, fraught, and contradictory endeavor—particularly in the context of the mass media, the beauty industry, the weight-loss industry, and the industrial food complex” (p. 954).

4 Scars are a typical subject of public conversation, since people want to know the “history” behind them.
see it, no matter how flat. It’s going to be gross, you’re going to be able to hear the noises, you’re going to see it and it’s going to be awful.” Despite her desire to hide these aspects of herself, Julianne shunned radical plastic surgeries. Like Leslie, she saw value in scars to claim uniqueness, stating “That’s part of what makes me, me. That’s what makes me different. I should cherish that.”

Kokoro and I had a vigorous exchange about the source of women’s insecurities about their bodies. She believed that every woman feels insecure because of ideals perpetuated by the media, but that women must resolve this by privileging uniqueness:

> For women you’ve just gotta look at yourself and just see what you got, and you know, it may not be what someone else has got, but it’s still something that’s unique, and something that’s yours. I mean it sounds so cheesy, something that I would hear in *7th Heaven* or *Dr. Phil*. [laughs] But it’s true.

I asked her if individual solutions were the best way to repair women’s warped relationship to their bodies. I introduced her to the concept of beauty hierarchies, and she immediately grasped how they were socially constructed to fit feminine imperatives:

> Everyone has a ranking system. And it just depends on how you change the ranking system. If the whole society had a ranking system was on like intelligent women, you would probably have a bunch of girls who were like, “I’m just not as smart!” instead of beauty it would be intelligence. There’s always going to be people who are closer to that ideal, and then people who are not so, and you’re just always going to be comparing. I mean like…it’s like this dog eat dog system…it definitely applies to media. Like if you’re conscious of how media affects you then it’s easier to go against it.

To remedy beauty hierarchies, Kokoro suggested that the media include women who are “relatable.” Celebrities are not relatable but they dictate ideals through their access to wealth. Though hierarchies are difficult to resolve among women, beauty as the number one quality to define womanhood *could* change. Or, to put Kokoro’s thoughts in more elaborate terms, “capitalism has truly created wealth, because it has found wealth
where it could not be seen. Thus it has created beauty, health, or youth as riches; that is, as qualities that possess you” (Anonymous, 2010).

**Conclusions**

Women in this study encountered vulnerabilities in three territories of young adulthood: the physically world, the moral world, and the gendered world. In each domain the body acted as a mediator for interpreting symbols and sensing stimuli. Data suggests that—contrary to social model advocates who want to exile it to the medical domain or postmodernists who relegate it to a construction—impairment is real because it is social. Put differently, the impaired body is socially produced by threats to the self. Difference is created socially. What I mean by this is that human differences are real—the value-judgments are not. The instances of disability oppression are clear in stories of intimate relationships, oblivious or ignorant responses to public illness, or limited community that exclude people with disabilities. Yet, difference is also created corporally, as participants told stories of bodies consumed by the grotesque and afflicted by pain (including physical/psychic pain). However much they were shuffled into categories, participants did not inhabit docile bodies. They were not, Foucault would claim, surfaces to be written on, to be fabricated by regimes of truth (Lash, 1984). Instead, participants actively worked on their bodies/selves in three concrete ways. First, in cases of pain, fatigue, malaise, and disgust, physical impairment posed a threat to a continuous, predictable life. Participants grappled with ways to make sense of their disfigured or resistant anatomy. Second, selfhood was contingent on the body as the women sought to minimize uncertainty and gain a predictable pattern for society’s response to them. It was important to the women to resolve their difference in ways that they could own it, rather than society defining it for them. Finally, the women parsed
through meanings of gender and ability as they collided with attitudes that framed their own sexuality, marriage potential, appearance, and fertility as feminine “impairments.” Broadly speaking, narratives converged around stories of psychic and physical pain caused by, respectively, two forms of difference: fabricated constructions and biological realities. Confusion about the two concepts comprised misunderstandings about the lives of ill, disabled, and disfigured people.
CHAPTER 7
RESISTING BODY TROUBLE: ACTION AND TESTIMONY

This Chapter details the community action phase of the project, which was an attempt to discuss and act on the social problems cited in the interviews. The participants asserted that barriers and attitudes in society, not their bodies, were responsible for two main difficulties: finding gainful employment and receiving humane treatment in medical care. In classic social model form, the word “disability” in this section refers to the loss or limitation of opportunities resulting from direct and indirect discrimination (Crow, 1996). I analyze the way in which impairments were discussed alongside this form of disability (also referred to as “disablements”).

Women with chronic illness and physical disabilities joined this phase.¹ The women met for two group interviews, lightly moderated by the researcher. After I presented data from the individual interviews, the participants chose their own form of direct action, speaking publicly to undergraduate students as “guest lecturers.” This activity was more than a lecture however; it was a “public testimonial” for two reasons: one, because the women spoke from personal/expert experience, and two, the act itself had a political goal in mind. Findings in this Chapter are grouped thematically around discussions of social justice, identity politics, group alliances, and public testimony. Data reported in this section is not as interpretive in the previous Chapters because the participants directed the research during this final stage of data collection.

¹ I decided to exclude women with skin conditions because the social problems confronting them were not as urgent as those from the other groups (see explanation in Chapter 4).
Meeting for the First Time

Natalie, Darcy, Saundra, and Paula answered my request to meet in a study room at the library. Coordinating the meeting was difficult but not impossible. Saundra and Darcy navigated bus schedules, and Natalie had to be careful not to let rain malfunction her wheelchair. I was worried that the room would be filled with awkward silences, so I planned an icebreaker. I asked each of them to bring a picture of themselves to share with the group. This activity worked out brilliantly and infused the room with a positive atmosphere. I did not want disability to be the “common denominator” for the group, and the photos gave us something to share outside of the research itself.

Paula brought in a family picture that included her cousin who had recently arrived back from a deployment in Afghanistan. Saundra, the military expert of the group, had no trouble striking up a conversation with Paula about it. Saundra shared a picture from her sophomore year, in which she was goofing around with her roommate in their dorm’s kitchen. The dorm was handicapped modified; a fact which Saundra said made her disability disappear in that space. This sparked a discussion about life in college and the accommodations that made it easy or difficult to adjust. Everyone at the table was college-educated or in college, so this formed a common bond between us. Darcy, for instance, proudly showed everyone her graduation day photo. She was dressed in cap and gown. I asked her how she felt on that day. She responded: “I was kind of apprehensive about what the next step was going to be, which was ‘Now that you’ve graduated from college, let’s go find a job!’…the photo doesn’t really show how much you had to put in to get there.” The room filled with sounds of agreement as we recognized that the ceremony’s significance was fleeting for those who did not have
jobs lined up (again, everyone at the table). Natalie, Saundra, and Darcy, all wheelchair users to varying degrees, chatted about the accessibility of the commencement space itself, voicing concern about navigating a steep ramp and walking/wheeling across the stage. “I was concentrating so hard walking across the stage” Saundra said. “Exactly,” Darcy replied, “You can’t really enjoy the moment” of receiving your degree. Ericka shared a picture of herself smiling in a restaurant; it was taken as an “introduction photo” for a guy she was interested in. I asked her if there was anything about herself that the photo does not show. She responded: “Yes, in a sense I was trying to be happy, but it’s kind of fake because right now I’m like under a lot of stress. My mom is really sick…sometimes we put smiles on when we have to, right?” Darcy agreed, stating that’s exactly what she was doing in her graduation photo. At that point, everyone had introduced themselves through their photos, so we moved on to more pressing matters, such as findings from the interviews (see Appendix E for the handout I distributed to the group).

“That’s a Load of Crap:” Using Anger

A body of research is being conducted on the lives of Americans who were born after the ADA who have no memories of widespread prejudice and discrimination before the landmark 1990 legislation. Whereas 90% of people with disabilities in a study by Frieden (2010) believed that their quality of life had improved since the passage of the ADA, the young women in this study expressed dissatisfaction with their social conditions. Anger was a useful resource to make sense of the social attitudes and barriers the participants encountered. They characterized society as uncaring toward people with disabilities—even more so because of the assumption that the ADA has solved most of their problems. I asked the group how they would respond if they met
someone who believed that disability discrimination was a “thing of the past.” Saundra said she would tell them they were disingenuous about what is really going on:

    We live in a closed society. I will say that right now, they say “no we don’t” but you can hear it in their voice and you can see it in their face, they may be saying those things and they may mean it in the sincerest way possible but you can see the reaction in their eyes, you really can. I think that’s what hurts the most, “yeah you’re saying that, but I’m not seeing it!”

I asked the rest of the group if they agreed with the statement “we’ve made a lot of progress for disability rights.” Natalie replied that she thinks it’s a “load of crap.” Darcy lamented that she was still educating people about disability even though the ADA had been around for twenty-one years.

    Ericka, Darcy, and Saundra were the most knowledgeable about the historical injustices perpetrated against people with disabilities as a group. This past was meaningful to them, as Saundra and Ericka tried to process this history through their present experience:

Saundra:    I wish we weren’t looked at as…
Ericka:     Invalids, I know that that’s a strong word.
Saundra:    Of course it is. They used to get stuck in institutions.
Ericka:     And we couldn’t even go to school. I can’t fathom that and I wish the world would adapt to us. Like there’s enough of people with disabilities now that certain things should not be an accommodation or a specialty to have a ramp at every door. It should be like…
Saundra:    Required! Like even people without disability use it.

Ericka correctly observed how the disability population is increasing, suggesting how “accommodations” become normal, everyday practices when they are mainstreamed.

Saundra, moreover, spoke of institutionalization in the past tense, but this harmful practice is going on today. Fourteen percent of young people, age 31-64 were nursing
home residents in 2010, up from ten percent in 2000 (Heasley, 2010). If we had had more time, perhaps we could have delved into these issues in more detail. The discussion moved quickly into anger with discrimination in employment and medical care. These two issues were of primary concern for the group.

**Disability and Employment: A Long List of Criticisms**

Despite advancements in assistive technology, rehabilitation practices, and antidiscrimination provisions of the ADA, U.S. unemployment rates among working-age persons with disabilities continue to be very high (14% as of 2011 as cited in Disabled World, 2012). Research consistently finds that women with disabilities are less likely to be employed than men with disabilities (McDonough, 1997). Considering these facts in the context of a deep economic recession, it is not surprising that participants in this study reported numerous grievances about job market conditions. I divided these grievances into four areas: superficial promises to address unemployment, vocational rehabilitation services, concerns about job accommodations/fringe benefits, and the application/interview process.

