

Feminist Disability Studies:  
Theoretical Debates, Activism, Identity Politics, & Coalition Building

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## Abstract

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Through two intellectual and activist spaces that are fraught with identity politics, people from feminist and disability studies circles have converged in unique ways that have assisted in addressing the gaps in their respective fields. Although not all feminist disability studies scholars are comfortable with defining feminist disability studies or having an established doctrine that sets the field apart, my eleven interviews with people whose work spans feminist and disability studies demonstrates a presence of, and the need for, a feminist disability studies area of study.

Utilizing feminist and disability studies literature and reflections by the participants, I argue that feminist disability studies engages with theories that may be contradictory and incomplete. This process has the potential to reveal power, privilege, and oppression, and therefore, it can provide opportunities for liberation. Methods in feminist disability studies emphasize the necessity of considering both disability studies and feminist perspectives while resisting essentialism in order to allow new identities to surface.

In addition, feminist disability studies addresses why activism must be made accessible in order to fight ableism and to support work across identity-based groups. Therefore exactly *how* we work together across identities and identity groups is of paramount importance for our anti-oppression work. This multifaceted process has given rise to an amorphous, porous, and yet burgeoning, area of study that is providing new insights and tools for working across minority groups.

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## Introduction

My research demonstrates that feminist disability studies provide an important space and network for those whose social justice work overlaps feminist and disability studies theories. A few of the participants were uncomfortable about identifying a feminist disability studies area of study, but both those who readily acknowledged feminist disability studies as an area of study and those who did not revealed a critical span of feminist disability studies theories in response to my interview questions. I argue that feminist disability studies is a critical location from which to analyze and address various intersections of privilege and oppression, and that developing unique tools for working across identity-based/minority groups remains important.

Since a primary concern of feminist disability studies is how to work across feminist and disability studies based groups and theories, I begin **Part I** by explaining a central concept for understanding my arguments throughout my dissertation about the importance of encouraging work across minority groups. I borrow and expand upon the term, “identity-based politics,” defined by feminists Gwyn Kirk and Margo Okazawa-Rey (2004). This term describes a mutual goal of identity-based groups working together to fight oppression. “Identity politics,” on the other hand, is focused on one identity-based group’s political goals. Identity politics tends to essentialize the social justice pursuits of that group, thereby not allowing for additional and perhaps conflicting forms of oppression to come into conversation and be addressed. While identity-based politics is not a term used by the participants, its concepts are embedded in their reflections.

By outlining critical theories within feminist and disability studies that inform, challenge, and expand the concepts and processes where these two areas of study are merging, I set the stage for the identity-based politics I saw emerge from my research across feminist and disability studies, as well as for my argument about how and why feminist disability studies expands upon the definition and process of identity-based politics. Literature and participant reflections regarding these two disciplines sometimes mirror each other, and at other times, they come into conflict and give way to new identity-based ideas and politics.

**Chapter 1** maps out the feminist theories that remind us that methods for seeking out

and supporting marginalized and intersectional voices must remain central to our social justice work. Feminist and American Ethnic Studies Programs and theories have helped pave the way for disability studies by outlining how women and people of color have been discriminated against and oppressed by systems of power and privilege. Identifying how minority groups are shaped by systems and structures of power has helped disability studies scholars and activists outline how some people are barred from physical and social access by systems of power, and not by their bodily differences.

While feminist and critical race theories have helped people with disabilities to join the “intersectionality” conversations, and to discover how they can identify themselves as oppressed and as a minority group, participant reflections discuss how feminist circles have frequently neglected disability studies perspectives and have perpetuated medical model beliefs about disability and impairment that are stigmatizing and oppressive. This has left those who are working across these two disciplines and activist groups feeling vulnerable, sometimes not supported within feminist circles, and in need of new and alternative networks for addressing the critical vectors of disability and feminism.

**Chapter 2** introduces disability studies concepts, including how disability and impairment identities are socially constructed concepts. Disability studies expands upon feminist theories and maps out the social systems and physical structures that create barriers for people with disabilities—demonstrating how these barriers are in of themselves “disabilities.” In addition, I explore the debates within disability studies regarding disability and impairment, and to what degree the barriers we face are due to socially constructed pathologies and stigmas. The potential fluidity of disability and impairment provides unique insights and challenges to our concepts of our bodies and our identities, as these comprise a minority group of which any person has the potential to become a member. Disability studies debates and perspectives inform and challenge our ideas about who is disabled, who is impaired, and even questions whether everyone could be considered limited, impaired, and/or disabled.

Participant reflections discuss how disability studies is slow at times to consider feminist concepts such as intersectionality, and that a few disability studies scholars still employ sexist beliefs and practices. While disability studies provides critical challenges to feminist concepts about what constitutes a normal body, feminist disability studies scholars



may feel impeded within disability studies at times from pushing for feminist practices, such as continually considering the critical overlapping areas of privilege and oppression.

**Chapter 3** explores further how the fusion of feminist and disability studies ideas is concerned with the importance of identity and working across identity-based groups (e.g. identity-based politics), as noted by feminist standpoint epistemologies and also by intersectionality concepts as well as disability studies theories and debates that reveal both the importance and possible instability of bodies and identities. Because both the feminist and disability studies disciplines have critical theories for looking at how various minority group identities intersect and overlap with disability, as a socially and culturally constructed concept, yet both disciplines can still be inhospitable for doing this work, feminist disability studies has been, and is emerging, as a unique area of study.

Disability studies, feminist disability studies literature, and participant reflections demonstrate the broad spectrum on the disability and impairment debates within disability studies and how this is influencing both the shaping of and sometimes resistance to there being a feminist disability studies area of study. I argue, with support from the majority of participant reflections, that there is and should be a feminist disability studies area of study. The interviews with the participants display a wide continuum of ideas and debates regarding the socially constructed elements of impairment, as well as whether or not we work together over commonality and/or difference. Furthermore, feminist disability studies provides avenues for particular kinds of social justice that might not happen otherwise, and it is developing a process or method for working across identity-based groups in more supportive, bold, accommodating, and encouraging ways.

**Part II** builds off of the theories and debates outlined in Part I and delves deeper into the participant reflections about how one's identity, when coming into conflict with another identity-based group or theory, has the potential to expose different forms of privilege and oppression. This in turn provides opportunities for addressing injustices and shows that this process is crucial for doing identity-based politics. The chapters in Part II demonstrate how moments of tension between identity-based groups and theories provide opportunities for social justice and refinement of the identity-based political process. Such moments of tensions are an especially important aspect of feminist disability studies, as it positions itself as an area of study that works to find ways to handle more internal conflict and contradiction

than could a more dogmatized theoretical process. This is one of the key aspects of feminist disability studies, which contributes to identity-based politics.

**Chapter 4** outlines the participants' perspectives on why our identities within feminist disability studies matter and also reveals a critical debate regarding the role of non-disabled allies. Feminist disability studies, using feminist and disability studies concepts that may be in contradiction with one another, demonstrates actions and a process that can help people work across identity-based groups and theories to fight oppression. As participants discussed, this includes the varied and sometimes contradictory ways in which allies can work against disability oppression. It can be contradictory because the action that an ally will need to take depends upon the situation. Allies may need to take on different roles at different times in order to provide the most liberating steps for, and with their colleagues with disabilities.

I argue in **Chapter 5** that participant reflections expose how traditional activism within feminism is frequently layered with ableistic beliefs and practices, and that we need to broaden our concepts of activism. In addition, in considering what qualifies as activism, I argue that a feminist disability studies definition of activism requires accessibility. Furthermore, I argue that this accessibility is necessary in identity-based politics.

After articulating how identity-based politics is an activist *process*, in **Chapter 6**, I share both my and my participants' reflections regarding "how to" and "how not to" work across the identity-based groups and theories of feminism and disability studies, as well as how to work better, or less oppressively, across identity-based groups and theories in general. I begin by addressing "barriers" that participants identified within feminist and disability studies circles, and within coalition building in general, to the work and issues that they wish to address, such as ableism, internalized ableism, and the ranking of oppressions.

The second half of this chapter explores the spaces wherein participants felt encouraged and supported in their work across these identity-based groups and theories, and reflects on ideas for how to better support one another in building coalitions and doing identity-based politics. An important concept is to continually ask the feminist and disability studies questions of, "Who is not here, why, and how do we become more accessible and welcoming?"

**Chapter 7** provides a brief conclusion that reviews the overarching themes of the

dissertation, while touching upon a couple of key current theories that resonate with the theories I saw emerge in my research. By providing one personal example of how feminist disability studies has helped me fight oppression within my own life, I support my argument that feminist disability studies exists because it provides avenues toward social justice that might not occur otherwise.

Finally, **Part III** discusses the feminist and disability studies theories I used to map out the methods and methodologies employed in this qualitative research project. I discuss critical hermeneutics as a method to explore one's cultural and historical location within one's research, and discuss how my experiences of privilege and oppression, particularly as a researcher, provide insights into and methodologies toward a feminist disability studies research methodology.

## **Part I: Foundations: Literature & Theories**

Entering into this research, I anticipated that there would be an overwhelming response that there is and should be a feminist disability studies area of study and that the conversations in my interviews would focus primarily on the content of what is and should be feminist disability studies. There was quite a bit of discussion about all of the topics that are considered feminist disability studies, especially looking at all of the forms of intersecting and overlapping identities of disability with gender, sexuality, nationality, race, class, religion, and so forth, with a feminist lens and a disability studies lens. However, albeit critical, interesting, and central, these topics for feminist disability studies became more secondary within my research data in comparison to the ways in which experiences that expose power structures, identity, identity politics and identity-based politics shape feminist disability studies and social justice pursuits as a whole, as well as what some feminist disability studies scholars think about the political process of identities and anti-oppression work.<sup>1</sup>

During this Part of my dissertation, I introduce feminist and disability studies theories that help explain theoretical and empirical arguments brought forth by the participants. Most distinctly, the literature and participant reflections demonstrate how feminism and disability studies have influenced and continue to influence one another. With a focus primarily on theories, this helps provide support and insight into the critiques and arguments I bring into conversation as well.<sup>2</sup>

There are several theories that I use that bring forth a process for working across identities and identity theories. The theories I use include identity-based politics and a “mosaic” approach for piecing multiple identities and identity-based theories together. Such an approach permits us to, hopefully, continually get closer to a more comprehensive anti-oppression process and strategy, working across and using multiple identity-based theories. Within this critical process, additional key identity-based theories come into play, often creating tensions that illuminate dogmatic boundaries around identities. Conversations between such theories as strong postmodernism, feminist standpoint epistemologies, intersectionality concepts, disability-impairment debates within disability studies (including dismodernism), and so forth, help reveal power systems that are analyzable, and therefore,

also transformable. Central to the social justice pursuits of feminist disability studies is a process that supports these often contentious identity politics spaces, whereby those who engage in identity politics are supported and encouraged in making connections across identities (e.g. identity-based politics).<sup>3</sup>

Whereas Kirk and Okazawa-Rey (2004) describe identity politics from more of a stereotypical view (which often has negative connotations because of the strong boundaries around identities that can restrain and oppress the intersecting, overlapping, and many nuances of identities from surfacing), I argue that when identities do confront each other, it provides an opportunity to see the disguised systems of power, privilege and oppression that help create boundaries around our identities and identity-based theories. Kirk and Okazawa-Rey outline identity-based politics as the space in which people do make connections across identities.<sup>4</sup> I want to make a stronger claim: it is not just when connections are allowed to be made across identities, but we must shift or refine the definition toward emphasizing a *process* that recognizes this work as critical (albeit also containing a labyrinth of contentious identity politics within it), as a process that we can continually refine together by piecing together our identity-based theories.

These distinctions are rarely made. I believe that it is important to create and use more refined definitions around identity issues in order to clarify the lived experiences, processes, and barriers present when doing identity-based work. There is a strong feeling among the participants that feminist disability studies recognizes the importance of difference and the need for intersectional and identity-based politics, where individuals and groups recognize critical issues across various oppressions, privileges, and identities. Too often, as raised within the interviews, identity politics slow the progress of a movement, or the movement fails because of the lack of work across identities and identity groups.

Feminism has frequently fallen short of recognizing disability-based oppression, and disability studies has frequently failed to address various additional forms of oppression (and intersectionality as a whole). According to many of my participants, with whom I agree, some disability studies scholars tend to universalize the experience of disability and impairment through a strict social constructionist lens, and thereby minimize or silence voices that do not fit neatly into such a box. This is one of many forms of identity politics that damages some forms of liberation (by ideas being ignored and people feeling ostracized

from disability studies groups) because one form of identity (in this case, a social constructionist view of impairment) takes rank over another identity perspective (in this case, impairments that are arguably not socially constructed).

Debates within disability studies, regarding how far one can take the socially constructed aspects of disability and impairment, challenge feminism to consider the barriers that may or may not result from one's social and physical environment. Additionally, theories such as Lennard Davis' dismodernism cause us to explore the boundaries we have around who is and who is not impaired and limited, and why this matters in considering disability liberation. Disability studies theories also challenge the static notion of identity, which does not account for the ability to fluctuate in and out of disability and impairment identities (this is discussed in Chapter 2). Critically, however, feminist history and theories remind us that the ways in which our societies differentiate bodies, regardless of how similar or different our bodies actually are or are not from one another, matters greatly and can impact if and how we pursue social justice. Interfaces between these identities, identity-based theories, and identity-based politics shed light on hidden or often covert social facts, such as privilege and oppression.

In her 1985 article, "What Do Women Want in a Moral Theory?" Annette Baier argues for a "mosaic" approach to moral theory, using multiple theories in order to create an increasingly comprehensive moral account. A similar "mosaic" or piecemeal approach to doing identity-based politics allows us to get closer to a more expansive account of how to do intersectional work—and to get closer and closer to a less oppressive and more liberating environment. Baier's moral and philosophical principles guided me in discovering how and why employing multiple identities, and therefore also multiple identity-based theories and concepts, helps us explore the necessary dimensions of cooperation and trust in doing political work around our socially situated identities.<sup>5</sup> As will be shown throughout this dissertation, this political process is quite personal, and therefore, is often difficult.

I argue, however, that the tensions between identities and identity-based theories often provide an opportunity for social justice. Therefore, we must be concerned with *how* to support this identity-based politics process, and we must deliberately bring identity-based theories that may contradict and conflict into the conversation. In order to understand some of the identity politics and identity-based politics in feminist disability studies, it is important

for me to introduce some additional feminist and disability studies core identity-based theories employed in my research and analyses in Part I, such as postmodernist theories, feminist standpoint epistemologies, feminist theories of intersectionality, feminist concepts around identity politics, the social cultural model of disability, Disability Studies as a field, the debates about dismodernism and impairment within disability studies, and what disability studies has to add to the feminist disability studies discussions around identity and identity politics.

Postmodernist theories reject the idea of universal or global concepts, especially in terms of ideas and language that are applied to people or groups of people. Instead, postmodernism seeks to unravel the ways in which power is ascertained and maintained between groups of people. A common tool, for example, is for postmodernists to attack the social construction of false binaries between groups, which society often employs to make one group dominant over the Other, such as men over women, white people over people of color, non-disabled people over people with disabilities, and so forth. Postmodernist feminists have outlined how and why universalizing theories are often used to reinforce oppressive binaries between people, and they emphasize bringing oppressed groups' experiences to the surface, while also considering the specific cultural and historical contexts. Focusing on these subjective experiences reveals how external, political forces exist to oppress certain groups of people, while sustaining the power of the privileged.