In 2010, President Obama signed an executive order that planned to increase hiring among the disabled population. The order states that the Federal Government “must become a model for the employment of individuals with disabilities” (Exec. Order No. 13548, 2010). Saundra took note of this act, stating,

> I was kind of suspicious of it, to tell you the truth, because I’m going OK, yeah, that’s great. I don’t think it’s going to work. It sounds like a publicity stunt. I don’t think it has any weight behind it, I really don’t. I hate to say this but I think it was more of a joke, plain [public relations]. I’m sure the President is a wonderful individual, but I just want to kick him in the shins. I know he was trying to show the private sector, “you can hire people with disabilities,” but they’re not doing enough. An executive order is not going to cut it. I think we need a few people [with disabilities] in Congress to tell you
the truth. I’m not talking about aides; I’m talking about Senators and Congressmen. And I’m not saying that because we’re a minority.

Saundra was wary of politicians who used disability as a “political football to make it seem like they care.” She was also leery of designated holidays and special events for people with disabilities (like “National Disability Day”), suggesting they were window dressing on a systemic problem. She believed that real change in unemployment conditions would not come from commemorations, executive orders, or political promises. She diagnosed the problem as a lack of political representation. In my own view, I think elected officials with disabilities are a necessity, but that is not all that is needed. The officials must be cognizant of their own identity as a minority class before they can enact meaningful legislation. When writing legislation, “playing to the center” (i.e. the middle class) takes precedence over the concerns of “radical” interest groups (even if that interest group is the largest minority in America).

A second grievance concerned state-federal vocational rehabilitation (VR) programs. VR deals largely with vocational assessment, work re-training, education and counseling, ergonomic modifications, and psycho-social interventions\(^2\) (Gobelet & Franchignoni, 2006). A VR counselor must help people with disabilities secure and maintain employment that accords with their aptitudes, interests, and education (Rumrill & Roessler, 1999). Darcy, Natalie, and Saundra viewed these services as inadequate to their needs as college graduates:

Saundra: I told VR about a specific career goal that I’ve had since I was 18. I still wanted to achieve that career goal. I have a Ticket to Work\(^3\). I understand

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\(^2\) Selander (1999) provides a comprehensive definition of VR: “Medical, psychological, social, and occupational activities aiming to reestablish among sick or injury people with previous work history their working capacity and prerequisites for returning to the labor market, i.e. to a job or availability for a job.”

\(^3\) A Social Security Administration program that temporarily allows new employees to keep Medicare benefits.
that they have a limited area within which they work. But you know it just kind of seems strange to me when they’re supposed to be helping people with disabilities, because they say, they consider any job that you pick up as a job.

Darcy: They don’t see a difference whether you’re working for McDonalds or whether you’re working for the federal government.

Ericka: Exactly so you have to be really, really careful about what you claim is what you want to do. Because they will write that off, send that to VR, and your case is closed.

Saundra: Even my parents who are very supportive of my career goals, you know they go “Well why isn’t she getting you to go where you want to go?” I said, Well one because it’s not really her responsibility really. I’m not trying to defend her position or anything but there’s only a certain amount she can do… but in certain ways she’s harming me I think because she’s going “Oh yeah you can go to Publix.’ I’m going look lady I’ve got a bachelor’s degree, I didn’t spend six years in college…

(crosstalk)

Natalie: They want you to work at Publix or Wal-Mart

Darcy: And my dad was like “Why don’t you apply to Publix [large grocery store chain]?” I’m like Dad, I did not earn three certificates in business to go work for Publix.

Natalie: And I’ve already had a career. I’ve worked for doctors. There’s no way I’m going to Publix! Like that’s just, no…

Saundra, Ericka, and Darcy expressed frustration with a mismatch between VR goals and their goals. This mismatch was likely caused by the organizational structure of VR, in which “successful placement” is measured according to the number of individuals placed into employment and not necessarily the quality of employment. This number determines the way in which counselors are assessed and funding is allocated to agencies. Hence, the participants described how VR was focused more on finding them any job than a career-oriented job.

VR policy researchers are aware of this problem. Rumrill & Roessler assert that “career development” and career counseling are focal points for a number of specific
recommended changes for the VR program. Schriner (2001), however, argues that these recommendations will be difficult to address because of the nature of VR’s focus on disability as a characteristic of individuals. As a profession VR counseling “attracts people who are more interested in producing individual change than social change” (p. 653). VR constantly retools its programs and services, but the changes may not come fast enough for the women in this study who were newly minted college graduates.

Landing a job (especially one that valued college degrees) was one difficulty; accommodations inside the job presented the next wave of challenges. Participants had two main concerns about their future as an employee: accommodations for sick days and health insurance benefits. Saundra worried that complications from her renal transplant may cause her to take weeks off at a time. She anticipated some pushback from her employers about using up her sick days, stating that people with disabilities have “been proving ourselves to people all our lives…so that’s second hat to us.” But she says “it does get tiring” having to lay the groundwork of trust that would ensure that she would be able to keep her job with her illness. Darcy and Ericka, meanwhile, had concerns about their assistive devices malfunctioning in the rain:

Ericka: Right now I’m just a student and I dread the day I have to go to work. Because I think like all of you, I fear like, am I gonna get fired? Like if I don’t show up? I can’t take this chair in the rain like it will break it. I’ve already had to replace the mechanisms once. And people don’t understand that, like I can’t go in the rain.

Darcy: If my braces for my legs get wet, I’m toast. It’s not that they break or something but it’s just not good for them to get wet. And people don’t understand that walking in the rain…

Ericka: Yeah no one gets that.

Replacement parts for assistive devices are expensive and time-consuming. Ericka and Darcy worried that their future employers would not be sympathetic to these facts.
The hurdle to gainful employment was stretched even higher when health insurance was factored into their chances. The women sought jobs specifically for health insurance with low premiums. Saundra and Darcy, both 25, were approaching the age at which they could no longer be covered under their parent’s insurance:

Saundra: I mean yes I want a good paying position. But we’re concerned about the benefits! The fringe benefits.

Darcy: Right now I’m working on an as-needed basis. I’m going I need a job that gives me full time…

Interviewer: And full time is forty hours a week, right? And to get the benefits, right you have to be full time?

Saundra: Yeah!

Darcy: And some people with their disabilities aren’t able to work full time!

From their dialogue above, one can see how the potential vectors for discrimination increase as the employment needs become more specific. First, the women would need a job that offered a “good” health insurance plan—this would entail a job that required full-time work. Considering this demands, smaller employers would be unlikely to hire the women since these jobs carry a heavier burden for health insurance costs. The best option would be a job that donated unused sick leave and instituted flex-time to work from home. These benefits were more likely to be found in career-oriented occupations than service-oriented jobs. These factors combined to present a picture of a workforce structured around able-bodied people. Hence, employment challenges were not located between counselor and consumer, disability and employer, but between historical workforce structures and labor policy regulations.
Finally, participants voiced frustration with the application and interview process. Darcy and Saundra were the most discouraged by the lack of response from their concerted job search efforts.

Saundra: I’ve gone to the mall and I picked up an application from every single store. After five applications, I’m done for the day.

Darcy: Well I had like three interviews in like six months, and I’ve been turned down every time. They come back and say “well I’m sorry but we’ve selected another candidate.” The third time just happened this past week.

Ericka: Even though they’re not supposed to discriminate, there is major discrimination…

Saundra: There really is.

Ericka: I mean I think some of it too right now is just our economy.

(sounds of agreement)

Ericka: And then even able-bodied people are having trouble…

Saundra: Well, that’s why I don’t complain about it.

Darcy: Although I admit you start to devalue yourself, like “what’s wrong with me?”

In the above dialogue, the women wavered between blaming themselves, blaming the recession, and blaming disability discrimination as explanations for their inability to find employment. When Darcy mentioned her interviews (all face-to-face), Ericka suggested discrimination as a reason why she did not secure the job. After our interview, I gave Darcy a job lead and encouraged her to follow-up on it; she interviewed for it, but was turned down to that job as well.

Simply getting to the interview posed another challenge altogether. Saundra recounted a story in which transportation affected her performance at the interview:

Saundra: I’ve had to walk to interviews, honestly. I had to walk half a mile for interviews from the bus stop. I left four hours early from my apartment, got there about an hour later, and spent the next three hours, just you know
wheeling myself up a hill, and then I got out of my wheelchair, and I walked the rest of the way down the road. I’m not complaining, because there wasn’t a side walk, there was a road, so it wasn’t through grass. But it was wet and it was cold and I wasn’t very happy.

The man who created the company, the founder, said “I am so inspired by your dedication!” And I’m going okay, thank you, I appreciate that…but by then I was so tuckered out, I was trying to pay attention, but I just didn’t give a crap. And then two months later, they go “oh I’m sorry we don’t have a position” That was a total flub!

(sympathetic laughs all around)

Interviewer: Well you want to go to an interview composed and sharp on your feet…

Ericka: Yeah, just ready to kick butt!

Some VR programs do provide transport to and from the interview. I was not able to determine if Saundra’s local VR program offered transport, however. They did give her a free bus pass, but the issue for Saundra was not economic. The barriers located in the built environment should have been remedied. Saundra’s fierce determination to arrive at her interview by herself could have trumped even the best services and modifications.

**Restoring Humanity to Medicine**

As I illustrated in Chapter 5, participants attempted to share medical power with doctors by appropriating medical terminology or diagnosing themselves. This desire came through in the group interviews as well, as the women compared their experiences with doctors and medical institutions. They identified an overarching theme in all of their medical encounters: the lack of a human touch and the acknowledgement of their own experiential knowledge. First I will relate a story to illustrating these two ideas and then I will describe how participants chose to take action in response.
Saundra showered her orthopedist with compliments: “he’s one of the few doctors who can empathize… and that’s what we need,” she remarked. One day while in clinic, he used her impairments (palsy, ataxia, spasticity) to educate a medical student. The orthopedist wanted to show the student how a person with ataxia walks, so he asked Saundra to walk across the clinic floor. “I hate it when men watch me walk, she said, “because I have a weird strut. But I survived it.” As she was leaving, she asked the student “what have you learned about cerebral palsy?” His answer did not impress her, so she told the student what he needed to know about ataxia and spasticity:

I show him what ataxia and spasticity looks like. I was basically educating him. I don’t know if my doctor appreciated that. But that was one of the main things that they were supposed to be learning, except [the doctor] did it in a very more technical manner than I did. I did tell this student or this resident that if you pushed on my leg with a certain amount of PSI [pounds per square inch] I won’t be able to lift it. And that’s going to be equal to weakened muscles or the angle of which I’m sitting. But [the student] went into this whole spiel and I’m like God, no, I just happen to drop on the floor every once in a while. You don’t have to go into an hour and fifteen minute lecture. I mean they can explain it to their colleagues with a perfect science, that’s perfectly fine with me, but when you’re telling me what you think is wrong… you know, treat me like I’m human…

This incident suggests how medical education fails to properly convey the human experience of impairment. Such education removes personhood and replaces it with medical jargon. Repeating Saundra’s impairment back to her in terminology that she would never use underscores the topologies of power between doctor and patient. In short, clinicians rarely think reflexively about their own medical knowledge. For example, Evans (2004) explains how the problem is not the expertise itself, but how it is exercised:

If our [diagnostic] label is like an oracle, the last word, rather than a heuristic, a helpful guide in a continuing conversation, then we have
misused our expertise. On the other hand, if we routinely examine our expert knowledge and how we apply it, our science then becomes a three-way conversation, with ourselves as well as with the patient. It becomes more appropriately collaborative. And if we use the knowledge of other kinds of experts – artists, writers, people with disabilities telling their own stories – the context of our work is broadened even more to an increasingly realistic level of complexity. Then our interaction with a patient becomes an ongoing inquiry into not only what the person means in his or her words and behavior, but also into what our theory or model means in the context of this individual and his or her world. It interrogates our own world as well.

Saundra was one of the few participants (besides perhaps Julianne) who felt like she could engage in a three-way conversation with her doctor. He allowed Saundra to act as the expert in this situation. She notified the student that medical terminology is best used between doctors than between doctor and patient. To reach patients, they must engage in a three-way conversation; the third speaker is the reflexive voice re-examining knowledge and how it is applied.

This story prompted the other women at the table to share similar experiences with medicine. They discussed how medical training changes people to make them relate to the world through “textbook thinking.” The problem, Saundra claimed, was that most people did not fit the textbook example. Eventually, I pressed them on what actions we could take as a group to address this problem. Paula, the quiet one at the table and the only woman with a chronic illness, piped up:

Paula: I think it would also be cool to kind of educate doctors or something at the med school.

Saundra: Yeah, if we could have a seminar or something similar for med students of different stages, like at the beginning, some are in the middle and maybe the end. And not just discuss the physical aspect of our disabilities, but the social aspect...before we get to the politicians we have to convince the doctors.
Their idea was an interesting one. I knew that medical schools were currently revising their curriculums to include humanities and social sciences. In this context, a class taught by people with direct experiences with illness could be valuable. I asked the women what they thought the medical students could learn from their class. They responded,

Darcy: The fact that we can think for ourselves.
Saundra: How they can get their humanity back?
Interviewer: They lost it? How?
Ericka: A lot of them, yeah. Like doctors in general, like I don’t know, just like, they don’t, you become not a human. I swear to God.
Saundra: I’ve had some really good doctors, I’ve had some really bad ones. I kind of give them a break, because they the HMO thing where you have to see a certain amount of people during the day and the doctors are so busy, they only allow you like 15 minutes.

In the above, Saundra recognized the limitations placed on doctors by a for-profit medical system in which insurance companies have large role in deciding medical care. Indeed, managed care ties doctors’ hands; participants were realistic about the structural incentives for changing behavior and attitudes.

As excited as I was about their idea, it was also a huge project that was not feasible at the end of my dissertation program. I confessed to them that it would take a lot of planning, and that I would prefer to win a grant so that I could pay them as co-researchers for their efforts. Ericka, however, suggested that we could engage in a “trial run” of the “chronic illness and disability class” with my students. At the time I was teaching undergraduates in a class called Sociology of Women. Ericka thought that the group could “test” their idea for public speaking on that class; hence, she believed that it was important to educate not just medical students, but all “able bodied people” on
disability and illness. In short, they wanted other students to understand impairment as a diverse human experience that can be used to question what is normal/abnormal. I agreed that inviting the women to my class was a reasonable compromise between their desires and my ability to facilitate them. In the next section I describe the outcomes of that event and expound on the meanings of this public testimony for researchers and participants alike.

**Findings from Public Testimonials**

Saundra, Paula and Emelia agreed to conduct the first public testimonial session in Summer 2011. Saundra and Emelia participated in the second session in Spring 2012. I told my students that we would be having a “panel of women with various disabilities and chronic illnesses,” and that they should submit questions to the panel based on their readings for that week. I assigned a mix of various readings, including Susan Wendell’s *The Rejected Body*, Nancy Mairs’ *Waist High in the World*, Debra O’Connor’s “Disability, Sexism, and the Social Order,” and Francine Odettes “Body Beautiful/Body Perfect.” The participants read these articles as well. I wished that I had given participants a role in this process of selecting an article, or at least offered to discuss the chosen articles beforehand. We did not get a chance to formalize what we wanted students to get out of this exercise; instead, we used student questions to guide the content of the panel discussion. It worked out well for the summer class, but the questions were of noticeably poor quality in the spring class, so participants went into the panel without much enthusiasm. In the following paragraphs, I draw from my own field notes to describe the event and convey the mood inside the classroom.
The First Session

Since the first session took place during a summer semester, the atmosphere was casual. Students were excited to have an interactive class session instead of a lecture. I imagine that the assembled panel—a mix of average-looking college students—peaked student curiosity about how the panelists qualified as “disabled.” Students appeared transfixed on the panelists as each woman “revealed” herself to the class. Student interest was maintained throughout the entire class period. I moderated the first few questions, but after that my role as a facilitator was no longer needed. The students filled any awkward silences, and (to my extreme satisfaction) referred to the handout containing a list of questions from all class members. The panelists appeared at ease discussing their disabilities and fielding student questions.

One theme in their testimony was how they did not fit the “typical” image of a person with a disability. “When was the first time you realized you were different?” was the first question posed to the panel. Paula responded that she felt different than her classmates in college when her illness took her away from classes and swimming practice. Saundra responded that she did not feel different growing up in a foreign country as a young girl, and that for most of her life her parents strongly emphasized her sameness. The first time she felt different from other kids, however, was when her family moved to the U.S. “Only when I was at a U.S. school did I feel different,” she said to the class, “kids shot rubber bands at me, that kind of thing.” Emelia jumped in immediately after Saundra with a similar story. Living in the Philippines as a child meant that her difference was unknown to her, until she moved to the U.S. “That’s when I started getting stares,” she told the class, “and I realized ‘oh my hand is a little different, I don’t have five fingers.’” She explained how disabilities were more widely known and
discussed in Filipino culture, while the U.S. is largely ignorant of it. The students tried to come up with various explanations for this gulf in understanding, hypothesizing that this problem began in the family, with U.S. parents steering their children away from children with disabilities.

Relating to the lack of disability awareness, Saundra also shared the story of meeting her boyfriend’s father for the first time. She told the class how the father felt like she was an “economic liability” for his son, and that this knocked down her self-esteem. She said “I respect him for it now,” which confused students. They asked her how she could respect him for saying something so mean—in fact, one student got visibly angry at the father’s attitude, stating that she would tell him that he was running away from reality, and that “when you die, your bills die with you, so who cares?” Saundra admitted that this student was correct, but struggled with a follow-up answer for why she said she still respects the man. I offered an explanation that people with disabilities have to navigate a wave of negative attitudes throughout their lives, and that they cannot hold grudges or burn bridges, especially in family situations like Saundra’s. She wanted to earn the respect of her boyfriend’s family, so she gave him as much as she would like to receive. The students again expressed wonderment and praise over Saundra’s amazing power for self-control in such an extremely prejudiced situation.

Next the panelists gave some examples of the prejudiced attitudes they had encountered in the medical profession. This topic deeply resonated with the class; I had a few students hang out afterward to share their own frustrations with health care access and delivery for their own sick family members. Saundra and Paula presented a shared “struggle with recognition” in medicine; Emelia noted that this discussion did not
include her because she had nothing wrong with her internally. One student confessed ignorance about cerebral palsy. Saundra was happy to explain her condition to the student and translated its “science” into very easy-to-understand language. Surprisingly, students had a great understanding of the cultural explanations for disability, cerebral palsy in particular. More than one student offered examples of ancient cultural explanations for cerebral palsy, like Greek myths that attempted to explain the condition. Saundra and I were impressed by these comments and their exposure to disability from a humanities perspective.

One student admitted that they were unsure how to phrase a question about sports. They wanted to know if the panelists had been steered toward one sport and away from another. The panelists loved this question because they could all participate in the answer. Saundra jokingly responded that she would not be playing football any time soon. Instead, she preferred to practice martial arts because it improved her focus, control, and movement. I asked Saundra what her favorite moves were, and she unhesitatingly offered to show the class. “I’m going to have to ask for a volunteer!” she shouted. We laughed, having no idea what was coming next. The student who asked the question volunteered, and Saundra demonstrated to the class how she would wound him if he was an attacker, bringing him to his knees. The demonstration was impressive and the male student appeared surprised at how quickly Saundra moved in her wheelchair. Saundra also mentioned that she also runs, swims, and rock climbs. “How do you run?” a student asked. “I use a stick,” she replied, noting that “what I call running is what most of you call walking.” Paula stated how she did competitive synchronized swimming in high school (but not currently because of her shoulder
Emelia talked about her experiences on the fencing team, and that “nothing affected” her with sports—she plays it all. This impressive resume from all members of the panel transformed the original question (a good one for its recognition of the subtle discrimination in sports programs) into positive affirmations on the body. They defied normative expectations of sickness, weakness, and frailty so often associated with disability and femininity.

The panel ended with an interesting question that the participants could not easily answer. A student asked if the panel considered people with body image disorders, like bulimia and anorexia, as having a disability. A few seconds of silence followed as the panelists waited to see who would answer first. Paula ventured with an answer from the perspective of a friend with anorexia:

I think she wanted to be treated like a normal person. It goes back to looking at a person as a person, not as a disease, and treating them as a person. And if you keep looking at a person with anorexia as a disease, they might constantly fall back on that, and say “this is who I am, I am this disease,” rather than “I’m a person with potential.”