In addition, well-known feminist epistemologies include "standpoint theory" and "situated knowledge," which argue that our experiences within our specific historical and cultural contexts directly inform what we know and that this holds significant political meaning in terms of understanding, naming, and fighting social injustices. Therefore, part of a feminist model of disability studies is to resist the recapitulation of old terminology and ideologies, and, rather, to identify as an oppressed group by naming the unique experiences we have as a group that has been socially constructed as subordinate, or less than, in some way. To come together as a coalition, we must name our experiences on our own accord, create our own definitions, create language, claim and reclaim language and identity, and engage in social justice to resist oppression and create liberation. Together we recognize barriers within society and the ways in which we have been designated as Other.

Although I will discuss the medical model of disability, I believe it is pertinent to

begin with and focus on a model that represents disability as difference and as a “minority group.” In their introduction to the 2006 anthology, *Identity Politics Reconsidered*, the editors Linda Martín Alcoff and Satya P. Mohanty distinguish the term ‘minority’ well:

Our working definition of “minority” refers to power rather than numbers; it seeks to connect contemporary uses of this crucial term with older debates about the nature and goals of democracy, especially since in formal political democracies power is not shared equally and social groups (defined by gender, race, or sexuality, or disability, for instance) often have unequal access to it. As we are combining a discussion of broadly different movements and programs of inquiry, “minority” is a convenient way to incorporate the diversity of differences and forms of oppression we are concerned to bring into dialogue. (p. 7)

Alcoff and Mohanty make the critical clarification that the category of “minority” refers to groups who have discovered political systems that have disempowered them. Too often ignorance of minority and identity-based work causes the belief that the term “minority” is actually meant to reflect a small percentage of the population or of a particular culture. If we focus on whether or not the group represents a small percentage, it often allows us to dismiss the political powers that have oppressed a group of people by saying that they either are not a minority (e.g. a small percentage of the overall group that is overlooked) or by rationalizing that it made sense that they were overlooked because there was not much representation or need. This contributes to oppressive systems by deflecting from the systems of power between people. Since people with disabilities are one of the largest minority groups, and since it is a group that people can slip in and out of (and are likely to be a member of at some point), such dismissals are important to debunk.

The feminist movement and women studies provide many useful tools to help us understand how society constructs people with disabilities as different, as “Other,” and as a minority group. As participants discussed, many disability studies ideas around the minority group model stem from feminist work. As Audre Lorde wrote in “The Master’s Tools Will Never Dismantle the Master’s House”:

Those of us who stand outside the circle of this society’s definition of acceptable women; those of us who have been forged in the crucibles of difference; those of us who are poor, who are lesbians, who are black, who are older, know that *survival is not an academic skill*. It is learning how to stand alone, unpopular and sometimes reviled, and how to make common cause with those other identified as outside the structures, in order to define and seek a world in which we can all flourish. It is learning how to take our differences and make them strengths. *For the master’s tools*



*will never dismantle the master's house.* They may allow us temporarily to beat him at his own game, but they will never enable us to bring about genuine change. And this fact is only threatening to those women who still define the master's house as their only source of support. (Lorde, 1983, p. 99)

While we might be able to use the master's tools, such as his language and theories about our bodies and their value, by deconstructing them, it is just as critical, if not more important, to begin with a focus on disability from the experiences of people with disabilities (versus how they are defined by the medical model).

Much of Disability Studies benefits from the interdisciplinary and foundational work that Women Studies and American Ethnic Studies have produced. Although Disability Studies arose out of the Disability Rights Movement that began alongside the Women's Movement and the Black Civil Rights Movement during the 1960s and 1970s, it was not until the last thirty years or so that disability studies scholarship appeared.<sup>6</sup> Common or similar experiences of oppression forged people with varying disabilities into a group and spurred them on to resist ableistic systems and institutions:

Ideas such as integration and equality of opportunity took hold among disabled people who began talking about how society needed to change rather than how they as individuals needed to "overcome their handicaps." There was a growing comprehension that they had rights, could make their own choices and could be full and equal participants in society. (Schneider, 2001, p. 541)<sup>7</sup>

Persons with disabilities came together to talk about their disability experiences and to create an opportunity to theorize and reclaim experiences and identities, which inspired disability studies.

Simi Linton provides one of the foundational introductory books to disability studies, *Claiming Disability: Knowledge and Identity* (1998), and there is a particular quote about claiming identity in her book that moves and re-inspires me every time I read it:

We have come out not with brown woollen lap robes over our withered legs or dark glasses over our pale eyes but in shorts and sandals, in overalls and business suits, dressed for play and work—straightforward, unmasked, and unapologetic. We are, as Crosby, Stills, and Nash told their Woodstock audience, letting our "freak flag fly." And we are not only the high-toned wheelchair athletes seen in recent television ads but the gangly, pudgy, lumpy, and bumpy of us, declaring that shame will no longer structure our wardrobe or our discourse. We are everywhere these days, wheeling and loping down the street, tapping our canes, sucking on our breathing tubes, following our guide dogs, puffing and sipping on the mouth sticks that propel our motorized chairs. We may drool, hear voices, speak in staccato syllables, wear

catheters to collect our urine, or live with a compromised immune system. We are all bound together, not by the list of our collective symptoms but by the social and political circumstances that have forged us as a group. We have found one another and found a voice to express not despair at our fate but outrage at our social positioning. (p. 3-4)

Disability Studies scholars identify the ways in which disability is socially and culturally designated, and provide a space for persons with disabilities to reassess what they have been told about themselves: their medical, psychological, rehabilitation, and/or general cultural experiences, and their rights. This recognition and awareness propelled thousands to reclaim their disability identity with pride. This “social constructionist model of disability” by disability studies scholars refines the observer’s palette to better understand how ability ideologies are constructed around us, rather than depicted as inherent to the body or mind of a person with disabilities.

As the authors of *Identity Politics Reconsidered* discuss, we need to address critiques of identity politics so that the wheels of social justice are less likely to stick and hold us up from addressing various forms of oppression. As also revealed in my research, Alcoff and Mohanty discuss how even, “some former supporters...have become concerned about an overemphasis on difference and identity at the expense of unity” (2006, pp. 2-3), and claim that we need to be “interrogating the postmodernist view that identities are purely arbitrary, and hence politically unreliable” (p. 4). They continue: “the editors of this volume wanted to ask how and when taking identities into account may be justified, both politically and theoretically” (p. 4). What the authors of *Identity Politics Reconsidered* and I conclude is that experiences and identities hold valuable truths that inform the relational and political process of power, privilege, and oppression between people.

Alcoff and Mohanty write about their anthology’s analyses of identity politics: “The legitimacy of some subjective experiences, we argue, is based on the objective location of some people in society; in many crucial instances, “experiences” are not unfathomable inner phenomena but rather disguised explanations of social relations, and they can be evaluated as such” (p. 5). Using postmodernist feminist theories, disability studies theories, the concepts used by the authors of *Identity Politics Reconsidered*, and my research data, I intend to support such claims by demonstrating the validity and necessity of experience, identity, and identity politics in our processes of addressing oppression. The political process in my

relationship to you, and between all peoples, holds historical and cultural truths that can be evaluated as a valid social process, albeit temporal, and to know this political process around our socially situated identities is critical for being able to name it and change it.

Dismodernist types of theories may influence some, including a few of my participants, to resist the idea of people forming groups around experience and identity (such as around concepts named as feminist disability studies) because they want to resist dogmatic boundaries that might keep some outside of the identity-based debates and movements. I believe they are nervous that we might limit anti-oppression work by having boundaries around identities and identity-based work. This perspective may hold some valuable and liberating truths as well, but it holds more potential to stifle liberation activities. The dismodernist debates within disability studies and feminist disability studies, for example, have the potential to silence the insights gained from experience and the identification of difference and minority statuses, all of which are critical for altering hierarchical and destructive power relationships between groups of people.

Coming to terms with the relevance and importance of dismodernism within my research and feminist disability studies became critical because it could hinder my ability to address the additional identity debates that, of course, surfaced within my research. I sifted through that which may have gotten in the way of recognizing the relevance and truths of experience and identity, and argued against theories that make experience and identity relative or universal (e.g. “we are all impaired”). It became necessary to argue for the validity of this political process around our identities in order to further address and demonstrate how political tensions over identities inform and shape feminist disability studies. For example, identity-based debates that arose among my participants inform the work that is feminist disability studies, and the unique issues that are exposed in the process help us address social oppressions that are not addressed as fully as they could be by other people and identity groups.

Disability studies discussions about the extent to which impairment is socially constructed, in comparison to disability, reveal some of our distorted realities around how we view and address our world and each other, including within minority groups (i.e. oppressed people can oppress those within their own group with their own distorted ideologies around identity). These conflicted, relational spaces create a spark that helps us see various

theoretical paths that may or may not hold more potential for political action to address a social injustice. It provides an insight and opportunity for activism. It is exciting because such contested spaces hold unlimited amounts of potential, depending on how we engage with this political process around our identities. Such debates around impairment among feminist disability studies scholars helps address internalized sexism and compulsory able-bodiedness in feminist, disability studies, and feminist disability studies circles, for example.

What became clear through my research is that feminist disability studies scholars are very concerned with *how* we participate in the political process around identities, so that it not only continues, but gains speed. To leave room for such conflicted debates of identity (e.g. identity politics and identity-based politics), many of my participants discussed the dialectical nature of identity-based politics. Several participants named to one degree or another that we have to risk the negative responses, such as exclusion and isolation, when we bring up identity theories that may challenge concepts already established by a group, because of the potential that it holds to create further liberation. At the same time, we must work to figure out *how* to make such spaces better able to sustain contentious positions and keep people included and engaged. This process, although often difficult and dialectical in nature, makes it possible for us to see potential ways to address oppression and then to take action to change our world.

Although relatively new to the minority studies scene, feminist disability studies is a ripe arena for identity-based politics. Feminist disability studies, and likely additional identity studies and identity-based politics as a whole, rely upon a variety of (or “mosaic”) of theories that get at what it takes to work together (e.g. various kinds and processes of trust), which is at the heart of all of these exchanges between identity groups and identity-based theories. We rely upon one another to engage, learn, and address the relational inequalities that have been socially constructed between us. It requires a huge amount of trust to extend and employ our wide variety of theories toward social justice.

## **Chapter 1: Feminism, Identity, & Identity Politics**

In this chapter, I bring into conversation the literature and the participant reflections on feminist concepts that influence disability studies and help create a feminist disability studies area of study. Feminist theories provide critical theoretical backing for understanding: systems of power, privilege, and oppression; outlining how minority identities are socially constructed; cautions over universalizing and essentializing theories; and the importance of continually bringing in marginalized and intersectional perspectives. The participants discuss many of the theories represented in the literature that have a pertinent influence on disability studies and feminist disability studies, and implicitly on identity politics and identity-based politics.

Identity politics and identity-based politics often determine who explores dimensions of trust and when and how to explore them, in hopes of achieving a mutual goal of a less oppressive society. It is inevitable that a variety of theories and methods emerge as identity or minority groups form and wish to address a social inequality, and that these theories, methods, and goals may be mutually supportive or in conflict with theories and goals of other identity groups' goals and theories, possibly at the same time. This is identity politics.

Identity politics, understandably, has a negative connotation because Other identity group goals often get “run over” or ignored in one group’s drive to address a particular social injustice. These moments of conflict can provide clarity, however, as they provide a unique opportunity to see a social justice issue and address it. The concern, of course, is that the clarity that occurs when conflict happens between identity groups is not taken up and addressed. Yet, such issues open up the potential for activism and change, and this aspect of identity politics can be positive and lead us to practicing identity-based politics, where we make a concerted effort to be proactive and avoid reinforcing one form of oppression while breaking down another.

Feminists have learned from a long history of negative implications of universalizing or essentializing identity-based political pursuits, and we remain watchful of this recurrent battle in our pursuit of social justice issues. Disability studies has had the opportunity to learn from this legacy within identity politics. There is often, however, a universalizing tendency of the social constructionist model of disability within disability studies that I have

seen and experienced. This sometimes makes it uncomfortable, for example, to discuss the lived experience of everyday implications of living with pain, fatigue, chronic illness, and so forth; that is, “impairment” that does not stem from cultural, medical barriers.

The women’s movement and women studies struggle with the essentialism of “women’s experience,” which has centralized women who are white, heterosexual, non-disabled, and of middle to upper class standing as the voice for “all women.” There are perceived “norms” which imply that “all women” or “all people with disabilities,” for example, have the same experiences of oppression. This is often based on what Audre Lorde terms “the mythical norm”:

Somewhere, on the edge of consciousness, there is what I call a *mythical norm*, which each one of us within our hearts knows “that is not me.” In America, this norm is usually defined as *white, thin, male, young, heterosexual, Christian, and financially secure*. It is with this mythical norm that the trappings of power reside within this society. Those of us who stand outside that power often identify one way in which we are different, and we assume that to be the primary cause of all oppression, forgetting other distortions around difference, some of which we ourselves may be practicing. By and large within the women’s movement today, white women focus upon their oppression as women and ignore differences of race, sexual preference, class, and age. There is a pretense to a homogeneity of experience covered by the word *sisterhood* that does not in fact exist. (Lorde, 1995, p. 285)

This problem of essentializing an identity is not unique to women studies, disability studies, or feminist disability studies, and there is a long history of groups who have split off and faced similar essentializing issues when trying to move away from an oppressive space that silences one minority group’s experience.

Similar to the Black feminist movement, feminist disability studies emerged out of the necessity to find a space that does not wash away or diminish our experiences as people with disabilities (from a social-cultural perspective), and as gendered persons with a multitude of intersecting identities. As “A Black Feminist Statement” by the Combahee River Collective has it, “We struggle together with black men against racism, while we also struggle with black men about sexism” (The Combahee River Collective, 1995, p. 235). New groups form, while we may or may not continue to fight various forms of oppression with prior, perhaps more essentializing and/or oppressive groups, out of the necessity to work collectively and with less resistance toward overlapping forms of oppression. Michele Wallace writes about such an experience in her article, “A Black Feminist’s Search for

Sisterhood”:

In the spring of 1973 Doris Wright, a Black feminist writer, called a meeting to discuss “Black Women and Their Relationship to the Women’s Movement.” The result was the National Black Feminist Organization,<sup>8</sup> and I was fully delighted until, true to Women’s Movement form, we got bogged down in an array of ideological disputes, the primary one being lesbianism versus heterosexuality. Dominated by the myths and facts of what white feminists had done and not done before us, it was nearly impossible to come to any agreement about our position on anything; and action was unthinkable. (Wallace, 1982, p. 11)<sup>9</sup>

There are always further intersections of privilege and oppression that create unique issues that we need to address, and the histories of our movements collectively reinforce the need for a feminist consciousness of “intersectionality.” I believe that these histories inform all of these movements. They provide part of the foundation for feminist disability studies and contribute to why some argue against any kind of feminist disability studies doctrine.