From her wording (“normal person”), Paula suggested that disability might be an unwanted, stigmatizing identity for someone with anorexia. She framed identification with disability as a crutch that limited possibilities for healing. Saundra shared similar thoughts: “Eating disorders…wow that’s a big question. I remember in high school struggling with [anorexia]. I will say this. I think disabled women strive to be just as normal as everybody else.” And that is all that Saundra wanted to say on the subject. I think the panelists were wise to avoid labeling other people and justifying “what disease qualifies” as an “official” disability. Nevertheless, I was surprised that no one (not even my students) made connections between the cultural demands of thinness and the
cultural demands for “fixing” physical disability. Perhaps women with skin conditions, if I had invited them to join the panel, could have offered additional insights into the cultural demands of physical perfection⁴.

**The Second Session**

With only two participants available at the second session (Ericka called in sick the morning of), Saundra was in control of the class. I noted a change in her demeanor as she assumed her “public speaking” self. She clearly enjoyed the attention and the ability to instruct the class. Emelia was more like the person I met in interviews: quiet and composed. She spoke deliberately and seldom. I sensed that Saundra was trying to prove something about herself—perhaps that she was a confident person. Certainly, public speaking, especially to a willing audience, can be a great confidence booster. Nevertheless, I feel like the personal stories that were brought up in the second session were difficult to work through publicly.

For example, a student brought up the fact that in some cultures, a child’s disability was perceived as a shameful for parents, especially the mother. Emelia and Saundra thought the questioner was asking about their personal relationships with their mothers. Saundra understood after I clarified the question. She told a story about going to the hospital because she stopped breathing and her mother worrying that it was something she had done. Another student asked the panel if parents were concerned about passing “bad genes” on to their children. The participants were visibly uncomfortable by this question, so I jumped in to respond. I told the students that in a culture that thinks eugenically about birth, any mother can receive blame for conditions,

⁴ In fact I would argue that they were more concerned with it than the rest of my sample.
regardless of genetics.\textsuperscript{5} I think Saundra felt insulted by the student’s question because her disability was not genetic and she did not think that the question applied to her. Emelia also chose not to respond to the question.

Saundra remarked that the students in this session seemed quiet and reserved. She believed that the quality of the questions submitted beforehand was not very good. I tended to agree. In the first session, questions were more mature and considerate. She did not like the focus on beauty and sexuality in student questioning, mainly because they were not topics that concerned her. “We’re worried about survival,” she said to one student who asked her why it is that women with disabilities put less energy into looking perfect than able-bodied women. Saundra liked the student’s question because it suggested that the lack of anxieties over beauty/body image was a positive trait, rather than a deficit.

Saundra surmised that the questions from the medical students might not be any better than the sociology students’. All of this is conjecture of course, but the Saundra did say that the question from a student about exploring alternative medicines sounded like a question a medical student would ask. Similarly, two students asked the panel if they sought “cures to become like everyone else.” Emelia said that she would not change her hand because she was born with it, and she could not imagine living any other way. Saundra said she plays around with the idea of a cure (like in the movie \textit{Avatar}), stressing that she wouldn’t wish her disability “on her worst enemy.” At the same time, however, the question showed limited vision and Saundra wanted to prove to that person that a cure was not necessary. She asserted that she can still walk. At

\textsuperscript{5} This inappropriate question made me want to assign Barbara Hillyer’s “Mother-Blaming” from her book, \textit{Feminism and Disability}.  

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that point she got up from her wheelchair and sat on the table to show students that her life was not as limited as the question would suggest.

Saundra said that she liked the questions from men better than the questions from women. The female students’ questions focused more on the body, beauty, and looking different, while men asked questions about literature, employment, mainstreaming (education), and medicine. Saundra found the question by one woman “What do you do to make yourself feel pretty?” particularly funny. She felt that “pretty” was a word describing a five year old instead of a mature woman like herself.

There was some tension between me and Saundra over the choice in assigned articles. For this session, I assigned Susan Wendell, Nancy Mairs, and Francine Odette. Saundra remarked before class that the Odette article was “overthinking” the issue too much, and that the Mairs article was much more “down to earth.” We began the panel with a discussion by comparing the two different writing styles. I made the point that even though both authors have a disability, their orientation to it differed. Saundra did not like the O’Connor article, which was more sociological in tone. She felt like it was too angry to be useful to students and that its anger might push able-bodied people away. I agreed that there was something about the memoir that makes disability much more relatable and less academic. Saundra convinced me that Odette’s article might suggest that women with disabilities are stigmatized for their bodies, which is not the message students should be wrestling with. Saundra told the class that she was amused by their tendency to ask questions about sex and beauty. One of the students responded that “this was what the article was talking about.” Saundra said that students need to challenge the text. I liked that she made this point.
Saundra liked the question about the best tactic/obstacle/trial that she went through to help her better understand herself. She talked about the experience of meeting her boyfriend’s family. The room got very quiet when she mentioned how that experience affected her. Some students in the class shook their heads in disbelief. She added a new interpretation of these events, explaining how social class may have played a part. With her boyfriend’s family looking down on her working class roots, she was stereotyped as a “gold digger.” This new element to the story revealed how class, gender, and disability intersect within families to create tension and hostility.

The final topic the panelists discussed was an issue particular to women with chronic illness. A student asked about gender imbalances in securing a relationship when the partner has a chronic illness. I brought up one study that found that male partners were more likely to divorce their wives if their wives were diagnosed with cancer. One student quipped that men leaving their wives in the middle of an illness “sounded like Newt Gingrich.” I was taken aback that the student knew about the alleged incident. Students laughed at this joke, and the panel session ended with jolt of positive energy.

**Participant/Facilitator Impressions**

Because I did not get IRB approval to evaluate the effectiveness of the panel discussion among the students, I can only report how participants received the experience. Participant feedback was important to the success of this exploratory project, but collecting it also encouraged me to finish the research. Sometimes I despaired that the public testimonies had no effect; but the women convinced me

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6 Gingrich served his wife with divorce paper while she was recovering from uterine cancer, as reported by *Esquire* in 2010. Source: [http://www.esquire.com/print-this/newt-gingrich-0910?page=all](http://www.esquire.com/print-this/newt-gingrich-0910?page=all)
otherwise. Ericka remarked that the experience was positive for her: “I’ve never been with other women my age that had disabilities, so it’s pretty cool for me to be able to talk to people, compare notes and that kind of thing.” Saundra agreed, stating that forming a women-only group was beneficial to the discussions because a woman was more likely to understand how she feels: “I’m glad it’s with women right now because there are certain things that women discuss that men would be scared of!” Then she added that men with disabilities would be more understanding, but they “would not understand everything.”

That the panel session could be unintentionally stigmatizing was another concern of mine. Paula mentioned how sitting separate and apart from the rest of the class at the front of the room made it seem like they were different from everyone else. I admit that the classroom space could have replicated dualistic thinking about able-bodied/disabled people. I asked Saundra “how do you educate other people about what it’s like to live with a disability or chronic illness without othering yourself?” Saundra thought that student reactions to her difference were normal because most middle class, economically advantaged students would not encounter a person with a disability anyway. She insisted that the public testimonies, even with the limited classroom set up, were worthwhile because, in her words “we have to change people’s minds before we can change policies.”

I could write an entire side project on the questions that students submitted to the panel. They varied wildly, from views on curing disabilities in the womb to charity drives for the disabled. Asking students to submit questions ahead of time, based on their class readings, helped kick start the discussion. But many questions went ignored to
make room for follow-up questions to panelist responses. By the end of the second session, for instance, students were simply asking whatever popped into their heads. It was difficult to stick to the “script” of the questions when the discussion took a lively, unexpected turn. My role as a facilitator was probably too laid back in this instance. I also likely overloaded the class with too much material as we jumped between panelists, articles, and student discussion questions.

A few rare students approached disability from a position of empowerment. For example, one student asked “Have there been moments in your lives when having a disability has improved your understanding of other people?” I praised the student who asked this question, for two reasons. First, the vast majority of students focused on difference and coping (as if they already assumed difference was a negative). Second, the question “how might disability be a positive thing?” is important to achieving participant goals of “humanizing” different abilities. The shift in thinking behind this simple question is enormous, as students ask themselves “why it is so difficult to answer this question?” Some embarrassing answers underscore how miniscule disability education permeates our culture: many thought that the only “positives” to disability were securing “better parking,” getting “disability income payments,” and “skipping in line at theme parks.”

Not surprisingly, participants had no trouble explaining how disability had enriched their lives in many ways by shifting their values about what it means to live a “good” life. I added to their discussion by bringing up Robert Murphy’s observation that the physical deficits from his paraplegia made him more productive as a worker/thinker. As he says in his book, *The Body Silent*, “I am incapable of doing anything else. I used
to waste time in the pursuit of distractions, and once painted our entire house in California to avoid writing a book. All I can do now is read, write, and talk—which is what academics call ‘work’” (1987, p. 192).

Saundra was a proud defender of the human rights for people with disabilities, and her dominance over the disability panel conveyed this fact. She told the students that she “wouldn’t wish her disability on her worst enemy,” implying that impairment does not function like a race or gender identity. The pain of being Black or a woman in a racist, sexist society has no equivalence to living with a body in pain. She did not want people to “walk in her shoes” to understand her, because suffering was too painful to share. Vicarious suffering, however, was not the necessary precondition for basic respect and recognition. In the future sessions, I want to make it clear to students that discrimination is a distortion of these impairments, and that persons with disabilities have effectively organized around these distortions—sometimes to the detriment of a frank discussion about impairment.

Conclusions

The addition of group interviews and public testimonials transformed this project from passive to active research. Drawing from Freire’s critical pedagogy as a conceptual lens, the participants used education to consciously shape society into their own image. Participant contributions were dynamic; they worked together to change consciousness and reclaim power. The women were excited to talk about themselves, educate the curious, challenge stereotypes, and “testify” about their experiences among their peers and wider society. I sensed that they were, for the most part, pleased with the opportunity to speak publicly and elevate their shared concerns. Likewise, students connected with the speakers and used the class day to talk about disability experiences
in their own families. Other students confessed that this was the first time they had met a disabled person, illustrating how invisible and private disability remains in our culture. Topics that were covered in the interviews and testimonials included: structural critiques of employment, restoring humanity to medicine, covert and overt discrimination, genetic ethics, violence, sports and exercise, disability’s effect on family and relationships, and the meaning of a “cure.” Of course, there was much more that we could have explored, like ADA/civil rights history, the difficulty of defining “disability,” dichotomous constructions of normal/different, environmental justice and disability, people of color with disabilities, and disability in an international context.

Because I cannot definitively confirm the efficacy of participant efforts, I will end this Chapter with suggestions for future research. If the participants were to continue speaking to college students, and we chose to work within a positivist framework, a controlled quasi-experimental design should be included. The control group could learn through traditional lectures and readings. Another class could include lectures, readings, and the panel session, using quantitative measures to reveal any movement in student attitudes. But this begs another question: what attitudes need changing in the first place? Certainly, my participants wanted to change attitudes of the medical profession by reaching out to medical students. Yet, students in other majors did not have a cohesive attitude toward disability, as evidenced by the wide variety of question topics submitted to the panel. That said, testifying to students outside of the medical profession may be more fruitful because medical students must adhere to the rigid structures embedded in the practice of medicine. Insurance rules and for-profit care control doctor’s behavior; not matter how compassionate or sensitive the healer, the
incentives for care must change as well. Thus, education has its limits (though it was meaningful for the educators, who felt that general knowledge about disability was within their power to control). Substantive social change for disability and difference, then, may require more than empathy or diversity education; real economic change is needed to improve relationship, health, and employment disparities.
CHAPTER 8
DISCUSSION

Relying on theoretical perspectives from the diversity of disability research both inside and outside of sociology, I extend conceptual frameworks developed from the social and impairment models of disability (Oliver, 1996; Crow, 1996). I conscientiously attend to the experiences of being/having a “different” embodiment within the context of young, female adulthood. At first glance, these experiences appear to split neatly into two realms: social oppression and physical impairments. Throughout this analysis, however, I stress how social oppression and exclusion work through embodiment to reveal how difference is maintained. Rejecting the dualistic thinking of dominant paradigms—disability/ability, illness/disability, disability/impairment, mind/body—I reveal the features of life for young women who inhabit a spectrum of abilities and embodiments. These features are strikingly paradoxical. Interviews reveal how young adult women negotiate the tensions surrounding disability in our culture, create new identities around these tensions, and take action in their community to spread awareness about the issues that affect their lives. In this Chapter, I summarize study findings, analyze the difficult tensions and paradoxes contained therein, and discuss theoretical applications for the disability rights movement.

Summary of Findings

In Chapter 5 I situate my findings within the context of the social model of disability. I detail how medical/bureaucratic power and social exclusionary practices impact the lives of the participants in ways that frustrated their claims to personhood. I show how powerful constructions of “normal” and “different” manifest in everyday interactions with able-bodied people in school systems, friend support networks, and the
workplace. I also illustrate how constructions manifest at the macro-level. Participants invoked critiques of three institutional practices: bureaucratic rationality in state computations of poverty thresholds, compartmentalized medical structures that slowed information sharing, and educational institutions unequipped to recognize nuances of ability. Blanket assumptions about “the needs of disabled people” were used as justification for physical segregation in school systems and emotional segregation from support networks. Participants defiantly resisted these obvious forms of discrimination in schools and workplaces.

Participant critiques of medical power were much more complex, however. The intimacy of the doctor/patient relationship and benefits of medical expertise explained this nuance. Some participants felt discounted and undercut by medicine’s rigid diagnostic criteria; others attempted to share power by asserting their knowledge as illness “experts.” When assuming the role of patients, the women valued personal responsibility as empowerment and shunned total dependence on a doctor to make decisions for them. Participants allocated responsibilities between doctors, bodies, and themselves depending on the contexts of their conditions. Based on the data, I suggest that medical discourse contains more words to convey the moral responsibility for health than the moral experience of suffering. Capitalist medical structures and Western medical vocabularies offer less time for patients to speak, so that suffering is normalized and silenced. And in some rare cases, personal responsibility for being a “good patient” meant bearing the suffering stoically without seeking treatment.

In Chapter 6, I offer data that explores linkages between the social model of impairment and the social model of disability. I elevate the former as a counterweight
scholarship that, in my view, has erased real experiences by relying too heavily on constructivist thought. Drawing on stories of pain, selfhood, difference, and gender, I report rich data in Chapter 6 relating to issues of power, physicality, and social relations. We see, for example, how women assess their own impairments when they speculate on childbirth or marriage. Impairments had social implications as the women worried about pregnancy’s toll on their bodies or mourned their exclusion from motherhood. The social model, in alliance with feminism, could alleviate some of this pain by seeking cultural changes around reproductive norms and risk discourses, but the limitations of this are clear if some women still desire children. Impairment works not only as a physical marker but a social marker when it is expressed eugenically; in short, women with disabilities and illnesses felt societal judgments against them in the confluence with their own judgments about their capabilities as mothers. This is perhaps the most critical finding relating to the liminal space of young adult/womanhood.

Chapter 6 further examines the lived experience of embodied difference. Many activists eschew discussions of difference, fearing that they bolster biological determinism. Shakespeare & Watson (1996) claim that to create a “truly embodied sociology,” we must explore the “vital and interesting things that are happening to people and their bodies” (p. 8). I do so by listening, without medical interpretations, to what women have to say about their bodies. As a result, difference became as complex as the people I interviewed. Embodied difference meant living in a world bracketed by biological and social facts. Participants tried to make sense of their own private experiences with pain and fatigue. They politicized private experiences by critiquing the medical mismanagement of pain and refusing to suffer in silence. At the same time,
falling narratives indicated how built environments denied private relationships with the body. Women resented how an unnecessary fear of litigation (a protection that able-bodied people have given themselves) made their falls a public concern. Embodied difference was also understood under the rubric of “the self.” In this context, difference was rarely static. Many of “veterans” of impairment told stories of how they realized that perceptions of difference were within their power to manipulate, implying that “self” and “other” are inherently unstable constructs (Broun & Heshusius, 2004). At the same time that difference was constructed relationally, participants spoke about the difficult divides that impairment created, implying that certain relations (like those between myself and my participants) could not be changed. This understanding resulted in some of the more painful, sensitive, and delicate discussions in the entire project for both me and the women involved. For this reason, I rarely challenged my participants on their claims to self-knowledge, respecting their intellectual and political capacities from the outset.

In Chapter 7 I embark on a new journey, attempting to move the research beyond medical sociology’s core (i.e. describing “adjustments to disability” and “repairing the self”). The participant-directed activities positioned disability as an experience that is shaped, just like gender or race, by power relations. This concept was imparted as a transformational “lesson” to able-bodied people, filtered through the experiences of college-aged women with a range of physical disabilities and chronic illnesses. The women decided to speak publicly about their experiences, inviting each student to think about disability for at least one 50 minute class. The purpose of the discussion was to help students understand the power imbalances between able-bodied people and people with disabilities.
Contradictions, Paradoxes, and Tensions

Some important tensions about difference and sameness radiate across these findings. Broadly speaking, the medical world creates difference by discounting personhood, while participants attempt to claim it. In this case, technoscientific language and enhanced medical understandings of the body clashed with more experiential, humanist desires to be seen as a “whole person.” Although the women asserted the latter, they drew from the former to reclaim power and convince doctors of their own expertise. This individual strategy did little to challenge pervasive paternalism (and maternalism) in medicine. For example, research by Paterson (2001) uncovered covert ways that practitioners contradict their claims to patient empowerment and autonomy even among those nominated as “expert managers of self-care” (Paterson, Russell, & Thorne, 2001).

Ironically, some participants suggested that medical settings allowed for slightly more autonomous decision-making than educational institutions. One explanation for this is how the women negotiated claims to sameness and difference depending on which institution they wished to engage. Unlike educational and employment in which claims to sameness were desired, medical power rendered them active participants in claiming difference. Put differently, in order to gain recognition, the women insisted on their differences in the medical world while emphasizing their sameness in the able-bodied world. Women who grew up with a disability or illness could move between these contradictory claims more easily, learning how to position themselves as different and not different in contexts that they wished to alter.

The limits of alteration were clearly identified when the women discussed their treatment in employment and educational institutions. Working/educational worlds
construct differences based on what majority groups think are impairments. These are not impairments, however; they are social judgments that create “disability.” An added complication is a sort of disability-blind ableism lingering underneath these judgments.

Zola (1982) observes how children tend to ask innocent questions like “Why are you in a wheelchair?” but they are scolded for asking. In effect, the child,

is taught to ignore it…they are taught to respond globally and not particularistically, to recognize a handicapped person when they see one but to ignore the specific characteristics of the handicapped. Is it any wonder that a near universal complaint is “Why can’t people see me as someone who has a handicap rather than someone who is handicapped?” Young children first perceive it that way but are quickly socialized out of it (p. 200).

This socialization process parallels the way that institutions conceive of disability as a justification for segregation, but ignore the particulars of each individual person.

Likewise, special needs education, health insurance rules, and public assistance, designed as “helping systems,” resulted in a social trap whereby the women were forced to prove their dependency, impoverishment, and neediness before they received even the most minimally necessary assistance (e.g. an extra $100 a week, an extra ten minutes on a test, for example). Women with physical disabilities, more than any other group in this study, felt the brunt of these contradictions from state institutions.

As I read more widely to contextualize these tensions and paradoxes, I discovered that they were typical artifacts of the cultural responses to disability. According to bioethicists, disability forces hard questions about what it means to be human (Scully, 2008). The hard questions result when pain is calculated into existing constructivist interpretations. For instance, when Fausto-Sterling (1993) argued (correctly) that intersexuality threatens an infant’s culture, not an infant’s life, I felt disappointed at how easily she had “won” the debate around a complicated issue. I wanted to think about
existences that are threatening to life, and the meaning of this for our concept of “rights.” Sociologists did not usually venture into such ethical territories. Unlike phenotypic variation between men and women or whites and people of color, disability hierarchies cannot be abolished by celebrating all embodied differences as if they were objectively equal. Ideologies of ability render disability a deficit, but this is not just discursive—bodies experience pain, and suffering is real.

Resultantly, scholars must contend with people who want to eliminate impairment and disability from their lives. How can disabled identities maintain value if pain is the payment for group membership? Isn’t the goal of eliminating pain just as important as the goal of eliminating oppression? Moreover, what about people who do not identify as disabled? Thriving in normalized/mainstreamed settings, some participants insisted, “We don’t think of ourselves as disabled.” Constantly challenged to think of oneself as different and not different, the participants reveal the political motivations behind such identification. Does thinking of oneself as able-bodied re-inscribe the idea that disabled is an undesirable thing to be? I always returned to this question throughout the project. The answer is fantastically difficult, but I found it easiest to ponder in the context of the disability rights movement.