Kimberle Crenshaw warns us in her article “Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color” (1991) that we must be wary of one version of anti-essentialism, which she calls “the vulgarized social construction thesis” (p. 1296). She also makes a case against theories such as Davis’ dismodernism (although Davis’ theories came later), meaning that it is problematic when we argue against the validity of a category, or try to erase categories, and make everyone the same, such as, “we are all impaired” or “we are all disabled.” Crenshaw highlights how not only that the categories matter, but that their intersections matter, and that to say there is one universal “Disabled” or “Black” or “Women’s” experience (to essentialize those experiences as a unified experience and political stance) ignores or erases the critical social and cultural factors that impact our lives in unique ways at the intersections of various identities.

Using the “Clarence Thomas/Anita Hill controversy” Crenshaw highlights how identities matter (and are more important at this point in history than to erase categories) by showing how issues of violence against women have faced many barriers due to essentialistic antiracist and essentialistic feminist discourses (pp. 1298-1299). Since the perspective of Black men primarily dominated work against racism, and white middle-to upper-class women primarily dominated feminism, those two political/activist groups suppressed and subordinated Black women’s perspectives and voices. Crenshaw writes:

Caught between the competing narrative tropes of rape (advanced by feminists) on

the one hand and lynching (advanced by Thomas and his antiracist supporters) on the other, the race and gender dimensions of her position could not be told. This dilemma could be described as the consequence of antiracism's essentializing Blackness and feminism's essentializing womanhood. But recognizing as much does not take us far enough, for the problem is not simply linguistic or philosophical in nature. It is specifically political: the narratives of gender are based on the experience of white, middle-class women, and the narratives of race are based on the experience of Black men. The solution does not merely entail arguing for the multiplicity of identities or challenging essentialism generally. Instead, in Hill's case, for example, it would have been necessary to assert those crucial aspects of her location that were erased, even by many of her advocates—that is, to state what difference her difference made. (pp. 1298-1299)

Therefore, as Crenshaw reminds us, we cannot think in terms of unidirectional theories of privilege and oppression. Antiracist theory and feminist theory cannot operate alone to address the Black women's experience, and often, to use both backgrounds in interpreting and addressing the oppression of Black women, remains lacking because women did not have much voice in the antiracist work that was done early on, and Black women's voices were likewise substantially silenced in the earlier waves of the feminist movement (Crenshaw, 1989 & 1991). There was an idea of a unified racist and unified experience of gender and sexism, and to name it as such was believed to be critical to the power or the movements in working toward eliminating oppression. However, this fostered ignorance of various forms of sexism and racism, thereby actually stifling the fights against these forms of oppression.

To push ourselves away from essentialistic tendencies and to embrace feminist intersectional analyses, we must make ourselves vulnerable to the ways in which our positionalities may influence our interpretations, and allow allies to interrogate and question our practices and interpretations. Part of this process requires that we be up front about who we are and how we perceive our individual locations within oppression and privilege.

Kimberle Crenshaw's writings on the struggles of Black women made me aware of how my perspectives are limited, and how we tend to speak to the dominant group, rather than between minority groups. Eunjung Kim spoke to this issue within identity politics, the need to complicate intersectionality, how we need to speak among the margins and learn how to develop languages that allow us to do that, thereby breaking from dominant and oppressive tropes. For example, just like the essentialistic tendencies to name the female



experience as one experience, as Crenshaw discusses, I too have used feminist theories that stem from white, middle to upper class women, to discuss a feminist disability experience. I too have found myself guilty of teetering on the essentialistic border at times. Crenshaw wrote:

Because the experiential base upon which many feminist insights are grounded is white, theoretical statements drawn from them are overgeneralized at best, and often wrong. Statements such as “men and women are taught to see men as independent, capable, powerful; men and women are taught to see women as dependent, limited in abilities, and passive,” are common within this literature. But this “observation” overlooks the anomalies created by crosscurrents of racism and sexism. Black men and women live in a society that creates sex-based norms and expectations which racism operates simultaneously to deny; Black men are not viewed as powerful, nor are Black women seen as passive. (Crenshaw, 1989, p. 155)

Some feminists have made the mistake of conflating one woman’s experience (i.e. white, middle class women) as the only experience, and this trickles over into feminist disability studies theory as well. Take, for example, feminist ideologies that work to counter the sexist beliefs that women are inherently weaker, irrational, emotional, and so forth. Counter feminist narratives at times further subjugate some people with disabilities by engaging in compulsory able-bodiedness;<sup>10</sup> that is, by striving to prove one’s abilities and hide one’s perceived inabilities or shortcomings. Some feminist disability studies theorists, including myself, have critiqued such sexist-compulsory-able-bodiedness as fueling ableism. I recognize, however, that it starts from a presumed position that all women are perceived weak, and men strong, when this was not necessarily the case within the Black community, as only one example.

Following Crenshaw, therefore, it seems we must ask: If we do not always focus on speaking to the center (i.e. the dominant group), how would our understandings and theoretical chains be different? Would women from various cultural backgrounds relate to this critique of sexist-compulsory-able-bodiedness within feminism? How do queer women and men understand such critiques, for example? Is there validity or falseness to it, or are there many ways that sexism, racism, and ableism, and so forth, intersect for different people? It seems that if we engaged in inter-minority group dialogues with an understanding of intersectionality—and our place within privilege and oppression (to the extent we can)—we would get “further from falsehood”<sup>11</sup> and closer to liberating more people from

oppressive forces.

Similarly, white and middle class men and women predominantly comprise disability studies and feminist disability studies, and feminism often neglects to include social-cultural (non-medical-model) perspectives of people with disabilities. It is thus critical to do this coalition work at the intersections of feminism and disability studies, so as to bring differences into focus. Feminist scholars have been learning to ask, “Who are we speaking of when we say ‘women’?” This is also a central principle for feminist disability studies.

Drawing from women studies, I incorporate the concept of “intersectionality” when I introduce people to disability studies in an attempt to diversify the understanding of the varied cultural experiences people have living with disabilities, as we are doing with the varied experiences of women.<sup>12</sup> Intersectionality, and the practice of such work, is a mosaic method approach to addressing social justice issues. There is a complicated web of intersecting forms of privilege and oppression, and to evade any thoughts of a unified disability experience, or unified women’s experience, it is pertinent not only to address the varied experiences people have with the wide spectrum of disabilities that exist, but also to discuss how other cultural backgrounds, and experiences of privilege and oppression, inform one’s feelings and experiences around disability.

### **Feminist Standpoint Practices**

One method to avoid universalizing or essentializing tendencies in feminism and feminist disability studies is to employ theories and methods for marginalized voices to surface and remain in conversation in order to break from hegemonic discourses. Feminist standpoint epistemologies strive to be attentive to the socially constructed power dynamics between people.<sup>13</sup> This gets at the heart of, or helps create the space for us to deconstruct, construct, claim, and reclaim, identities. Minority identities typically do not have or are not allowed to have a voice in how they are socially situated. Sandra Harding writes in “Rethinking Standpoint Epistemology: What is ‘Strong Objectivity’?” (2004), “Standpoint theories simply disagree with the further ahistorical and incoherent claim that the content of ‘modern and Western’ scientific thought is also, paradoxically, not shaped by its historical location” (p. 133).

Standpoint theories and critical hermeneutics (which is discussed in my research

methods section) insist that we be reflective in our practice about the ways that we may recapitulate privilege and oppression in our language and our actions. They make historical location and societal influences (e.g. privilege, oppression, and one's entire "cultural horizon") central in their considerations.<sup>14</sup> Standpoint theory argues that we should start from the vantage point of marginalized lives, which motivates us to look at everything from a multidimensional and intersectional perspective. Harding discusses this when reflecting on Bettina Aptheker's perspectives on this matter:<sup>15</sup>

Bettina Aptheker has argued that starting thought from the everyday lives of women who are holocaust survivors, Chicana cannery workers, older lesbians, African-American women in slavery, Japanese-American concentration camp survivors, and others who have had lives different from hers increases our ability to understand a great deal about the distorted way the dominant groups conceptualize politics, resistance, community, and other key history and social science notions. (p. 129-130)

Starting from the perspective of marginalized voices not only supports exploring disability oppression, but also explores disability issues from multiple perspectives. This includes not only perspectives from people with disabilities who are facing sexism, classism, homophobia, racism, xenophobia, and so forth, but also multiple perspectives from people who have varying disability and chronic health experiences.

Using feminist ideas, such as feminist standpoint epistemologies and those of Sandra Harding in *The Science Question in Feminism* (1986), helps us address how identities are socially constructed within particular historical and cultural locations, and how such socially constructed identities, situated as subordinate, can also be identified and evaluated in and through oppressive functions and systems (institutional, symbolic, and individual levels). Such theories and methods encourage us to trace disability oppression, according to Harding. Unknowingly, knowingly, implicitly, or explicitly, feminist thought influences disability studies scholars in their work of understanding disability from a social-cultural or minority group model framework.

Patricia Hill-Collins provides a great summary and analysis of institutional, symbolic, and individual systems of oppression in her article, "Toward a New Vision: Race, Class, and Gender as Categories of Analysis and Connection" (2001). Both she and Harding acknowledge that oppression operates on many levels throughout society. Consider who controls most social institutions and who has the ability to climb the ladder toward success.

This is one way to analyze who is dominated and subordinated and who is privileged by the system: “Systemic relationships of domination and subordination structured through social institutions such as schools, businesses, hospitals, the work place, and government agencies represent the institutional dimension of oppression” (Hill-Collins, 2001, p. 59). As I will discuss further, medical institutions (e.g. “the medical model”) play a central role in creating stigma and discrimination against people with disabilities and influence other institutional attitudes toward people with disabilities.

Regarding symbolic systems of oppression in relation to disability, disability images often invoke pity. What symbols or stereotypes come to mind when one thinks of disability, or particular disabilities? Some common stereotypes of disability, aside from pity, are weakness/helplessness, evilness/possession, non-sexual, not parents (or should not be), less intelligent and/or child-like, and as having qualities we want to cure or eradicate. As Hill-Collins explains, “Central to this process is the use of stereotypical or controlling images of diverse race, class and gender groups” (pp. 59-60). Unfortunately, she neglects to recognize disability. There are many disability stereotypes that contribute to the pervasive system that prevents people with disabilities from climbing institutional and social ladders (such as finding a partner and having children).

Finally, oppression can also occur on an individual level. Negative images and symbols of disability (stereotypes, or lack of representation) are everywhere, and we all encounter the institutions that subordinate certain groups of people, while privileging others. This impacts us on the individual level, regardless of whether they are conscious or subconscious beliefs and actions. We externalize these beliefs onto Others, and also turn it inward on ourselves (e.g. internalized oppression).

The pervasiveness of discrimination alerts us to where and how oppression is occurring, and this highlights where we need to break down barriers. Feminist theories challenge us to look at disability from a minority group model, rather than always using the “master’s tools” to try to understand and deconstruct disability oppression. Another feminist theorist, Peggy McIntosh, provides great tools for understanding the ways in which privilege and oppression operate on individual levels; although, of course, these are still linked to symbolic and institutional forces of oppression. Although McIntosh does not address disability within her work, the tools she provides in her article, “White Privilege and Male

Privilege: A Personal Account of Coming to See the Correspondences through Work in Women Studies” (2001), are easily transferable to disability issues.

McIntosh’s article challenges the reader to examine the ways in which we structure our environment around us to fit a certain type of race and gender, thereby creating privilege for some and oppression for others based on these differences. Through writing this article, McIntosh came to realize her own position of power as a white woman in a racist society. McIntosh’s method of targeting racism by listing the way she is privileged as a white person makes race-based oppression an issue of the privileged white group, rather than trying to “fix” the problem continuously via the marginalized group—just as we also try to “fix” individuals with disabilities. This places the responsibility of the oppression on those in a position of privilege and on that social system that perpetuates biased privilege rather than tokenizing and expecting oppressed individuals to name and work against their oppression.

Many of the details outlined in McIntosh’s list of race-based privileges could easily be transposed into ability-based privileges. First, consider the following quotes by McIntosh based on white privilege and then read them a second time, inserting “ability” where “race” would be. This will demonstrate how privilege and oppression are implicitly and often unknowingly socially constructed and maintained.

6. I can turn on the television or open to the front page of the paper and see people of my race widely and positively represented.
20. I can do well in a challenging situation without being called a credit to my race.
21. I am never asked to speak for all the people of my racial group.
27. I can go home from most meetings of organizations I belong to feeling somewhat tied in, rather than isolated, out of place, outnumbered, unheard, held at a distance, or feared.
46. I can choose blemish cover or bandages in “flesh” color and have them more or less match my skin. (McIntosh, 2001, pp. 98-100)

Number 46 of McIntosh’s list is what really drove home the correlation between women studies, American ethnic studies, and disability studies for me. I felt bewildered after I realized how naïve I was, that I had never thought about the fact that “flesh-colored” Band-Aids and nylons were not for everyone. It made me realize that a position of assumed privilege and power has been handed down to me as a white person. Similarly, just as we pass down white privilege from one person to another, we also construct our physical and social environments to privilege one type of body, mind, and emotions (e.g. the “able-

bodied” or “the normals”), thereby creating a disability class.

Looking at able-bodied privilege prompts us to think about all of the things that are physically and socially created to privilege one type of person, while barring another person. Consider the following examples:

1. I can walk up the stairs to an apartment and not have them be barriers to my living or visiting friends there.
2. I do not have to buy additional specialized and expensive software in order to use my computer effectively.
3. People think of me as a sexual being, and they believe that I could be a good partner and parent.
4. I am not taken out of my class for “specialized” classes, because I look, read, speak, move, and/or act differently.<sup>16</sup>

By creating these privilege-lists and then asking ourselves for whom these things were created and why, we unravel how we base privilege on types of body, mind, and/or emotions. This process takes us to the individual level of the systems of oppression and how they directly impact us as individuals and our interactions with people in our lives.

Those who are not privileged are socially constructed as deviant and a problem for society because they do not fit into these arbitrary and constructed norms. Seeing and acknowledging able-bodied privilege is a great tool to help us realize that we construct disabilities with the way we create and maintain our physical and social environments. This encourages one to think of disability in terms of diversity, with some groups of people situated as the norm, and some as “the Other,” rather than looking at disability in the stereotypical “medical-model” view of disability as deficit (which portrays disability as inherent and static, and a problem residing in the individual body). The latter model demonstrates how disability is culturally created and maintained and how we could address and erase oppression through how we socially and physically structure our environments.

The social-cultural model of disability resists the idea that disability and disability oppression stem from individual bodies, but rather identifies and places responsibility on societal structures and systems. Systems of oppression influence one another at different levels from the individual to the institutional. The symbolic, such as the lack of positive disability representation in media and the portrayal of people with disabilities as being needy and pitiful, influences able-bodied people to treat people with disabilities as such. Similarly, institutional entities, such as the medical establishment, influence both symbolic and

individual forms of oppression. Therefore, it is necessary to address and challenge all systems of oppression.

Challenging individual levels of oppression helps challenge institutional levels of oppression because individuals engage the institutions that create and maintain disability oppression through multiple avenues. For example, a doctor who individually learns theories of able-bodied privilege through such exercises as that which McIntosh provides us can take his or her new-found perspectives and use them to challenge and change the institutional level that operates from the “medical model of disability” perspective. Simi Linton notes that the “medical model of disability” describes disabilities as “deviance from the norm” (Linton, 1998, p. 11)<sup>17</sup> and as pathological problems that reside in and must be addressed through individual bodies, instead of recognizing and addressing how people with disabilities are limited by socially and physically constructed barriers.