**Theoretical Applications for the Disability Rights Movement**

Having advanced understandings of complex embodiment across young women’s lives, I can move to a more critical analysis of body trouble as a device for aiding in the disability rights movement. I attempt to use the knowledge that the participants and I have produced to work toward a theory of body trouble and its application for social movements around disability and body oppression more generally. But first, I would like to establish my theoretical contribution to the field. Some argue
that the omission of the body from disability theorizing creates a “social or cultural essentialism” which “has produced an unsatisfactory conception of social relations” (Shakespeare & Watson, 1996, p. 4). I believe my study, grounded in conversations with 20 women with various physical differences and impairments, presents a clearer picture of the social-relational qualities of embodiment. By doing so, I anchor women’s personal thoughts and experiences about their bodies within social institutions and practices.

**First, I discovered similar social experiences of embodiment across all of the women in this study.** The women forged identities that opposed the negative or uninformed assumptions that bombarded them on a steady basis throughout their lives. While Goffman would focus on how these bombardments create a “spoiled identity,” I argue that my participants were not passive recipients to their stigmatization. In fact, they did not internalize or respond to stigma at every moment of their lives as Goffman would suggest. Yes, women with skin conditions used to make-up and creams to normalize their facial features; women with chronic illnesses wished that their illness did not dictate their sense of self; and women with disabilities sometimes found themselves compensating for their disability. Nonetheless, pleasing others or adaptation to difference was not an all-consuming goal for their lives. These findings are supported by Frank (1988), who found evidence that critiquing other people’s responses was a more salient strategy for making sense of the world than struggling to meet their approval. For these reasons, Gill (2001) suggests that disability is not a case of “spoiled identity” but a case of “mistaken identity:”

Many disabled persons spend much of their lives grappling with a sense of mistaken identity that dominates and diminished their experience…they
want acknowledgement of who they are, and they seek this from family, acquaintances, and strangers on the street. When, instead, they repeatedly intercept entrenched misconstruals of who they are and what it means to be disabled, they swing into action to correct the wrong impressions and to reestablish identities. They wage an exhausting struggle to be known (p. 364).

We could include women with skin conditions into this framework as well, as women with acne, port wine stains, and vitiligo had to deposit meanings and explanations into incorrect assumptions about their appearance. Certainly, whether these conditions can be included under the multidimensional disability umbrella is still up to debate. The fact remains that all participants confronted the dilemma of mistaken identities to some degree. Confronting mistaken identities was a way to make sense of difference and clarify assumptions without absorbing the cultural demands for unblemished perfection.

*Despite these similarities in experience, I observed how social arrangements worked differently on the participants despite similarly situated embodiments.* To paraphrase Simone De Beauvoir (1952), the body is not a thing but a set of relationships that inputs the self into our social world. Cultural ideas about illness and disability, sometimes conflated, sometimes distinct, underwrite these relationships. A quick glance at the voices present in Chapters 5-7 tells us a cursory story about how embodiment, and society’s reaction to it, organized people’s lives. Figure 7-1 presents a visual map of findings from Chapters 5-7, illustrating how the themes clustered around the three groups I interviewed. Women with disabilities and chronic illnesses crossed paths throughout Chapters 5 and 6, but their experiences converged most notably in the section on physical realities and gendering body trouble. This suggests that they shared overlapping disability experiences relating to pain and functional limitations that cannot
Figure 7-1. Conceptual map of dissertation findings
be reduced to social constructions. I can emphatically assert, however, that these difficulties did not cause the risk discourses associated with motherhood and the guilt of caregiver burden. Instead, impairments were overgeneralized or interpreted in isolation from the women’s particular situations, evoking “distorted wholesale disparagement of the disability experience” (Gill, 2001, 365). A bridge between the two groups also appeared in Chapter 7 when participants found common ground in their desire to restore humanity to medicine, indicating their shared values about what constitutes a worthy life within the confines of the medical model. Their desire for recognition, and their inability to get it, pushed disability and illness into what Murphy (1987) calls the “twilight zone” of existence between two worlds (p. 193). In response, both groups used considerably more skill and effort than women with skin conditions to assert their presence in the face of exclusion. Their differences were more pronounced, moreover, when women with disabilities sketched the particulars of employment, education, and safety net programs for their lives. Women with chronic illnesses (including Emelia, the woman with a congenital hand) did not languish in the “acronym soup” of CILs, VR, SSDI, or ESE programs.

So, why were women with disabilities singled out for these client-service social arrangements, while women with skin conditions and chronic illnesses were not? I maintain that experiences from the former group in my sample fit most comfortably into the well-documented qualities of the “disability experience.” Distilled into its most form, disability engages the medical model from a very young age (and in some cases, from birth). Disability labels, applied throughout childhood and adolescence, come packaged
with neediness and tragedy. Barnes (2003) explains how these labels subsist on a hierarchy of values for “being ill” or “being disabled:"

[It] is hardly surprising given that in an increasingly competitive and unequal society the label “disabled” is still widely associated with abnormality, social and psychological inadequacy and incompetence, and that, in one way or another, all of us are socialised into the view that to admit to such things is a sign of weakness and failure... To be “ill” is far more socially acceptable than it is being “disabled” [emphasis mine]. Moreover, given the various deprivations generally associated with disability it is a miracle that anyone would want to adopt the label (p. 14).

As Barnes states, people with chronic illness are averse to adopting a disabled identity. Again, I assert that these hierarchies were not lodged in material, physical differences; as I show in Chapter 6, experiences of women with disabilities and women with chronic illness overlapped considerably. Yet, one group was shuffled through a myriad of “helping systems.” This divergence is what social geographers call “geometries of difference” (Parr & Butler, 1999, p. 15). Collapsing physical and mental impairments into a “special” need, like adaptable housing, creates social divisions at the same time that it makes living easier for some. For this reason, Fraser (1995) argues that group identities like “disability” leave deep structures intact, benefiting a vocal minority, and stigmatizing everyone else who does not identify with the label.

These complications bring me to the usefulness of disability identity politics in social movements more generally. The cornerstone of this discussion deals with how to utilize the particulars of personal experience and impairment in activist strategizing. I see a few possibilities, but limitations as well. By highlighting the corporeal nature of impairment in this project, I show how physical realities are filtered through moral attitudes about how bodies “ought” to work, what spaces they should take up, or how they should look. This means that physical realities like pain, fatigue, falls, and body
horror, previously thought to sit within the medical domain—could be socially understood as a status.

For example, the women’s disgust with the unpredictability of their bodies invites parallels to society’s lowest members working under filthy conditions. Grotesque narratives about excrement I explored earlier share similarities with immigrant experiences from the film Las Cartas de Alou. The film follows Alou, a Senegalese immigrant, as he struggles to create a hospitable life while living in Spain’s sewer system and working at the garbage dump. Deconstructing the meaning of “waste” in the film, Burkhart (2010) remarks that,

Even though they are living in degrading conditions…African immigrants refuse to allow their personal integrity to be compromised by their physical surroundings and by labels and stereotypes. By embracing their potentially degrading conditions, they actually make their environment bearable and salvage a modicum of dignity.

Visually distressing, the film captures the living conditions of Spain’s African immigrants and their proximity to waste and filth. Images of feces and disorder convey immigrants’ plight in dramatic ways. I see parallels between these living conditions and Wade’s revelations on the disordered, dependent body that I discussed in Chapter 4. People suffering in isolation and shame could organize around the hard reality of bodies. According to Siebers (2010), this would mean explaining how disabled bodies actually work to an otherwise ignorant public. He summarizes the end goals for such a movement as follows:

The challenge is not to adapt their disability into an extraordinary power or an alternative image of ability. The challenge is to function…People with disabilities want to be able to function: to live with their disability, to come to know their body, to accept what it can do, and to keep doing what they can for as long as they can. They do not want to feel dominated by the people on whom they depend for help, and they want to be able to imagine themselves in the world without feeling ashamed (p. 69).
Based on the interviews I present here, I think it is safe to say that my participants desired the same goals, though Morris (1991) expresses trepidation about volunteering private accounts in the service of social change. She argues that people with disabilities are already curiosities for the non-disabled: “our physical difference makes our bodies public property,” available for questions like “how do you manage?” (p. 29). Hence, I see a need to balance the invisibility of the everyday realities of disability with highly visible, exaggerated, and tragic images. This message may be too complex for activist strategizing that demands simple, digestible sound bites for public consumption.

**Implications for Sociology and Feminist Scholarship**

Researchers have increasingly recognized the interplay between lived embodiments and constructed ones. Attention to the lives of young adult women with different embodiments extends understanding of how “the body” sits within social structures and practices. Understanding embodiments in contemporary society requires awareness of disability and impairment—two concepts thoroughly interrogated by disability studies. Sociologists do studies these concepts, but usually from the view of functional capacity, aging, or constructivist ruminations on the self. Williams (2001), in his criticisms of how sociologists study disability, says that sociological approaches, Fail to retain a sharp enough understanding of the politics of both the experience of disability and the construction of the categories we use to speak about it. In short, the sociological imagination has not been exercised sufficiently robustly by sociologists (p. 133).

If the sociological imagination had been used to its fullest, says Williams, sociologists would not have produced a totalizing picture of illness as something that causes certain social consequences. Considering this criticism, dangers increase for any research that explores the personal experience of disability through the framework of the body. While
I do touch on medical sociological concepts like “self repair,” and “embodied distress,” I do not make it the focus of my dissertation. Instead, I try to move fluidly between physical and the social states, zooming in on the political wherever it may emerge.

Accordingly, the knowledge that I produce attempts to move beyond a purely constructivist model to politicize the experience of disability and illness. I do so by finding empirical basis for the political and cultural practices that shape impairments within the context of young women’s embodied milieu. Resistance is integral to avoid the “causal” trap in body research. Thomas (2004) argues that Bury’s (1982) style of medical sociology leaves no room for challenging oppression. People need to feel like they are more than just “good” recipients of rehabilitation programs; this means “adjust”/”adapt” theories of disability cannot attend to issues of equity, political recognition, or exploitation. For instance, how does one “adjust”/”adapt” to constant pain and/or discrimination? I chose to facilitate a direct action in order to move beyond what has become an increasingly “descriptive” mode of thinking and writing about disability in sociology. In addition, I hope that this project opens doorways to reintroduce disability and the sociology of the body. I argue that it is necessary to include bioethics in future theorizing. Thinking about what makes a life worth living, and what does not, is a fruitful scholarly enterprise that sociologists too rarely explore.

Out of all of the theoretical positions I encountered in my research, I believe my theories closely resemble Thomas’ social-relational model of disability, which she developed from Finkelstein’s original propositions. In her study on disabled mothers, she remarks:

My starting point is that the study of personal experience can powerfully illuminate aspects of these ‘social barriers’, and so point to areas for social
change. This reaffirms the sociological position that the study of individual lives can very effectively illustrate the social.

I conceive of the “social” as a site for making sense of one’s body and making sense of one’s marginalization. Rarely did participants fall back on the former to explain the latter.

My findings are also relevant for feminist theorizing. I contribute to the rich research on disabled women’s experiences, and extend this knowledge to young women coming of age in the late 2000s. My feminist education has taught me look for and listen to women’s experiences, without assuming a right to define their reality. My task as a feminist sociologist is to synthesize multiple realities into a complete picture while carefully negotiating the complex space between sociality and corporeality (Witz, 2000). Scully (2008) notes that it is “quite a trick” to do both, as feminist theorists attempt to

give accounts of the body that resist the temptation to pin it down as either biological or social, but allow it to be simultaneously composed of limiting parameters and sites open to manipulation and change (p. 170).

My findings show how, at the same time that artificial cultural constructions work on women’s bodies, the body’s sensations are real. This study captures how young women “live” or “work through” constructed states of being that are inherently contradictory—body vs. society, weak vs. strong, dependent vs. independent, young vs. old, sick vs. well, clean vs. messy, feminine vs. masculine, in control vs. out of control.

I also feel that my findings move between women who have adopted a political or cultural consciousness that centralizes difference and other women who identify as “typical.” For some participants, the experience of not being normal was liberating, and they enjoyed the fact that they were different. Their positivity was infectious—a reminder
of the strength that difference contains. Others did not even think of themselves as different, illustrating how impairments recede in importance as they are integrated into daily routines (Gill, 2001). Understanding difference has implications for future work that explores the relationships between identities, embodiment, and political consciousness. Similarly, I explore women’s lives from the margins to the center, showing how the margins are maintained. These margins cannot be justified by medical categories, leading to me to explore the meaning of disability itself. This journey reflects the same journey that race and gender scholarship has taken in the past few decades. In studies of race and gender the social constructivist perspective introduces an unavoidable sense of contingency. Inquiring “What is race?” Lee (2005) wonders how we can attribute an independent causal force to such an unstable, inconstant object. Just like race and gender, scholars analyzing disability have shifted from studying experiences of what are assumed to be invariant disabled groups to the constitution of disabled groups themselves. Accordingly, my findings offer a glimpse of “belonging” to an identity group whose basis is just as complex as race and gender.

Limitations and Reflections

All research suffers from limitations, and this project is no exception. Findings should be viewed in light of the narrow sample demographics and the group labels used to classify participants. Few women of color’s perspectives are included, and the narratives emerged from a white, heterosexual, middle class, U.S. setting. I could have arrived at different results if I had actively recruited people based on class, race, gender, and sexual diversity. I also wished, at times, that I was including more queer people in my research—even if that meant recruiting from a range of gender/sex/sexuality configurations. I wish that my research could have fully
incorporated a queer perspective on disability, since scholars have begun to explore interesting intersections between the two identities.

Producing any knowledge about embodiment required relying on contested labels that did not always reflect reality. Though I claimed to sample from a range of embodiments, that range, in the end, was not as wide or as deep as I had anticipated. I realized throughout the research that a true “spectrum of embodiments” could include anyone. Likewise, in my quest to understand the uniquely situated experiences of embodiment, I had to question why I chose to start from the “deviant” position of disability, skin conditions, or chronic illness. I sampled women from these three groups unaware of the complications this would result later on when developing the public testimonials. At times, I thought I should have included all women to explore how constructs of difference are justified and maintained. This would involve studying what Garland-Thomson (1997) calls “the normate”, or the figure outlined by deviant others who create the norm’s boundaries by stepping into a position of authority and wielding the power it grants them (p. 8).

Several limitations and ethical questions emerged as soon as I made the decision to report interview findings to the participants. First, I had to tread carefully when conducting AR to avoid research paternalism. Unlike some participatory projects that view participants as ignorant of a critical understanding of their situation, I did not want to presume to “educate” them about their own oppression. Participants were not necessarily the ones whose lives needed transformation: the students and the researcher did as well. I discovered that other AR projects had similar concerns; researchers apprehensively called their efforts “emancipatory.” Broun (2004), for
instance, a researcher and a woman with a physical disability, strove for a collaborative relationship between herself and the women with disabilities she interviewed. She discovered, however, the problematic assumptions behind collaboration and empowerment. To her, action researchers insisted "You need to be empowered, you need to be transformed, you need to be emancipated from the fetters of your dispossession – and I can help you" (p. 8). She responded to these demands with a feminist question: "What privileged status do I have as researcher to determine who deserves/ needs emancipation through my efforts?" (p. 9). Navarro & Zeni (2004) agree, adding that enlightenment of people other than the researched should be the end goal. Indeed, this project became more than just “research on women.” It became a space to interrogate my own knowledge about disability. It was difficult to ensure that transformations took place with, not to, subjects.

Second, I struggled with choices about how to involve participants in the research. How much of this research was truly participatory? I could not consult participants about every decision due to the need to get the project rolling without communication delays. Moreover, the interview findings, which revealed overlapping experiences between each participant depending on their conditions, necessitated a decision on whom to involve in the group interviews. Could I reasonably expect to conduct multiple group interviews with women around each of their own health/cosmetic conditions? Would I be launching three different activist projects if I divided the sample into chronic illnesses, skin conditions, and disabilities? These decisions were not open to democratic debate, but could have been if I had the time and resources to encourage women to talk it over together. In the end, I decided to extend group interview invitations
to participants who had on-going health, illness, or disability issues. I excluded women with skin conditions because they shared fewer life experiences than the other women (see Figure 7-1). While women with skin conditions spoke mainly about make-up and topical creams, women with disabilities and health problems spoke of job discrimination, medical frustrations, insurance woes, family caregiving issues, and social exclusion. Their stories seemed the most pressing but also the most similar. For this reason I contend that my decision to invite only women with disabilities and illnesses to a group interview was grounded in the original interview data.

Finally, sharing intimate accounts—first with other women who could relate to each other, then with students who, for the most part, had no prior introduction to disability as a relational concept—made me wary. Even though participants voluntarily chose to answer questions in the service of knowledge, classrooms can be hurtful places, even if unintentionally. Students, myself included, have trouble determining where a “line” should be drawn in their questioning. Broun’s words resonate here:

There is a common, silent understanding among persons with disabilities. This understanding allows the sharing of information to flow, but there is also a keen sensitivity as to where to draw the line in asking questions in those areas where we know too much and hide it from ourselves. The non-disabled researcher may ask the hard questions out of ignorance of where the "line" should be drawn. Researchers must be attentive to this moral dimension and are confronted by the dilemma of how deeply they can probe in order to receive "richer" data before this probing becomes voyeurism.

Even in the interviews I had no qualms about asking the “hard questions” related to bullying, ridicule, or shame. I thought I could skate through these topics on my empathetic talents, but I later asked myself why I needed to delve into people’s sorrows and humiliations. Was I, like my students, oblivious to the privileges that I enjoyed by not having to carry these experiences around with me? Part of the reason I felt so
conflicted was that the panelists insisted that they wanted students to ask any question they wanted—Ericka, in particular had a “bring it on” attitude. She said she had “heard it all” and that nothing shocked her anymore. Participants sought to set the record straight about who they were collectively, but in doing so, oppressive questioning could not be completely contained. For this reason, the hidden underworld of illness is not always a negative state—sometimes private accounts should stay private. Zola (1982), though, is aware of the paradox in the silence around disability:

The story is inevitably difficult to hear and difficult to tell. The teller finds it especially hard to acknowledge the central difficulty. Even to think of the world in such a realistic, paranoid way might make it too depressing a reality to tolerate. The only defense, the only way to live, is to deny the reality. But then it becomes socially invisible to all…Both those with physical handicaps and those without—all—are deprived of the knowledge, skills, resources, and motivation necessary to promote change” (p. 211).

This small attempt at action research has been at times painful, inspiring, confusing, and exhilarating. Pushing research out of the academy was a wildly unpredictable activity. Conducting AR properly means I could not just work from home, tinker with “my” data, and close the project after I published an article. I had a responsibility listen to my participants and not impose my values on them. Along the way I discovered the possibilities and limitations of launching activism directly out of research. Despite the difficulties in conducting such a project, I see the value and the necessity of this effort and I will continue to incorporate it into knowledge I produce in the future.

Trouble and Transformation

I began this dissertation thinking about how the body—as an object of study—troubles simple beliefs about permanence, inclusion/exclusion, normality, hegemony, and privacy. Throughout the research I discovered that bodies were difficult subjects to broach for both the participants and their able-bodied counterparts. Especially when
asked to articulate pain or suffering, participants had few vocabularies to deploy or models to emulate. Some did not wish to explore intensely personal issues or identify with a disability community; others wanted to rewrite assumptions about who they were as a group. Indeed, who were they? They were not a collection of medical conditions or even a collection of individuals. Disability is more than just a group of wheelchair users—it is everywhere we look. By this I mean that our institutions are legally, socially, medically embodied insofar as they structure our lives around a narrowly-defined ability and normality. From young women’s location, moreover, it is possible to conduct cross-disability work that is so desperately needed to understand disability on a deeper level. I am especially proud of the discovery that people with different embodiments can build bridges to each other as the women with chronic illness and the women with physical disabilities did in this project. This act was a smaller iteration of the cross-disability work accomplished in Berkeley, California, when blind people and wheelchair users united to design curb cuts amenable to both groups. About designing a city for users with different impairments, Dmitri Belser said, “You can approach this as a big pain or as an interesting puzzle. But ultimately, you have to acknowledge that you can’t do everything” (Kushner, 2009). The same could be said of my entire dissertation.