### **Participant Reflections: Women Studies Influences on Disability Studies**

*Interview Question #3b: Has women studies/feminism informed your disability studies thinking?*

Women studies, preceding disability studies, provides many critical insights for disability studies. Most notable, as already discussed and highlighted in the literature, theories, and participant reflections, is women studies or feminism’s role in addressing power structures and analyses for understanding the development of “identity” (in relationship to oppression and identity politics), intersectionality, and the layers of privilege and oppression. Women studies makes feminist disability studies much more attuned to noticing when “voices are missing.” Such awareness is sometimes already included in disability studies projects, although many are unaware of the feminist activist and scholarly roots behind it. The social constructionist theories around gender, sex, race, and so forth stem largely from women studies and other identity studies, upon which disability studies largely relies.<sup>18</sup>

At least nine of the eleven participants implicitly or explicitly addressed intersectional types of work within their definitions of feminist disability studies.<sup>19</sup> Brenda Brueggemann, for example, responded to the first question with the following: “I think identity is big, and particularly the notion of not identity, singular, but identities...and I think the global...I’ve

never been fond of the word, “transnational,” because I am at core disturbed by nationalist impulses anyway.”<sup>20</sup> Susan Schweik also commented that feminist disability studies scholars attend to issues of intersectionality,<sup>21</sup> and Eunjung Kim noted her awareness of the need for intersectionality by criticizing herself for the missing layers of analyses in her own work. Additionally, Alison Kafer and Susan Burch brought up multiple identity topics, such as race, class, nationality, and so forth within their responses.<sup>22</sup> Licia Carlson commented that “identity, identity politics...[and] theorizing oppression” are central topics for feminist disability studies. The feminist topics of intersectionality, and understanding social constructionism and the minority group model were also brought up in a few of the responses.<sup>23</sup> We have been able to transfer many of these feminist theories to better understand disability experiences of oppression and able-bodied privilege.

The following responses were prompted by this interview question: “Has women studies/feminism informed your disability studies thinking?”

Georgina Kleege: Yeah, I would say so, because I think...given my age and...my own education, I would say a certain way of looking at the world came to me through feminism, a way of analyzing power structures, for instance. And so it comes very naturally to then shift attention slightly and say, “We see power structures imposing certain behaviors on women. What’s happening also to disabled women, and disability in general?”...I think it was kind of a natural progression.

Susan Wendell: Oh yeah [I]...had been a feminist theorist for about ten years before I became ill. So...I can’t imagine how I would have thought about disability studies, except with a feminist perspective. Because that was (what I was always doing) (...). And there were so many parallels as well, and I should give feminism credit for this. The social constructionist analysis was there, of course, in feminism as well, and in relation to women’s bodies, specifically, and that is very interesting as well; not in relation to disabled bodies but in relation to healthy, non-disabled bodies, and women’s healthy non-disabled bodies. The social constructionist was already there in feminism, and so when I saw it [in] disability activist writings and disability studies, I recognized it at once. And it was easy for me to start parallel lines of thought. So, that’s (something...). Yes, I can’t imagine...I think it would have been much harder for me to adopt a disability studies perspective had I not been a feminist philosopher first.

Susan Burch: ...absolutely...when I started doing deaf cultural history and deaf community history, I was mostly looking at elite, white, otherwise able-bodied Deaf men, because those were the sources that were most available to me. And the secondary sources I was reading almost exclusively talked only about that population. But the nagging, annoying...recognition that there were literally, you know, almost



no Deaf female bodies present, and I sought out any kind of reference I could find on members of the LGBT(Q) community and found virtually nothing, which I think says something, which I think can be unpacked as well, and was also wondering about the boundaries of disability at that time...wondering how people who identified as [culturally] Deaf responding to people with disabilities, as they perceived it, and what happens when you have “Deaf plus” [meaning deafness in addition to other disabilities]? (...) And so that kind of drew me to very specific studies of Deaf women’s bodies, and from that it kind of unfolded to broader things.

Licia Carlson: Yeah [laughter]. I mean, I think in some ways differently. I feel like my experience of those two fields (as) separate is that...feminist philosophy or feminist theory is much more, was much more entrenched, and established. So, I think the way that disability theory informed my relationship to feminist theory was as this kind of...critical, challenge to it, and a really exciting challenge to what was going on in feminist theory. Whereas I think that, in terms of feminist theory informing my disability theory, (or) my work on disability, I feel like it’s been...more of a resource for me methodologically to think about some of these issues. I think because disability studies emerged already rooted in some feminist theory, and although I know there is a whole dimension of disability theory that doesn’t address feminism. But because my introduction to it was already sort of engaged in some of those issues, going in that direction...it didn’t feel as subversive, or there wasn’t a sting to it. It was sort of like, “Oh, this is part of it. This is part of the arsenal of tools that we have, and I’m going to use it;” as opposed to saying, “What’s wrong with feminist theory that it hasn’t looked in this direction?” ...so they both informed the other, but in somewhat different ways, it feels to me.

Catherine Kudlick: Oh, sure...that too. I mean the whole minority group model thing. I think more the history of sexuality and, homosexuality and stuff, because of the lack of family ties. It’s not an identity that is handed down through generations, but it’s a (formational) identity based on community, politics, and activism, and I think that has influenced how I think about disability studies as a minority group model, maybe more than race or gender studies per say. But sexuality...I put sexuality (stuff in) feminism. I just think it’s there. But in terms of other things...Yes, I think my feminist stuff opened the door for disability studies, and I think it can’t get much bigger than that as a connection. In terms of the new stuff that is coming out, I’m finding that disability studies has more to teach feminism at this point. That’s my personal prejudice. That’s my thinking.

Responses from the participants continually remind us of feminism’s role in educating us about the minority group model and how identities can be socially constructed, shape power structures within different cultures in various ways, and challenge boundaries around “identity.”

However, while we recognize the critical role of feminist intersectionality theories for disability studies and feminist disability studies, Kim and Kafer remind us that parallels can

too easily be made between various minority groups:

Eunjung Kim: ...I saw the potential of feminist theories to address disabled people's situation in society, because I hadn't found any theoretical explanation why disabled people are marginalized. So, I went to graduate school in women studies to do that in 1996, and it was successful and not so successful at the same time, because I didn't want to replace "women" in feminism with "disabled people." So, if I apply a feminist framework to disabled people as it is, I would take out the word "women" and put "disabled people." And it never worked for me. I mean I really resisted doing that. Because when you hear "disabled people" it usually means men. So, I was very uneasy about applying feminist theories to disabled people simply, and that's why I started having a lot of trouble with feminist theories not including disabled women in their framework. Although feminist theories address so many different forms of discrimination in society, and it never really addresses disabled people, and that was very problematic. I was very troubled with that. So, I started to seek out if there is any writing by disabled women, and I found important books that solved my trouble. They explained the problem so well. I agreed with most of the parts, but I didn't agree with everything. [KK: who...?] Well, Susan Wendell and Jenny Morris were the first start. I mean our libraries in Korea have a lot of publications from America and [the] UK, but those are the ones I found initially, and I think I read Rosemarie's article, not her book, but her article about illness and she reviewed several books on illness early on. I read that. Also I read a lot of anthologies of disabled women's experiences including "Women with Disabilities," by Asch and Fine. But at the same time our group was putting together first person narratives by disabled women and non-disabled women about their own bodies so I was more interested in Korean women's narratives.<sup>24</sup>

Alison Kafer also brought up the common issue of making parallels between minority groups too easily and how this caution stems from her feminist background:

I think my training in feminist studies and teaching feminist studies, and the fact that, both as a student and as a teacher, I teach courses that aren't explicitly disability studies, or in fact maybe just have a little bit to do with disability studies but are mostly feminist studies courses. I think doing that work has made me have very little patience with disability studies work that doesn't attend to gender or sexuality, or to...people...who want to make...to my mind...what are too easy parallels between race and disability, or sex and disability, claims like "people would never accept this behavior if someone said it or did it about black people, but they accept it about disability, about disabled people." I think my training in feminist studies makes me very suspicious of those kinds of comments.<sup>25</sup>

Feminism not only makes us ask, "Who is missing at our table?", but "What makes this minority group's experiences of oppression different from that of other minority groups, and what can we learn from this political process of identity-based politics?" Feminism demands that we attend to the unique manifestations of oppression, and that we not make comparisons

too easily between various forms of oppression and privilege, including how they can overlap and intersect. There are new and unique aspects to each type of oppression that may go unscrutinized without openness to exploring unfamiliar territories. Feminist disability studies encourages us to delve into these sometimes-uncomfortable explorations, moving from “identity” to an ever-emerging overlapping of identities.

In some ways, as Catherine Kudlick, and Licia Carlson argue to some degree, as stated above, that disability studies has more to offer women studies. These reflections come from the perspective of one’s feminist disability studies stemming from, or already being rooted in feminism; whereas, on the other hand, women studies is not stemming from, or rooted in disability studies. Disability studies has some completely new concepts to introduce to feminism—primarily that many, if not all, bodily experiences (with a focus on disability, impairment, and health) are culturally and politically inflected. In addition, many of our preconceived notions of disability and health fuel additional forms of oppression, such as sexism, racism, xenophobia, and so forth.

Feminist theories provide tools for scholars and activists to address how disability and impairment are socially constructed, and provide a history of foundational perspectives for wariness of essentializing or universalizing theories. However, although most understand minority positions via deconstructing how particular people are socially constructed as “less than” and “Other,” understanding the socially constructed nature of disability is still often a surprising and sometimes challenging concept for even some well versed anti-oppression theorists, including some feminists. Disability studies is often still sorely lacking in feminism. This makes outlining the development of disability studies and understanding the social-cultural model of disability pertinent, so that understanding the ways disability studies challenges stronger forms of postmodernism and explores the dimensions of the materiality of the body in the politics of our identities.

## **Chapter 2: Disability Studies, Identity, & Identity Politics**

There are many theories and debates in disability studies, as well, that influence feminism and encourage us to explore the contours of identity formation and identity politics. First, disability studies has established how disability is socially constructed through built, and social environments. Second, disability studies debates around disability and impairment contribute even more nuanced understandings of the limits, contradictions, and interplay of experience and identity. I argue that these discussions impact some of the resistance to boundaries around identity groups and identity-based theories, and, in hand with feminist theories, create an emerging process for working across identity or minority groups. Disability studies literature and participant interviews reflect the wide spectrum of debates having to do with disability as a minority identity, how they influence feminism, and how they “shake up” and solidify the necessity of identity politics and identity-based politics at the same time.

There is a long history, even prior to medical establishments, of sorting out those with bodily differences (including intellectual, psychological, and emotional) from bodies that were considered the average, normal, and “right” way of being. It is not always clear what kinds of barriers actually exist within the body (e.g. impairments) and what barriers society creates due to a perception of unhealthiness or deviance (e.g. disabilities). Historically, there has been little distinction between impairments and disabilities, thereby making the problem that needs to be “fixed” solely within individual bodies for people with disabilities versus fixing the social and physical barriers within society. Many scholars use the two terms interchangeably. The medical model of disability tends to treat disability as impairment and usually does not recognize the socially constructed aspects of determining and treating impairments. This failure to address the structural and social barriers maintains disability oppression.

While the medical model treats impairment and disability as relatively the same, and both as being issues or problems that individual bodies need to address, disability rights movements and disability studies have created a backlash against this disability oppression. The confusion and controversies over the distinctions between disability and impairment exist within the disability rights and disability studies movements as well. Some make a

sharp distinction between impairment and disability, while others question the socially constructed nature of impairment and blur the lines between the two. A few argue that we are all impaired (e.g. that we all have bodily variations and limitations), but that only some of us face discrimination and stigma, according to the social and minority model of disability.

People who fight oppression have learned to be good anti-essentialists from a long history of universalizing experiences that have tended to Other and oppress additional identities with a unilateral focus. With good reason, some disability studies scholars question whether all of our limitations, barriers, and oppressions begin and end with a lack of physical and social access. Although disability studies scholars do not all agree on how to define the distinctions between impairment and disability, most, if not all, argue that there are social and cultural influences that create a social stratification between those deemed “disabled” and those thus implicitly determined non-disabled. The social-cultural model of disability resists the medical model of disability by taking a more postmodern approach to understanding disability and impairment, pointing out and addressing how we create disability (and impairment, for some disability studies scholars) by the ways in which environments are socially and physically structured.

### **Disability & Impairment Debates**

There are many emergent debates over distinguishing disability and impairment, and there are many cultural and historical influences that are hard to trace. Through scholarly reflections, what becomes clear is a lack of recognition of how people with disabilities have been situated as deviant and abnormal. In “Disability Definitions, Models, Classification Schemes, and Applications” (2001), disability studies scholar Barbara M. Altman outlines several of the many ways in which impairment and disability have been defined, all of which are closely aligned or make no differentiation between disability and impairment (or the social-cultural influences on disability).

Due to the significant international influence of the World Health Organization (WHO) (especially in terms of definitions of impairment and disability) and the responses by disability studies scholars toward the WHO’s International Classification of Functioning, Disability and Health (ICF or ICFDH) reports, the ways in which WHO has defined

disability and impairment deserve analyses here.

The 2001 ICFDH report, which outlines definitions of health, functionality, impairment, and disability related definitions, somewhat addresses the societal influence on disability. The World Health Organization in Geneva created these reports with a goal of creating a global language around health, functioning, impairment, and disability. Needless to say, this has had a powerful influence over people with disabilities and impairments. The ICFDH report still maintains that there are or can be bodily limitations or impairments. Altman outlines WHO's definitions of impairments, stating:

The concept of *impairments* from the first WHO model is identified as “body function and structure” in the second WHO model, *ICIDH-2*, and described as “problems in body function or structure as a significant deviation or loss” (WHO 1999:16). The emphasis in the definition is that this dimension refers to the body, although the indication is that *body* refers to the whole human organism, including the brain and its functions. Limitations in certain functions such as the inability to carry out a basic function of the body or body part, a concept that was included in 1980 within impairments, is still included in the new version. Reference to the impairment as a deviation from “generally accepted population standards” in the biomedical status of the body and its functions is more clearly expressed in this version. Definition of those “standards” is to be arbitrated by “those qualified to judge physical and mental functioning according to generally accepted standard” (WHO 1999:16). The implication is that such judgments are carried out by professionals, are outside the person's own experience with the impairment, and are based on a group standard rather than the person's capabilities prior to the impairment. (Altman, 2001, p. 105)

After the first two reports by the *International Classification of Impairment, Disability, and Handicap (ICIDH1 and 2)* in 1980 and 1999 by the WHO, disability rights activists and disability studies scholars made sharp critiques of the lack of distinction between impairment and disability, and the disregard for acknowledging how society socially and culturally creates barriers for people with disabilities. According to Altman's interpretation of Michael Oliver's reflections on the social model of disability, “The definition of *disability (A)* is based on the Disabled Peoples' International definition, which interprets it as ‘the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’ (Oliver 1996: 56)” (Altman, 2001, p. 105). Altman and Oliver point out that the social model of disabilities has the perspective that disability lies within the context of social and physical barriers, and not within individual bodies. Oliver outlines some of the original social model definitions and clarifications

between impairment and disability in *The Politics of Disablement* (1990), wherein people with disabilities (such as The Union of the Physically Impaired) began to analyze, define, and/or reclaim their experiences and identities:

*Impairment* lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body;

*Disability* the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (p. 11)

The social model of impairment and disability, which has undergone many changes and redefinitions, is continually being debated.

While the WHO's 1999 report refrained from including impairment within its disability definition (Altman, 2001, pp. 105-106), the medical-model ideas of impairment still implicitly represented ideas of limited biological functionality, ability, and so forth. There is still no clear separation between bodily difference and social forces that create disability (and no acknowledgment that disability can be a purely social phenomenon). It is a positive step that there was a move from focusing on causal, biological aspects of limitations to focusing more on limitations within one's environment and needing to address access. There still remains the requirement, however, to have medical professionals determine what the impairment and/or disability is, as well as what accommodations are suitable, thereby neglecting individual perspectives and collective experiences, such as that of chronic fatigue syndrome or Gulf War Syndrome (Altman, 2001). WHO's ICF report still utilizes perceived medical notions of bodily norms or averages to determine disability, rather than changes in one's individual functioning and needing access or accommodations to maintain one's daily activities. However, the WHO recognizes the social model of disability, to a degree:

#### The Model of ICF

Two major conceptual models of disability have been proposed. ...

The *social model* of disability... sees disability as a socially-created problem and not at all an attribute of an individual. On the social model, disability demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment.

On their own, neither model is adequate, although both are partially valid. Disability is a complex phenomena that is both a problem at the level of a person's body, and a complex and primarily social phenomena. Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external. In other words, both medical

and social responses are appropriate to the problems associated with disability; we cannot wholly reject either kind of intervention.

...

This more useful model of disability might be called the *biopsychosocial model*. (World Health Organization, 2002, pp. 8-9)

A key problem that continues with definitions such as that of WHO's above ICF report is that there is a social-culturally determined category of what is considered the average and normal body, and that, subsequently, the medical, psychological, and rehabilitative fields depend upon this notion. This makes impairment a necessary precursor to disability. Disability has yet to be dislodged from impairment, which inherently still requires perceived problems or issues always needing to be addressed within individual bodies. Meanwhile disability studies scholars argue that many people with disabilities only face barriers through society because they are perceived as having abnormal and deviant bodies from the norm. The only barriers are a lack of access to physical objects for accommodations and social opportunities. Although the WHO took a big step forward from their 1980 ICIDH report, where they recognized that there are social and cultural influences that create barriers for people with disabilities so that impairment and disability remain inextricably linked.<sup>26</sup>

Disability rights activists and disability studies scholars have begun to collectively recognize the ways in which barriers to life and happiness do not reside in their individual bodies, but rather in the attitudes and physical barriers within society. This understandably creates a strong backlash against theories and practices that identify the "disability problem" as in the body, and a push instead to have the societal and cultural barriers recognized and addressed. This has had enormous impact on many, including me. Had disability rights not been recognized, I could not have attempted to write this dissertation. Accommodations, such as books on cassette, CD, and other electronic forms, give me more equal access to an education similar to that of people who can use traditional books. Those who can read visual material, however, do not have to get doctor's notes or permission slips from professors to get access to their books. But, there is still a long way to go.

In addition, the medical model's insistence on connecting impairment and disability causes some disability studies scholars to ignore the critical aspects of living with something that creates a barrier to life (i.e. impairment), something that resides within the body, and has nothing or little to do with societal barriers (i.e. disability). The social constructionist model



of disability has led at times to the universalization of disability, which proclaims that there is a unified disability experience that our environment alone creates, rather than our body. This universalization of disability does not speak to the experiences of all persons who are either labeled or identify as disabled.

The distinctions between disability and impairment, and definitions of impairment, create quite rich, complicated, and sometimes contentious debates among disability studies scholars. Some disability studies scholars have questioned for decades where impairments, such as chronic illness, pain, fatigue, and so forth, fit into the social constructionist model of disability, and this issue is still fraught with much controversy. In 1996, Liz Crow published an article titled “Including All of Our Lives: Renewing the Social Model of Disability” in *Encounters with Strangers: Feminism and Disability*. It is not surprising to me, since she comes from a feminist background, that she argues against what appears to be an essentializing notion of disability within the social model of disability. She argues that such a notion not only neglects, but silences people who feel that not all of their barriers were strictly exterior to their bodies.

If our movement excludes many disabled people or refuses to discuss certain issues then our understanding is partial: our collective ability to conceive of, and achieve, a world which does not disable is diminished. What we risk is a world which includes an ‘elite’ of people with impairments, but which for many more of us contains no real promise of civil rights, equality or belonging. How can we expect anyone to take seriously a ‘radical’ movement which replicates some of the worst exclusionary aspects of the society it purports to change? (p. 210)

Crow lays out some reasons why many disability studies scholars are wary of aligning themselves with impairment, as people with disabilities and impairments have been constructed as and treated as inferior, a problem to be cured, and even, at times, to be killed. Many such ideologies, such as eugenics, believe that the issues or barriers reside solely in the limits of the body (impairments). This is then further interpreted as making a person less valuable or even a nuisance for society. Herein, according to Crow, lies part of the problem and the missing piece for deconstructing oppression of not only people with disabilities, but people with impairments.

Fear causes many to latch on to a purely social constructionist model of disability or what Carol Thomas calls “strong postmodernism” (Thomas, 1999, p.143), and often to ignore and shun impairment discussions. She argues not only that we must consider impairment

alone, but that we must also consider how disability and impairment interact, including over one person's life. Crow further points out that if disability oppression ever ended that discrimination and barriers to housing, jobs, and so forth would still exist for people with impairments (p. 218). From a position of strong postmodernism, our job of fighting disability oppression would be far from over even if disability oppression did end. Thomas also complicates the impairment-disability divide in *Female Forms: Experiencing and Understanding Disability* (1999), critiquing strict postmodernist and post-structuralist's views and arguing for a "non-reductionist materialist feminism" (p. 143):

From their constructionist point of view, impairment (the 'signifier') is seen to be entirely constituted through discursive practices and has no necessary relationship to any 'real' bodily state (the 'signified'); this is not a view which I share.

...in my view it is too limiting to think of impairment as connected with a biological substratum, 'the human body', which is fixed (albeit overlaid with social meanings which change in time and place). Rather, this 'biological substratum' is itself a social product, as well as a physically changing 'biological' entity. Human bodies possess a materiality which exists in a relationship of dynamic interaction with its social and physical environment (p. 9).

Crow and Thomas recognize that there is a social impact on individuals, in light of the materiality of ever-changing bodies, and that it is to the detriment of the disability rights movement and disability studies to neglect reflections about the complicated interplay between our corporeality or materiality and our social and cultural interactions that give meaning and value (or lack thereof) to our lived experiences. Thomas argues against "strong" postmodernist tendencies that say using any terminology that signals a link to the materiality of the body will cause a "descent into a modernist ontology of the 'fixed', 'unchanging' and 'transhistorical' human body, with an accompanying categorization of bodies into 'normal' and 'impaired' types, and a belief that the biological will determine the social" (p. 143).

One of my research participants, Susan Wendell, adds an interesting twist to the definitions of and divide between the materiality of the body, impairment, and disability in her 2001 article "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," in which she focuses on what it means to be "healthy" or "unhealthy" disabled. She makes it clear that there are some limitations that cannot be resolved through deconstructing social positionings:

Social constructionist analyses of disability, in which oppressive institutions and policies, prejudiced attitudes, discrimination, cultural misrepresentation, and other

social injustices are seen as primary causes of disability, can reduce attention to those disabled people whose bodies are highly medicalized because of their suffering, their deteriorating health, or the threat of death. Moreover, some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate. Therefore, some very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it. (p. 18)

Although I agree that the degree to which disability studies scholars tend to adhere to the social constructionist model of disability does seem to create an additional barrier to the sharing and dissemination of various disability experiences that encompass pain, chronic illness, and so forth, I agree with Crow and Thomas that the social constructionist model has a lot to offer bodily and impairment experiences as well. What appears to be surfacing among feminist disability studies scholars is a resistance to one way of understanding and claiming identities. Instead, many of us are growing increasingly interested in theories, even if contradictory at times, that help us understand how politics, power, and privilege inform and impact our social interactions and lives. I agree with this process that is surfacing within feminist disability studies.

I appreciate and agree with how Thomas distinguishes the shift from bodily experience to social interpretations of that bodily state that can liberate and oppress. While perhaps what we can do about the lived experience of pain is limited, as Wendell argues, how we treat people with pain is paramount. The medical model of disability usually insists that it knows more about our bodies and minds than we do.<sup>27</sup> When there is no medical logic or theorem for the pain, one may be dismissed with no pain-reducing measures and may even be belittled for “overreacting.” The pain, although not necessarily itself created by society, has to be medically validated in order to receive any form of accommodating methods. Social constructions or interpretations are heavily value-laden and often and easily switch into patronizing and oppressive reactions to people with impairments and disabilities. The negative impact that comes from barring certain people from physical or social spaces is pervasive. That pervasiveness maps out the oppressive systems of ableism. Again, oppressive systems operate on institutional, symbolic, and individual levels (Harding, 1986).

I often hear a different and quite contentious disability and impairment debate among disability studies scholars, frequently in terms of juxtaposing two of the more extreme sides of the disability-impairment continuum. While Simi Linton tends to support the more strong

postmodernist side, Lennard Davis' dismodernist theory has a heavy post-identity ring to it. Linton wants to draw a harder line between disability and impairment, but some scholars, like Davis, argue that we are all more or less impaired, limited, non-normal, or interdependent. We feel concerned over the oppression that comes with the labels and pathologies of medical and psychological establishments, as Linton briefly outlines:

Another way to answer the question is to say that disability "is mostly a social distinction...a marginalized status" and the status is assigned by "the majority culture tribunal" (Gill 1994, 44). But the problem gets stickier when the distinction between disabled and non disabled is challenged by people who say, "Actually, we're all disabled in some way, aren't we?" (46). Gill says the answer is no to those whose difference "does *not* significantly affect daily life and the person does not [with some consistency] present himself/herself to the world at large as a disabled person" (46). I concur with Gill; I am not willing or interested in erasing the line between disabled and non disabled people, as long as disabled people are devalued and discriminated against, and as long as naming the category serves to call attention to that treatment. (Linton, 1998, pp. 12-13).

Our identities present a covert story about relationships of power and disempowerment between groups of people. As Linton and other postmodernist disability studies scholars point out, those labeled as disabled have very different social and cultural experiences with other groups of people because of their pathological labels.

Lennard Davis, on the other hand, focuses more on everyone being impaired, limited, or non-normal. He works to debunk that there is such a thing as a "normal" subject who is free from dependency and interdependency, as he says,

This new way of thinking, which I am calling dismodernism, rests on the operative notion that postmodernism is still based on a humanistic model. Politics have been directed toward making all identities equal under a model of the rights of the dominant, often white, male, "normal" subject. In a dismodernist mode, the ideal is not a hypostatization of the normal (that is, dominant) subject, but aims to create a new category based on the partial, incomplete subject whose realization is not autonomy and independence but dependency and interdependence. This is a very different notion from subjectivity organized around wounded identities; rather, *all* humans are seen as wounded. Wounds are not the result of oppression, but rather the other way around. Protections are not inherent, endowed by the creator, but created by society at large and administered to all. The idea of a protected class in law now becomes less necessary since the protections offered to that class are offered to all. (2002, p. 30)

Davis hopes to diffuse disability by making everyone realize that we all have the commonality of being dependent and interdependent by being embodied in temporal, ever-

changing and limited bodies. Making everyone imperfect or impaired destabilizes disability (and additional identities) because it makes limitation and impairment the norm (versus an abnormality that needs to be made normal). Davis seems to want to take away the concept of normal, which would also take away its “Other.” This argument plays its role in breaking down disability oppression, in that it is true that we are all needy and interdependent, susceptible to change, and are and will be incapable, or considered unable to do certain things, without certain social and physical provisions. Growing awareness could help destabilize disability oppression, but it depends on how the theory is used, as one could use this theory to say “we are all limited and should just fend for ourselves,” thereby sidestepping the oppression that undeniably exists in our society.

On the other hand, Davis’s theory could turn on itself and reflect back the socially constructed nature of disability and impairment, but from a position of non-disabled privilege. McIntosh’s theories about privilege reveal that we all use various physical and social objects, tools, and so forth (through financial and political means), and that we would be limited in our activities if we did not have these things. This in turn also demonstrates that not everyone has these privileges and that some are socially situated as oppressed group. There is the potential that someone could read Davis’ article and not take responsibility for figuring out how they are privileged, but rather, dismiss access and accommodation as an individual issue. I do not think that Davis intended for this to be a privilege studies article, but could it be used as such? Studies of privilege do help reveal the socially constructed binaries of identity and, therefore, simultaneously destabilize identity and affirm socially constructed oppression.

Davis, however, recognizes the everyday factors and implications of disability oppression and how it is socially and culturally created. He notes:

Clearly, what I am describing is the beginning of a long process. It began with the efforts of various identities to escape oppression based on their category of oppression. That struggle is not over and must continue. While there is no race, there is still racism. But dismodernism argues for a commonality of bodies within the notion of difference. It is too easy to say, “We’re all disabled.” But it is possible to say that we are all disabled by injustice and oppression of various kinds. We are all nonstandard, and it is under that standard that we should be able to found the dismodernist ethic. (2002, pp. 31-32)

The dismodernist ethic recognizes that oppression such as racism and ableism are authentic

experiences and still need to be fought. At the same time, the dismodernist ethic accounts for how we are all limited and different, which flips the dominant standard of creating access for a special class to creating physical and social access for everyone. Davis' dismodernism argument can potentially help diffuse all forms of oppression by taking away claims that one group is dominant and more able than another group of people. However, many scholars and activists, including myself, disagree or are uncomfortable with this idea that we are all impaired or non-normal because of the potential implications described above.

Davis goes so far as to hint in his online article for *The Chronicle of Higher Education*, "Why Is Disability Missing From the Discourse on Diversity?" (2011) that all forms of oppression are built off of a neo-liberal disablism that depends upon certain groups of people having bodies that are inherently not as able as the dominant group. Therefore, many oppressed groups "Other" people with disabilities by implying that "They are 'the they' that we are not. They are the incapable, unable, abnormal, and deviant group. We, on the other hand, are capable and able." Davis argues:

I would argue that disability isn't just missing from a diversity consciousness, but that disability is antithetical to diversity as it now stands....