To that end, I would like to move out of body trouble into something more celebratory: transformation. A careful reader will discern my naiveté about my own dissertation topic. Even at the end of this project, I am uncomfortable even calling myself an “expert” on something I have not directly experienced. Nonetheless, this research transformed my thinking (as well as my life!) in profound ways. Broun had a similar reaction to her forays into AR, confessing that it never occurred to her that she
would be the one transformed by her research. As much as I studied it in others, I find difficulty in writing down these changes that took place in my own self-concept and relation to the world. All I can say is that I wish that every able-bodied person would embark on similar journeys. They, like me, can try to understand not only how other people live, but how their own able-bodied existence actually lacks the shift in values that disability gains.
APPENDIX A
DEMOGRAPHIC QUESTIONNAIRE

1. What is your age? ______________

2. What is your gender?
   □ Male
   □ Female
   □ Transgender
     □ Male to Female
     □ Female to Male
     □ In transition
     □ Gender queer

3. How do you identify yourself, racially speaking?
   □ Black—not Hispanic
   □ White—not Hispanic
   □ Hispanic or Latino
   □ Asian or Pacific Islander
   □ American Indian, First Nation, or Alaskan Native
   □ Other

4. What is your ethnicity (cultural background)?
   ________________________________________________

5. What is the highest level of education you have completed?
   □ Some high school
   □ High school diploma
   □ Some college
     If so, specify highest class level completed____________________________
     If so, specify major _______________________________________________
   □ 4-year college degree
   □ Some graduate school
   □ Graduate degree

6. What is your occupation/profession?
   ________________________________________________
   ________________________________________________

7. Are you currently employed?
   □ Yes
   □ No

8. Describe your physical disabilities, chronic illnesses, or skin conditions.
   ________________________________________________
   ________________________________________________
9. **Time of onset for this disability or facial difference:**
   - □ Pre-natal disability (PND)
   - □ Childhood-onset disability (COD)
   - □ Adult-onset disability (AOD)
   - □ Childhood-onset facial difference (COFD)
   - □ Adult-onset facial difference (AOFD)

10. **Which of the following is your primary assistive device?**
   - □ Power wheelchair
   - □ Manual wheelchair
   - □ Single-point cane
   - □ Quad cane
   - □ Walker
   - □ Fore-arm crutches
   - □ Leg brace
   - □ Hearing aid
   - □ Service dog
   - □ Not applicable
   - □ None
   - □ Other _____________________________

11. **Do you receive attendant care?**
    - □ Yes (if Yes, go to question 10)
    - □ No (if No, go to question 12)

12. **Can you describe the kind of attendant care you receive?**

13. **How do you pay for this attendant care?**
    - □ Own income
    - □ Parent’s income
    - □ Social security (disability)
    - □ Medicare or Medicaid
    - □ Grants
    - □ Charities

14. **Can you describe the kind of services you receive?**
15. Are you or have you ever been involved in community activism for women or people with disabilities?
   □ Yes (if Yes, go to question 12)
   □ No (if No, go to question 13)

16. How would you describe your sexual orientation?
   __________________________________________

17. What is your relationship status?
   □ Married
   □ Engaged
   □ Living with a partner
   □ Widowed
   □ Divorced
   □ Separated
   □ Never married
   □ Don’t know
   □ Other
   □ Please specify: __________________________

18. If married or dating, what is the length of time of your current relationship?
   □ Less than six months
   □ Between six and 12 months
   □ Between one and three years
   □ More than three years
APPENDIX B
INTERVIEW GUIDE

1. Tell me about yourself – hometown, major, life goals?

2. Tell me about yourself and your [disability/illness/skin condition]

3. [if applicable] What was it like growing up as a young girl?

4. [if applicable] Did you ever have the feeling that you were different than other people? If so, did any events trigger this realization?

5. [if applicable] Growing up, how did you feel about being different from other people? How did you understand it?

6. Can you talk about what is important to you in your life right now? 
   **Prompt**: Does your [disability/illness/skin condition] impact this in any way?

7. [if applicable] Can you talk about how your [disability/illness/skin condition] affects you physically? 
   **Prompt**: How do you feel physically most days? Is this feeling consistent or unpredictable?

8. [if applicable] And when you go out in public, what makes it easy or difficult to get around? Can you talk about any issues you have going out into the community?

9. [if applicable] Can you show me how you use your assistive device? What did it enable you to do that you couldn’t do before? What does [this device] mean to you?

10. What is your attitude toward your [disability/illness/skin condition]? 
    **Prompt**: love, indifference, grudging acceptance?

11. Is your goal to be seen as normal or do you resist the pressure to change yourself for the sake of others?

12. How would you describe what it’s like to live with this [disability/illness/skin condition] on a daily basis? 
    **Prompt**: It might help to tell me what happens on a “good day” and what happens on a “bad day.”

13. I’d like for you to talk about the things you do before going out in public on any given day. What changes do you make to your body? How are these changes important?

14. What contributes to you having control over your life? What can’t you control?
15. Can you talk about any interactions with doctors, cosmetic surgeons, or therapists? What have these experiences been like?

16. Can you talk about what it means to be a young woman with a [disability/illness/skin condition] in a culture that stresses women’s appearance?

17. Is there anything about the way women are portrayed in the media that bothers you? Can you give specific examples from television, ads, magazines?

18. How do you respond when women without a [disability/illness/skin condition] complain about their bodies?

19. Let’s move to the subject of romantic relationships. What has dating been like for you?

20. After all the issues we have talked about today, what do you feel needs the most attention for people with [disability/illness/skin conditions]?
   **Prompt:** What changes need to be made in the community and/or culture for your difference to be seen as normal?

21. Finally, how important is it for you to meet other women [disability/illness/skin conditions]?
   **Prompt:** What does it mean for you to talk to other people like yourself? Would you consider being a public speaker or activist for other people like yourself?
APPENDIX C: INTERVIEW GUIDE: AFTER PUBLIC TESTIMONY

1. Explain why you volunteered to be a guest speaker. What are the goals that you want to accomplish with this activity?

2. I’d like to hear your thoughts on the panel session today. How do you think it went?

3. How does it feel to be speaking about your experiences in public? What is it about making your story public that you enjoy?

4. What was the most uncomfortable moment? What subject are you most comfortable speaking about?

5. Are you seeing any evidence to suggest that there might be a change in attitudes among the students?

6. Is there anything that you feel that the students just aren’t “getting” about disability or illness?

7. What comments or questions from students surprised you the most and why?

8. What do you think we could do better to improve for the next panel session?

9. Are there any other actions that you would like to do to bring disability awareness to campus?


APPENDIX D

FLYERS FOR RECRUITMENT

![Flyer for recruitment of young women with physical disabilities or chronic illnesses](image)

<table>
<thead>
<tr>
<th>Purpose</th>
<th>To understand your experiences as woman with a physical disability and/or chronic illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligibility</td>
<td>Must be age 18-29 and a woman with a physical disability and/or chronic illness</td>
</tr>
<tr>
<td>Benefits</td>
<td>Meet other women like yourself. Work toward bringing about social change for people with disabilities</td>
</tr>
<tr>
<td>What is needed</td>
<td>A 60-90 minute interview at a location of your choosing</td>
</tr>
<tr>
<td>Compensation</td>
<td>You will receive cash compensation for participation</td>
</tr>
<tr>
<td>Contact</td>
<td>Meggan Jordan, Principle Investigator (407) 923-2363 or <a href="mailto:megganj@ufl.edu">megganj@ufl.edu</a></td>
</tr>
</tbody>
</table>

Disability Research Study
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megganj@ufl.edu

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Are you a woman with a facial birthmark, scar, or burn?

Your participation is needed for a research study on body image

Purpose: To understand your experiences as a woman with a facial difference.

Eligibility: Must be age 18-30.
Must have one of the following facial marks:
- Port Wine Stain
- Severe Acne or Scarring
- Vitiligo
- Any other obvious facial mark

Benefits: Meet other women like yourself.
Voice your concerns about unrealistic beauty standards.
Work toward bringing about social change!

What is Needed: A 45-60 minute interview at a location of your choosing.

Compensation: You will receive cash compensation for your participation in the interview and the workshop.

Contact: Meggan Jordan, Principle Investigator
PhD student in Department of Sociology, Criminology, & Law
(407) 923-2363 or megganj@ufl.edu
Preliminary Study Findings

Conditions present in disability/chronic illness sample (n=10)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital hand</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>Crohn’s</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>Paroxysmal dyskinesia</td>
</tr>
<tr>
<td>Ataxia</td>
<td>Seizures (undiagnosed)</td>
</tr>
<tr>
<td>Missing bones (leg)</td>
<td>Lupus</td>
</tr>
</tbody>
</table>

- 7 out of 10 reported being **bullied** as a child/adolescent because of looking different.
- BUT it gets better in **college**, where everyone mentioned they felt accepted for who they are.
  - This suggests that independence from parents and living alone for the first time is a milestone in transition to adulthood.
- Responses varied by **4 main factors**: 1) whether disability is physically identifiable 2) age of onset 3) whether disability is diagnosable 4) health related or non-health related disability
- **Parents** had strong influence over participant’s lives, monitoring their bodies, providing their care, and (sometimes) dictating appearances
- Life “**at the margins**” of able-bodied society - society was not always inclusive of difference. Ex: loss of friends, fewer of dating/relationship opportunities, smaller network for social activities
- On the whole, interviews reveal stories of **stigma**.
  - For example: not all stigma was based on appearance – it only became relevant in particular social situations. Was not always present; some, especially for those whose disabilities were more chronic-illness related, could escape it momentarily.
  - Stories of how the disability didn’t necessarily threaten their health but it threatened their ability to be successful in school, with friends, or in a job search.
  - How strangers reacted to the disability played a large role in creation of stigma.
  - Idea of stigma as a medical cure/diagnosis: searching for more social remedies to lessen stigma or disability discrimination. Normalization in schools, media, peer groups.
Lots of different experiences with doctors: searching for diagnosis, cures, treatments, therapies. Familiarity with the medical world ties is a bond all participants shared.

- Doctors/parents had a lot of power when younger, but less in adulthood. It seems like many participants were trying to advocate for themselves and their own care.
- The less diagnosable the illness/disability, the more participants expressed dissatisfaction with the medical community in general.

In questions about body image, a lot of participants talked about appearance comparisons to other women their age.

- For those disabilities that are health-related, the body’s unpredictable behavior required careful maintenance and monitoring
- Participants did not appear to be in a “crisis mode” about their body image, but they express fleeting thoughts about a desire to alter their appearance.
LIST OF REFERENCES


Meggan Jordan received her Ph.D in sociology from the University of Florida in the fall of 2012. She has been involved in a diverse range of research under the “health” umbrella, including walking recovery in people with spinal cord injury, health education resources for caregivers of Veteran’s with stroke, and the neurological brain structures of chronic pain. Her primary teaching and research interests include disability studies, sociology of health and illness, science and bioethics, qualitative methodology, and sociology of the body. In the future, she plans to produce translational research across disciplines of sociology, feminist studies, disability studies, public health, and biomedicine.