I would add that diversity also represses difference that isn't included under the better-known categories of race, ethnicity, and gender. In other words, diversity can exist only as long as we discount physical, cognitive, and affective impairments. (para. 4-5)

I find Davis' argument to be illogical. While diversity may or may not repress differences that do not fall under the typical identity categories of race, ethnicity, and gender, this does not mean that diversity can only exist as long as we more or less discount impairment.<sup>28</sup>

Davis ends with, "The question remains: Is this simply neglect, or is there something inherent in the way diversity is considered that makes it impossible to recognize disability as a valid human identity?" (para. 14) Luckily, "identity" can be claimed for the purpose of pointing out structures of power, correcting false claims and theories, and perhaps channeling humanity toward a better future. We have the ability to impact political processes. Identities are not solely dependent upon the *multiple* ways in which identities have been constructed, including the construction of the normal and abnormal bodies. Therefore, identity politics and diversity can also be claimed.<sup>29</sup> The seemingly illusive stronghold that disability versus impairment debates have on identity and identity politics in and of itself creates new insights into identity and how to do work across identity groups.

Like Thomas, Tremain draws upon how the materiality of the body and how impairment is heavily influenced by social-cultural influences in its definitions and treatment in her article “On The Government of Disability” (2001). Drawing from feminist theorists, such as Judith Butler, Tremain highlights how we cannot disconnect the materiality of the body from societal understandings of and influences over the body. Whether it is impairment or disability, both terms are subject to the social and cultural influences of their time without taking away individual, lived experiences. As Tremain explains, however, we cannot get away from the social influences that the cultures of our time have on that materiality, nor can we discuss that materiality (our bodies) without our culture’s impacting how we view, name, and treat the body:

This argument begs the question, however; for the materiality of the “(impaired) body” is precisely that which ought to be contested. In the words of Judith Butler, “there is no reference to a pure body which is not at the same time a further formation of that body.” Moreover, the historical approach to disability that I recommend does not deny the materiality of the body; rather, the approach assumes that the materiality of “the body” cannot be dissociated from the historically contingent practices that bring it into being, that is, bring it into being as that sort of thing. Indeed, it seems politically naive to suggest that the term “impairment” is value-neutral, that is, “merely descriptive,” as if there could ever be a description that was not also a *prescription* for the formulation of the object (person, practice, or thing) to which it is claimed to innocently refer. (p. 621)

Tremain compares impairment and disability to feminist analyses of sex and gender. While it is easier to sort out how gender is determined socially and culturally, the stability of “sex” has also been thrown into question by the fact that some bodies are born intersexed to varying degrees. This debunks the binary of a strict male and female system of understanding. Not only do such cases call definitions of gender into question, they do the same to strict definitions of sex, although we often consider it a factual part of our bodies. While impairments may reference factual, biological parts of our bodies, our definitions of “sex” and “impairment” are still socially constructed. In addition, understandings of “sex” and “impairment” are influenced by the social and cultural understandings and treatments of “gender” and “disability.” Notions of gender and disability create an investment in the terms “sex” and “impairment.”

Linton, on the other hand, makes defining disability a political statement by emphasizing that the experience of disability oppression (through physical and social

barriers) is “disability,” and that not everyone, therefore, experiences disability (even though we may all be different or impaired in some way). Not everyone who is “different” is subjected to ableism. People are treated differently according to the ways in which we socially construct some differences as deviant and needing to be fixed, while other differences (or impairments or non-talents) are not subject to stigmatization and discrimination. In other words, disability is more or less the experience of ableism. This theory rests primarily on the idea that once the social and physical barriers are removed, the disability will no longer exist.

The hyper-focus on disability from the perspective of strong postmodernism and as a purely socially-constructed oppression tends to universalize disability and impairment as non-bodily and non-material experiences. As Susan Wendell notes, however, no amount of resistance against certain social and cultural forces will alleviate pain, fatigue, and so forth. These issues of impairment are critical to the disability movement. A person can be discriminated against for being sick, and a movement that recognizes disability oppression only through seeing the barriers as being within society bars or silences those whose barriers may reside at least in part within the body.

Disability studies not only adds the critical postmodernist and social constructionist perspective of disability as an oppressed class to political discussion of the many Other identities (and, therefore, also feminism), but it also challenges purist or strong postmodernist perspectives of identity. Disability studies reveals a materiality of the body and its interplay with the social and cultural world in ways that other identity categories perhaps cannot. These explorations are, in part, built from feminist theories. Some feminist theories are being challenged and some, such as social constructionist theories, also provide foundations for critical disability pride narratives to emerge, which then helps reveal the complex vectors of disability oppression.

### **Participant Reflections: Disability Studies Influences on Women Studies**

*Interview Question #3a: Has disability studies informed your feminist thinking?*

Disability studies throws multiple wrenches into many identity-based theories, and



women studies is not immune. In a discussion with Susan Schweik, during our interview, she commented on the fact that even though feminists may be more aware of many, varying, and overlapping forms of oppression, we still more or less expect feminists not to be influenced by the medical model of disability. Although feminism and women studies may be familiar with social constructionist perspectives and the minority group model, that does not mean that feminists are immune to the cultural mores of ableism. Medical models of disability and health are heavily embedded in many cultures, including feminism.

Susan Schweik: Impairment scares people. Contingency and vulnerability scare people. And I don't think for all of the work that has been done in feminist studies, and it has been profound work that has to do with...questioning the mind-body binary and valuing the body, and speaking from the body, and (claiming one situation) in the body, and all that kind of postmodern (trend) of the body, sometimes in precise proportion, it's very much only been a certain kind of body, and, you know, I think of a story I was told about a year ago about admissions at a graduate department at a university where a faculty member said blatantly that we are going to have too many people around who it is hard to understand what they are saying—talking about what students with cerebral palsy or something...I don't know. (...) I don't think anyone in the academe is immune to that, so why should feminist scholars be, even if they are way more hip to pregnant bodies or transgender bodies, or...[laughter].

Kristina Knoll: Well, one thing I have seen that there is actually rhetoric of, "I am just as able as my male, white colleague," or particularly from the second wave. There is that really strong presence of both of mind and body ability.

Susan Schweik: That's right. Well, there is a wonderful phrase. I can't remember who coined it, but sometimes talking about the "severely able-bodied." And I personally think in the realm of queer theory in the academe, if I just had to judge I would say that it is exceptionally severely able-bodied bodied group—you know, in most places [laughter]. There is a great deal of "same old same old" dynamic. I mean it is not as if it is anything new, but kind of standards of attractiveness and of strength and of course of mental (acuity).

Kristina Knoll: What could we call it...like...“compulsive heterosexual...”

Susan Schweik: I like compulsive, compulsory, but...compulsory able-bodiedness or something...[laughter] compulsive able-bodiedness [laughter].<sup>30</sup>

Amy Vidali and Susan Wendell also referenced this compulsory able-bodiedness that has spurred feminism for so long: we must be active activists and fiercely independent in order to be good feminists. Disability studies provides rich insights into the theories and practices that fuel these ableistic tendencies within women studies.

Alison Kafer also noted how disability studies gave more depth to her cultural analyses of bodies, even beyond disability to additional bodily experiences such as queerness:

I do think that disability studies has pushed me to think of the specificities of bodies...maybe in ways I don't know if I would have otherwise. I mean feminist studies and feminist theories are very much interested in bodies. And there are feminists who don't do disability who talk about embodiment and embodied experience, but I think disability studies helped me see that more. It actually made me think about bodies in their particularity, about the different cultural weights different kinds of bodies bear, and about bodies in terms of feminist, queer, or crip resistance.<sup>31</sup>

Disability studies provides new layers of analyses for bodily experiences—from the intersectional influences of sexism and ableism on feminism to the influences of compulsory heterosexuality and able-bodiedness on queerness.

Participants also responded to this question: “Has disability studies informed your feminist thinking?”

Susan Wendell: I begin to realize there is such a disconnect between what I saw as mainstream feminism's understanding of the body as something that needs to (take) control of our bodies, back from men, and then everything is going to be ok. And eventually that was the picture of...of mainstream, western feminism, of the body, in mainstream western feminism. And...when I realized that I began to see an enormous gap between people with disabilities, women with disabilities, and other feminists...the...and that's just one of them. But certainly in theorizing the body, the body being theorized was the body of a healthy thirty-year old, non-disabled woman. And everybody was essentially left out of that. And, yes, we admired older feminists, but the terms of admiration were, “She's still so energetic. She's still so active. She is still at every demonstration, and so on and so forth.” Those were the terms of admiration, and if you were a feminist who had become too ill in old age, and so no one saw you, then there was a lot less interest in talking about reclaiming (you). There were exceptions to that, but, by in large, I was very...shocked (...) at how ignorant...my own conception of the female body. And even though the analysis is very complex, and deals with many issues...how left out women with disabilities (and illness is) from feminism.

Amy Vidali: Definitely...definitely in terms of, you know, my whole concept of feminism when I was young was just fierce independence, and disability obviously changes the way you think about...being interdependent, and things like that. So, that would be the most profound.<sup>32</sup>

As Catherine Kudlick explains below, “disability studies muddies the waters” of feminism. Disability studies provides new insights for women studies, such as how we value or devalue certain bodies, and also provides an understanding of some of the oppressive forces behind

such perspectives.

From cultural, philosophical, and historical slants on women being predetermined as weak in body, mind, and emotions, women studies challenges how women are socially constructed as weak, and disability studies challenges how the social constructions of weakness, be it the female and/or disabled body, are negative or bad. This tension and muddying of the waters between feminism and disability studies challenges concepts such as the internalization of sexism and ableism, in wanting to be active and strong feminists (in terms of mind, bodies, and emotions), and it challenges, as well, additional oppressive theories and practices, including which fetuses we allow to live and which fetuses we decide should die. Catherine Kudlick discussed these issues in our interview:

Oh yes. It makes it more interesting. For those of us that are wary of a party line in the field, disability studies muddies the water so much. Just take something like abortion, right, and the knee-jerk reaction of feminism is, “Yes, we have a right to choose. I should be able to abort that disabled baby that I don’t want.” You know? And you start asking people what they can do. So, in these cases I think it has had a huge impact just making it more complex. I think any good idea should be as complex as it can be.

Feminist disability studies and disability studies are also providing a safe space from which to work on some of these complex and sometimes very sensitive issues.

Where we might feel as if we were working in total isolation, disability studies and feminist disability studies provide a unique space that is accessible. We work to make our physical spaces accessible, and we are employing multiple theories that help us unravel the ways in which sexism and ableism are used to oppress certain people. This was mentioned by both Licia Carlson and Susan Burch:

Licia Carlson: Yeah, absolutely. (...) The first time I went to SDS [Society for Disability Studies] was in ninety-five. And I was in graduate school, and actually that is another pivotal moment...I felt like I had been working in total isolation on this topic. The University of Toronto’s philosophy department is huge. It’s like eighty-five faculty, two hundred graduate students, and I knew of only one person working on anything remotely related to disability. And I went to this conference, and it was amazing. So, the whole experience for me was really reinforced by these glimmers of the connection between feminist theory and disability theory.

Susan Burch: Absolutely. In very practical ways, as well as theoretical ways. I can no longer tolerate [academic] conferences that are not accessible, and feminist conferences that are not accessible...[this] draw[s] my very vocal and immediate response...So, making things accessible for any variety of people with disabilities,

but also any variety of feminists. I'm finding that assumptions about people's feminisms can also produce exclusionary dynamics that I don't find comfortable. Now that's really idealistic, and I have to own that I have some very set ideas about feminism that may clash with other people, and I may not really want to embrace another perspective on things. But that said...I think the importance of creating safe space, accessible space, inclusive space is vital...to the survival of feminism and disability rights.

Burch makes the critical point that feminism does not always create safe spaces for us to work because if it is not physically accessible (i.e. accommodating to varying bodies and minds), we are implicitly or explicitly being told that we are not welcome in that space as people with disabilities and various impairments.<sup>33</sup> We know that it is an ableistic academic culture when our bodies and minds are treated as outsiders, or a nuisance, which is reflected in the lack of accessibility. Disability studies actively seeks to create such spaces, however, and has made feminist disability studies scholars much less tolerant of inaccessible feminist environments, as well as inspiring political change and activism to make women studies more accessible.

Disability studies, being a new and emergent identity among identity studies and identity politics, enters into identity-based politics and reveals identity politics within, for example, women studies. Dogmatic ideas around not only what constitutes a normal body, but what a good feminist is, are being challenged by this political interaction between those who are combining and exploring these two identities, and the theories built from that exploration. In Chapter 6 I discuss, for example, how Susan Wendell challenges the common practice within Women's Studies Departments of having all day "retreats," and the pressure to engage in activities that require a lot of physical energy to be considered a good feminist.

Finally, as will be discussed in more depth in Chapter 3, disability studies debates around disability and impairment are calling into question our notions and functions of identity. The insights provided by the identity-based politics between feminist and disability studies (e.g. feminist disability studies) radically alters ideas about how to engage with the politics of our identities.

### Chapter 3: Feminist Disability Studies, Identity, & Identity Politics

As demonstrated by the convergence of ideas from feminist and disability studies, and by participant quotes in the latter half of this chapter, feminist disability studies spans more than the simple, yet critical and complex, intersections of narratives by women with disabilities and theories that intersect these disciplines. Such work quickly transverses into more collective, intersectional, scholarly, and theoretical writings as well. I argue that feminist disability studies is challenging and expanding the typical political processes between identities and identity-based theories. Feminist disability studies explores how to maintain a process that is neither dogmatic, nor essentializing, therefore remaining open to all identities and identity-based theories. A persistent openness does not mean acceptance of *any* theory or treatment by a person (e.g. any potential negative or oppressive implications), but rather a willingness by those working on anti-oppression issues to work together to look at and analyze if and how a political identity or identity-based theory reflects power imbalances through various systems in our physical and material worlds.<sup>34</sup>

What feminist disability studies discovers is that part of this process is comprised of incorporating sometimes seemingly conflicting feminist and disability studies theories and principles. This is to ensure and prioritize that marginalized voices are not barred from being heard and woven into the political process of our identities. Therefore, the feminist principle of continually asking who is not present, and of supporting marginalized voices, remains critical to feminist disability studies.

The literature, theories, and participant interviews support or reflect my argument that the tensions between identities and identity theories reveal a political process that is transformable, and that we should be concerned with how to maintain political spaces that remain open to the revelations of power imbalances in identity work that can silence and oppress. This makes our personal narratives critical in order for us to begin unraveling the political nature that is woven into our identities and to deconstruct, reclaim, and even to create a whole new mosaic of identity theories to address imbalances of power in the politics between groups of people. This is what feminist disability studies is in the process of developing.

### **Feminist Disability Studies Literature & Theories on the Political Process of Identities**

Narratives that begin to introduce new theoretical perspectives about identities are a critical part of the political process for naming and addressing forms of power, privilege and oppression. They often spur additional people with intersecting or overlapping and perhaps subversive identities to emerge. Participant interviews and feminist disability studies literature reveal and discuss the importance of emergent, marginalized, and intersecting voices.

Several earlier texts by women with disabilities that bring the oppressive and liberating narratives of the lives of women with disabilities to the surface include Susan E. Browne, Debra Connors, and Nanci Stern's *With the Power of Each Breath: A Disabled Women's Anthology* (1985) and Harilyn Rousso, Susan Gushee O'Malley, and Mary Severance's *Disabled, Female, and Proud!: Stories of Ten Women with Disabilities* (1988). These are just two of many examples of women with disabilities who reflect upon their personal experiences from positions of pride and seek new ways to think, theorize, and act collectively against the unique intersections of ableism and sexism.<sup>35</sup>

The liberation process often starts with bold, brave, and sometimes awkward reflections about our personal experiences, as well as alternative perspectives on key historical events and people. We begin claiming a different idea about ourselves from that which we have been told, and we resist oppressive forces by claiming, resisting, and reshaping our identities and the theories, practices, and power imbalances that shaped them. As Rosemarie Garland-Thomson explains, we begin to "reimagine" our identities and the politics that have shaped them (including using standpoint epistemologies) and how they might be thought of in a different way by using social constructionist perspectives.<sup>36</sup>

The tension between identity theories can provide us with information about the political process of our identities. Our language can also show us where we are, as scholars, (at the time of our writing) on the disability and impairment continuum. I believe, however, that the sometimes implicit or explicit resistance to being fixed on the continuum shows an informative feminist disability studies process that wants to resist dogmatic and essentializing theories that might silence marginalized voices. This position and process insists that experience and perspectives on how the disability identity is socially constructed through systems of power must remain a cornerstone of our work. Rosemarie Garland-

Thomson, similarly, reflects on feminist disability studies:

Feminist disability studies...tends to avoid impairment-specific or medical diagnostic categories to think about disability. Certainly, feminist disability studies acknowledges communities of people based on shared disability experience, and it recognizes the differences among the wide variety of stigmatized forms of embodiment that constitute disability in its broadest conceptualization—from blindness to intersex to dyslexia, for instance. Nevertheless, it focuses on examining the patterns of meaning attributed to those bodies rather than specific forms, functions, and behaviors. Feminist disability studies scrutinizes how people with a wide range of physical, mental, and emotional differences are collectively imagined as defective and excluded from an equal place in the social order.

...

This focus on how identity operates promoted an interest in the relation between bodies and identity. As a category of analysis, disability provides fresh ways of thinking about the complexity of embodied identity. Feminist disability studies defines disability as a vector of socially constructed identity and a form of embodiment that interacts with both the material and the social environments. (2005, pp. 1558-1559)

Both Garland-Thomson and I maintain that we must use practices and theories that encourage marginalized and overlapping identities to surface, revealing how we are shaped as an oppressed group through systems of power and discrimination. Again, participant narratives provide part of the buttressing for our identity-based theories, which helps us to continually piece experiences and theories together in new ways, with the goal of social change and social justice. In the following sections of my dissertation, participant quotes reveal a desire, and ideas for how to sustain spaces that permit and even encourage conflicting identity-based theories to emerge (e.g. speaking up about a form of oppression at the risk of possibly being ostracized for doing so, while at the same time working to create spaces where people feel safe enough to speak up without the threat of being ostracized).

This process of creating ways for sustaining critical and conflicted spaces can help reveal where oppression may be hiding because it works to create the means and spaces that encourage, rather than impede the process. When there is not as much fear of speaking up, due to the possibility of a backlash by colleagues, for example, people are more likely to share, collaborate, and work through ideas and theories that may reveal or create tensions; thereby allowing more opportunities for the exposure of systems of power, privilege, and oppression. This creates opportunities for perhaps more liberation because we are more likely to expose systems of power more expediently.

This is what makes non-dogmatic and sometimes dialectical spaces exciting, but we

also must remain attentive to how such spaces can ostracize, silence, and oppress. This is why I argue that theories and practices that bring marginalized voices to the surface and help to sustain them are essential and a principle that feminist disability studies must maintain. *How* we do this is a process we are discovering as we weave together this mosaic of anti-oppression theories and identities and is one to which many feminist disability studies scholars must remain attentive.

Social constructionism and feminist theories that highlight the emergence of overlapping identities, I argue, are a cornerstone to, and should remain a principle of, feminist disability studies. Feminism reminds us at the same time, however, to be vigilant about theories and practices that essentialize, such as strong postmodernism, purist forms of social constructionism and dismodernism. Many feminists and feminist disability studies scholars, including some of my participants, bristle at theories about identity that essentialize or universalize identities and social justice movements. Dogmatic ideologies set off alarms for feminists (including feminist disability studies scholars) and make us ask again, “Who may be silenced here, and why? Who is not present, and why? Are our theories and practices silencing?”

For example, Carol Thomas argues that even though the foundations of materialist and postmodernist theories may make them incompatible. This does not mean that we have to take one and discard the other in our social justice pursuits, and even that to do so might be problematic, leading to oppression through essentialisms, universalisms, and dogmatisms that exclude. However, after exploring these theories, we may realize that one helps expose systems of power, while the other does not and is therefore not useful in pursuing a certain form of social justice.

Calling for syntheses has a certain ‘wouldn’t it be nice’ appeal, but a synthesis is not an option—the philosophical, epistemological and ontological foundations of these theoretical approaches make them incompatible. This does not mean, however, that only one theoretical perspective should be pursued at the expense of others. On the contrary, dogma and rigid orthodoxy should be avoided at all costs. Disability Studies is enriched by accommodating a range of theoretical perspectives, and through the purposive and lively intellectual engagements between those adopting different approaches. Of course it is true that historical materialism, and Marxism generally, has had no shortage of dogmatists in its time, but the more recent postmodernist tradition, in feminism and elsewhere, is sometimes equally dogmatic, uses inaccessible language, and frequently adopts an arrogant disdain for all versions of ‘modernist’ thought despite an avowed tolerance of ‘difference’ in the realm of



ideas. What is required is tolerance and openness on all sides (Thomas, 1999, p. 142).

To add to this, Crow writes,

Yet our insistence that disadvantage and exclusion are the result of discrimination and prejudice, and our criticisms of the medical model of disability, have made us wary of acknowledging our experiences of impairment. Impairment is safer not mentioned at all.

This silence prevents us from dealing effectively with the difficult aspects of impairment. (Crow, 1996, p. 209)

What is key is that identities can be markers that lead to understanding structures of power and privilege between groups of people, and there is a social and political process that can be analyzed. As Crow points out, even though both disability and impairment identities are enriched by understanding the socially constructed aspects of our identities, we should not let our fear of past experiences of the medical model attributing our disadvantages to our bodies (versus our built and social environments) keep us from exploring how material and embodied experiences can be informed by our socially constructed identities (and vice versa).

Socially constructed identities, including ones informed by material and embodied experiences of impairments, can expose systems of oppression and power, such as institutional, symbolic, and individual interactions.<sup>37</sup> Identities are signals toward the social and political interactions between people. Once we are able to know, name, and resist the political systems of oppression that get overlaid on a group of people deemed different and “less than,” it is possible for us to create social change.

Encouraging open conversations around our identities can usher in and expose social facts that are mutually analyzable, revealing systems of power and privilege between groups of people. Permitting the weaving together of many identity-based theories can help reveal dogmatic assumptions about some of our identity-based theories and praxes, challenging us to explore all identities and identity-based theories. These politics of our identities keep us not only perpetually in a process, but insist that we be actively engaged across identities and identity-based theories.<sup>38</sup> Using participant reflections in Chapter 5, I also argue that resistance to acknowledging discussions and theorizing across identities and identity-based theories *as activism* and as a part of social change is fueled by elements of ableism and

sexism. “Consciousness raising groups” have created a watershed of various forms of activism as well, time and again.

Feminist disability studies argues for the necessity of, and is working toward, piecing together a mosaic of identity-based theories that help us address *how* we do identity-based politics. We need a commonality of pursuing an inclusive practice of anti-oppression, which could, as one example, be drawn from “universal design” theories.<sup>39</sup> By employing the disability studies method of universal design to identity-based theories and politics, we account for all of the theoretical pieces we have in order to create as inclusive and informative a space and practice as possible. At the same time, however, we recognize that this system can still be exclusive or inapplicable to certain people. Such theories, albeit critical at times, can essentialize and silence oppressed people. This reminds us that we must maintain a feminist practice that also seeks out and accommodates specific, individual, silenced and marginalized voices and identity-based theories that may be missing or lacking in our identity-based politics.

The next section explores some of the identity-based theories within feminism and disability studies with which the participants grapple, and how many of their ideas point us toward this feminist disability studies process that seems to be emerging and relying upon contradictory, contentious, and dialectical theories and practices. They continually remind us of the importance of employing feminist theories that draw out marginalized voices that may have many overlapping identities that have yet to be identified, and, therefore, are not politically recognized and addressed within what we hope to be our most inclusive, “universal” practices. Feminist disability studies offers up an opportunity to engage in a process that can potentially use the tensions between our identities and identity-based theories to inform our understanding of systems of power, privilege, and oppression—so that we might better address them. Critically, being aware that this is a process fraught with these tensions and emotions, participants also discuss *how* we should attempt to do this work together, which is outlined most fully in Chapter 6.

While feminist disability studies is defined, in part, as the simple overlapping of women’s and disability experiences with feminist and disability studies theories, I also chose to look at what appeared to be bubbling below the surface in my data and in feminist disability studies as a whole: a dialectical approach for working across identities and identity-

based theories. This feminist disability studies method now seems to be more fully surfacing among feminist disability studies scholars. In the recent 2011 *Feminist Disability Studies* book, Rosemarie Garland-Thomson and Ellen Samuels argue for a feminist disability studies method very similar to that which I see emerging from my own research.

Samuels shows that while there may be some contradictions and problems with making parallels in disability studies with some of Judith Butler's theories, the process of mingling disability studies concepts with Butler's theories can help us get to new social justice theories. Encouraging a system or process that allows for theoretical inconsistencies helps us get closer to anti-oppression theories and methods. Samuels argues:

One can reasonably be left confused as to Wilchins's ultimate feelings about gender theory in general and Butler in particular. Yet, perhaps her contradictory attitude can actually provide a useful model for disability theorists as we begin to formulate more nuanced and liberatory ways to integrate Butler and her fellow constructivists into our own scholarship....Like other critics of postmodern body theory, [Carrie] Sandahl observes, "Butler's theory of performativity...relies on a metaphorical association between gender 'freakishness' and deformed bodies....In a sense, then, Butler uses disability (or the deformed, abject body) as a metaphor for gender and sex difference, and...ignores the identities and concerns of actual people with disabilities" (1999, 15). Yet on the very next page, Sandahl decides to use Butler anyway, because "Butler's theory...allows us to see the performative parallel between gender and disability" (16). It seems that Butler's work exerts a powerful influence, not only on our academic discourse, but perhaps also on our minds and hearts. Her insights have the potential to be so far-reaching and liberatory that even as we formulate critiques of her theories, we are also drawn in to the possibilities those theories offer. (pp. 62-63)<sup>40</sup>

As Samuels demonstrates, even though tensions and contradictions may occur when bringing various identity-based theories into conversation, feminist disability studies is embracing the possibilities that can come from such a process. We include theories that we may be critical of into our conversations because of the knowledge that can be produced, not only in finding the limits of theories such as Butler's or Davis's, but also through establishing parallels with our own theories. However, as argued above, we must simultaneously be vigilant of the negative ways in which identity theories can be used toward oppressive means and not dismiss the emotional and personal implications of theories potentially implemented.

In a reprint of her 2002 article, "Integrating Disability, Transforming Feminist Theory," Rosemarie Garland-Thomson more explicitly states that such a dialectical and sometimes seemingly incoherent process, while stemming from feminism, is being

influenced by disability studies concepts that resist “fantasies of wholeness” (p. 42). Instead, we argue for a process, what Garland-Thomson defines as “academic activism,” which supports individuals in this political and highly personal process around our intersecting and overlapping identities and identity-based theories. Garland-Thomson states:

Academic activism is most self-consciously vibrant in the aggregate of interdisciplinary identity studies—of which women’s studies is exemplary—that strive to expose the workings of oppression, examine subject formation, and offer counter-narratives for subjugated groups. Their cultural work is building an archive through historical and textual retrieval, canon reformation, role modeling, mentoring, curricular reform, and course and program development.

A specific form of feminist academic activism can be deepened through the complication of a disability analysis. I call this academic activism the methodology of intellectual tolerance. By this I do not mean tolerance in the more usual sense of tolerating each other, although that would be useful as well. What I mean is the intellectual position of tolerating what has been thought of as incoherence. As feminism has embraced the paradoxes that have emerged from its challenge to the gender system, it has not collapsed into chaos, but instead has developed a methodology that tolerates internal conflict and contradiction. This method asks difficult questions but accepts provisional answers. This method recognizes the power of identity at the same time that it reveals identity as a fiction. This method both seeks equality and claims difference. This method allows us to teach with authority at the same time that we reject notions of pedagogical mastery. This method establishes institutional presences even while it acknowledges the limitations of institutions. This method validates the personal but implements disinterested inquiry. This method both writes new stories and recovers traditional ones. Considering disability as a vector of identity that intersects gender is one more internal challenge that threatens the coherence of woman, of course. But feminism can accommodate such complication and the contradictions it cultivates. Indeed the intellectual tolerance I am arguing for espouses the partial, the provisional, the particular. Such an intellectual habit can be informed by disability experience and acceptance. To embrace the supposedly flawed body of disability is to critique the normalizing phallic fantasies of wholeness, unity, coherence, and completeness. The disabled body is contradiction, ambiguity, and partiality incarnate. (p. 40-42)

In other words, again, feminist disability studies is less concerned with whether or not any particular identity-based theory is right or wrong than with a process that embraces using multiple identity-based theories, albeit imperfect, conflicted, and partial, since such a process provides opportunities for better understanding oppression and for creating and refining social justice tools.

### **Participant Reflections: Feminist Disability Studies**

All of the interview questions have informed the reflections below, and my arguments for what feminist disability studies “is,” but the first is central:<sup>41</sup>

*Interview Question #1: If someone were to ask you what "Feminist Disability Studies" is, how would you define it?*

Although I was anticipating a resounding enthusiasm for identifying and defining a feminist disability studies area of study, there was a range of responses, including concerns over fragmentation, dogmatism, and essentialism. Participants also described feminist disability studies as consisting of the fusion of both narratives by women with disabilities and of feminist and disability studies theories.

The high majority of participant responses to the first interview question underscored the overlapping of intersecting perspectives of women/gender/feminist studies with disability studies, or between the topics of women/gender/feminism with disability, impairment, and/or health.<sup>42</sup> For example, Georgina Kleege and Catherine Kudlick initially identified feminist disability studies as an overlap between disability and gender:

Georgina Kleege: I would say it's...looking at culture, however you want to define culture, with an awareness of both issues related to disability and issues related to gender, specifically women, and how those intersect and overlap.

Catherine Kudlick: I think feminism would bring in the gendered components and really think critically about the gendered aspects of disability studies, and that would always be at the forefront of people's considerations of disability studies.

Kleege and Kudlick's responses are examples of a more clear-cut initial definition of feminist disability studies.

Licia Carlson and Susan Schweik, however, begin to blur the boundaries with which we initially start out (e.g. gender and disability, and feminist and disability studies theories), complicating what we are looking at, who we are talking about, what issues we are talking about, and what is the necessary theoretical or experiential background to be looking at these issues:

Licia Carlson: I view it as an intersection between feminism and disability studies, but I think that that's an oversimplification in some ways. From a theoretical standpoint, it involves using gender and disability as two lenses of analysis in various ways. But I think that each complicates the other. So, on the one hand, I think, you

have a tradition of feminist thought, feminist theory, and feminist activists that for quite some time were not incorporating the perspectives of persons with disabilities. And from a political standpoint, as the disability rights movement emerges you have challenges to traditional feminist theory, coming from women and activists with disabilities. So, I think that as a field I would say that in an academic context it's the bridging and the simultaneous critiquing of feminist theory and disability theory, and it's forging a kind of dialogue between those two schools of thought. This newly emerging field takes them both together. I would argue that you can't really have one without the other. To talk about disability in a neutral way is highly problematic, and to talk about feminist theory or gender without taking disability into consideration is really a gross oversight in a lot of ways.

Carlson and Schweik expand upon what it means to be at the intersections of these two fields. Carlson comments on how it is not just about the overlap of the two fields, but is also about a self-conscious critiquing of one another.

Feminist disability studies seeks to remedy the absence of feminist or disability studies theories in the each field, thereby creating a group of people who concentrate precisely on doing this type of work. From that point, emerge issues that are considered unique to feminist disability studies, as noted by Susan Schweik:

Feminist disability studies, to start out with a trend (...) to gender as an issue that is...inextricably intertwined with any other reading of the body that occurs sexually (...). But I would say more than that. Feminist disability studies can only be defined as that if this project is to systematically challenge sexism. In the same way that I believe disability studies is, as a field, has to have at its core, the understanding that its motive is to challenge ableism. And similarly, gender, studies of gender and disability don't necessarily have to proceed from the "nothing about us, without us" principle. But I think that feminist disability studies does, and around both the issues of gender and disability. It doesn't mean that a non-disabled male cannot engage in feminist disability studies. It just means that there has to be a very self-conscious understanding of privilege involved.<sup>43</sup>

Similarly, Schweik pointed out how both gender studies and disability studies omit certain perspectives and that feminist disability studies works to include all intersecting and overlapping identities. This includes those who work from analyses that understand sexism, ableism, and so forth, even if one does not identify as belonging to one of these groups. From this theoretical perspective, if one is an able-bodied man doing work in feminist disability studies, it means that he is working not only from analyses of oppression based on

sexism and ableism, but is looking at male and/or able-bodied privilege as well.

Brenda Brueggemann and Alison Kafer both argued for the necessity of intersectional analyses that stem from feminism and how in some ways disability studies unwittingly incorporates feminist theories. Yet in other ways, there are gaping holes in each field.

Brenda Brueggemann: I think there is this way in which disability studies was always a kind of feminist disability studies, but didn't realize that itself...in that earlier some of the moves that we were trying to make about identity, about changing the language, about connecting grassroots activism with also scholarly work was very much like what feminist studies and women studies had done fifteen, ten, fifteen, twenty years before us. But the people doing the work hadn't yet realized that, or made that connection. So, in some ways it was like disability studies was feminist studies all over again...now when I think about feminist disability studies I think that feminist disability studies is the branch area, arena of disability studies that's particularly concerned still with identity, but particularly now with intersectionality...with intersecting identity...with the fact that so you're disabled, but you're also X, Y, and Z...that's thinking...oh...if we, I, say we're thinking about materialist stuff that doesn't quite sound right, because, of course, people with disabilities have always been thinking about their role in the material world. But it is different. And I think also that feminist disability studies is where most of the work around global disability is happening, and is kind of informed and enriched by that... But they are of course in many ways just discovering disability studies and realizing that wow, you know, all this stuff that we thought was old and (passé) is still going on and very interesting in disability...about the body.

Both Brueggemann and Kafer highlight how feminism works to address issues of identity and intersectionality. Brueggemann even comments specifically about how feminist disability studies brings new insights into issues in relation to feminist perspectives on materiality and global issues, and how feminist intersectional and social justice theories inform that scholarly pursuit and analysis within disability studies. As Kafer remarks, while we wish that saying that we do “feminist work,” or do “disability studies work” is enough, it usually is not.

It's interesting, because...I use that term, “feminist disability studies” in my own work. But if I think about defining it, I would like to think that just saying, “feminist studies” would mean the same thing...or even just saying, “disability studies”...even though I know that's not true. But I think such usage would attend to the ways in which different kinds of bodies, minds, practices, and identities...get labeled as normal or abnormal, and how both feminist studies and disability studies examine those histories of representation. Adding feminist to “disability studies” means

always being aware of gender and sexuality...and I would hope race, and class, and nation (...). I've been writing...or rewriting the introduction to this book I am working on. So, there is this piece where I have to talk about this very thing—what is feminist disability studies—and I think what feminist does when you add it to disability studies, or the reason why I would want to place what I do as feminist disability studies...instead of just disability studies...is that I think that there is this real focus on justice and politics and theory and activism. And I know that that is true of disability studies too. I mean I think most people would define disability studies that way as well. But I guess what the difference would be is that...every now and then I read these disability studies texts and they want to dismiss feminism...as if disability is more important or as if because feminism has ignored disability then we should just ignore feminism altogether. But feminism has all these great resources around these very issues about justice and about theory and activism and practice. And although disability studies has been talking about those things, too, I don't know that we have that same kind of academic-activist history that is so tightly wound the way it has been in feminism. Again...it's not always been done well, but people have been working on it, I think.<sup>44</sup>

Currently, each field often lacks critical social justice theories, which fosters oppression. There are specific ways that women/gender/feminist studies can influence and impact disability studies (and vice versa).<sup>45</sup> However, as Kafer points out, feminism has a longer activist and theoretical history from which disability studies benefits. While our end goal in disability studies and feminism studies is to be non-oppressive, each respective field is missing theories and tools necessary for the fight. Therefore, it is critical to maintain an exchange or bridge between disability experiences, women's experiences, and feminist theories.

At least four of the participants argued how one could take virtually any topic, or any women's or disability experience, and inflect it with both feminist and disability studies analyses. This reflects the multifaceted and intersectional quality of feminist disability studies.<sup>46</sup>

Susan Schweik: To start out with, there is no topic in any given women's studies department that could not be inflected by attending to disability. There is no topic in disability studies curriculum that could not be inflected by attending to gender, and, further, by attending to women. And, then, of course attending to all the other things that both topics should, that both fields should attend to: race, class, etc.

Catherine Kudlick: Well, women's experiences, and there would be things that would be unique to womanhood, like childbirth, or issues about abortion, or sterilization...anything around birth, and birthing practices. Things like marriage. You know you could actually take the life course and map it onto women's



experiences, and it might be an organizing principle, where you start with say birth, and go through to death. It could be things like adolescence. You know...things like strictures against who should marry and who shouldn't, matters of sexuality, homosexuality, of course...things related to race as well. But that would have to be brought in with women and gender, and sexuality would...always be part of the conversation.

Susan Wendell: All of them I guess. Yeah.

Adrienne Asch (AA) in discussion with Kristina Knoll (KK):

AA: I just told you. I would not...I don't believe in the category.

KK: Or, how about topics that cross over women studies and dis...

AA: Well, lots, sure, but...I would just infuse feminism into disability studies and women studies and disability into women studies.

KK: In what ways do you see that happening?

AA: Well, every way...I mean pick your topic...Pick whatever it is, whether it is violence, abuse, or socialization, or employment, or family life, or education, or reproduction, or health.

As most of the participants remind us, including Kudlick and Schweik, feminism insists that we attend to many varied overlapping experiences and analyses, and the same is true of feminist disability studies.<sup>47</sup>

Responses to the first interview question tended to start off with either that all experiences having gender, sexuality, disability, and so forth layers of analyses, or participants would list many topics, as mentioned above, that have become central to feminist and disability studies books, research projects, and teaching. Susan Burch begins her response with the reflection that there are many relevant topics, and then starts listing some of them. She then discusses how the limits are boundless, as it is difficult (or impossible) to fragment ourselves into these many categories—which is similar to the critique or concern Asch has with fragmenting our conversations down into smaller and smaller categories based on difference.

Susan Burch: Oh, I think there are lots of topics there that fall very easily and powerfully into a feminist disability studies course...notions of normalcy, independence and dependence. I like to teach on topics like beauty and representation, because I think they're very accessible, and relevant to people's current lived experiences and understanding of our past and present. Power is a great

intersectional topic. I said representation...activism. But also things like sexuality and family dynamics, access. I think there are really no limits between, to the possibilities between the two. Because, at least in my own lived experience, I can't separate out...I do this talk all the time...I can't separate out in my own lived experience and body where I am, for example, a white person...a female...of a certain age, geographic background, ability, disability, political bent, religious affiliation...relational to other people, etc., and so, for me, the micro-history in that...any of those issues would lend toward feminist and disability, and putting them together has, I think, exciting new possibilities....I think one of the things I really like about seeing feminist studies and disability studies coming closer together is that, like I said, my own lived experience shows me, for me at least, I can't separate out the way that the academic in me would like to...in certain ways. It's great to be able to say, "gender studies," because, while it's expansive, there are some boundaries to that; or "race studies." There are boundaries that are more or less recognizable. But that's not how we actually live in the world, in those single lenses. But by adding in, you know, multiple layers or lenses, we actually get closer to lived experience, which is personally important to me as a scholar and advocate. But it also, of course, makes it more difficult to juggle all those possibilities, and we think we have to think more expansively and creatively all the time, as we chase down these ideas.

As poignantly stated by Burch, and as will be discussed later in this chapter regarding concerns of fragmentation, the process of feminist disability studies pursues an ever-emerging process that allows for the overlapping of identities and identity-based theories to emerge and inform one another. Feminist disability studies strives to create an inclusive process of multiple identities and non-essentialism. Feminist disability studies works to critique boundaries around identities, and, hence, makes it hard to define boundaries. Yet, while participants made commented about how this boundless aspect of intersectionality theories stems from feminism, feminism sometimes resists disability studies perspectives. This is why the mosaic of theories and emerging process for managing identity-based politics offered by feminist disability studies is so critical to scholarly contemplation of identity issues, where not only multiple vectors of identities but also various identity-based theories are explored.<sup>48</sup>

At this point, although women studies and feminism may like to believe in and may want to work toward an all-inclusive intersectional analysis, disability, impairment, and health analyses within women studies are nearly always entrenched in the medical model—therefore are sorely lacking disability studies perspectives. It is still uncommon for there to be a general expectation for women studies to attend to disability issues from a disability studies analysis. Disability studies, on the other hand, still being somewhat in its fledgling

stages, tends toward single or perhaps double-oppression dimension analyses and universalizing theories of disability and impairment, and so it frequently neglects how the many potential layers of identity inform disability and impairment experiences, and vice versa. In addition, those who do intersectional work in disability studies tend to be feminists and/or those using feminist theories. Again, the dialectical space of feminist disability studies is critical in addressing these problems.

This does not mean that scholars in the respective fields are not fusing the two fields, or that departments, programs, and the like oppose a combination of the theories that come from the two fields. In fact, some women studies departments quickly added women and disability studies courses, as Georgina Kleege pointed out. There is some resistance within both fields, however, which I discuss in Part II, and there is not yet an expectation that both disability studies and feminist analyses be incorporated into both fields, whereas feminist disability studies does have this expectation. While we are not there yet, it remains important to listen to the points of tension between the two fields that provide new insights and tools for fighting oppression. Tensions often emerge when rigid boundaries around identity and experience that limit certain perspectives and issues from being addressed are challenged by other intersectional identities that cannot conform (e.g. women with disabilities fighting for their rights to be sexual beings and parents; also to fight selective abortion that seeks to eradicate disability, thereby sometimes going against feminist agendas, such as pro-choice). Both fields contribute rich insights that help construct the expansive and elusive area of feminist disability studies.

Feminist disability studies complicates pure social constructionist perspectives of disability, impairment, health, gender, and the body. The challenge to pure or dogmatic social-constructionist perspectives on disability, impairment, and the body often exists in both disability studies and feminist disability studies, but it stems originally from feminist and critical race theories.<sup>49</sup> The move to resist arguing that disability and/or impairment are purely socially constructed refuses to put disability and/or impairment in a strong postmodernist box. Rather, it opens up the possibility to intermingle lived bodily and socially constructed experiences. For example, Licia Carlson points out below, disability and impairment are life experiences that any one of us may have, or will acquire, if we live long enough. Many disability scholars make similar comments that the disability identity is one

identity that anyone could potentially slip in and out of, and calls into question some of the bodily connections to the social and political environment. This also causes critical reflections on the stability of identity from a strong postmodernist and pure social constructionist perspective.

Disability studies pushes feminist theories and questions regarding essentialism to new limits. Much of this work is thoroughly intertwined with both disability studies and feminist studies. Carlson refers to what has been referred to as the “Davis versus Linton” debate among disability studies scholars over trying to define not only the boundaries of the disability identity, but also how this pushes on the boundaries of Other identities. There is a struggle and tension over this as we base so much of our politics on finding a group identity and collective movement from what has been argued as the reality of our socially constructed identities. Both having an identity and not having an identity feels threatening to the movement. Carlson commented on how the disability identity calls a lot of theories about identities into question, especially the very salience of identity:

I think that one question that emerges is really the question of identity and group identification, because...some people talk about disability as a permeable category, as a category, you know, anyone could eventually be a part of, if they aren't already. And while I think that is actually true about gender, and certain postmodern views of gender would view it as sort of equally either permeable or performative...I think that question, with respect to disability and identity is much more salient than it might be, let's say, for race. So, even if you view race as a social construct, there's a sense in which, all ethnic or racial identities aren't available to me, as a person in this particular racialized body and location, whereas I think a question that feminist disability theory is wrestling with is how to define the limits, or the boundaries of disability. Because I think there is tension. On the one hand, there's a sense in which there's this critical interrogation of the category of disability itself, and invoking the social model and wanting to say, or, even dramatically from a postmodern perspective, that impairment itself is constructed. And yet at the same time from the perspective of identity politics and services and oppression, people like Simi Linton want to resist the idea that, “Oh, we are all disabled somehow, and that we can do away with the category.” So, I think, I think that even though feminists have wrestled with that question, in terms of gender, and defining gender, I think it is much more pronounced, and even more murky I think, and politically charged, than it is to sit back and say from purely a kind of gendered perspective, “Well, to what extent is my gender really fixed or not?” And that's an important question, but I think disability adds this new dimension to questions of essentialism and identity. And, then, I guess another issue pushes feminism to define its actual lens of analysis, and ask what place should gender have? Is disability more fundamental in some contexts, as a lens of analysis than gender is or can be? I mean, my concept of feminism, I think, imagines

it as...as an instrument of analysis that includes men and women. I mean, I think, gender sort of broadly speaking. So, I think that in terms of disability studies too, I think there's this concern with looking at not just the exclusion of women from feminist theory, but how to theorize male and female gendered identities with respect to disability. And...and really, again, it really comes back to this question of how to find some sort of ground for similarity or commonality, and also how to address the question of difference. And that tension there, I think, becomes even more extreme...when one thinks about disability in relation to gender...<sup>50</sup>

Feminist disability studies muddies the waters of both women studies and disability studies. From typical feminist intersectionality theories that move away from essentialism of women, gender, and identity, exploring issues of racism, sexism, homophobia, xenophobia, and so forth, to feminist disability studies questions that resist essentialism and universalizing ideas of disability, impairment, and the body, feminist disability studies cannot help but resist boundaries around this movement that depend upon dogmatism and orthodoxy. Yet, while I agree with Carlson that there should not be a set doctrine to feminist disability studies, I argue that there should be some principles or tools that we always use when engaged in politics around our identities, even if such principles or tools are seemingly in conflict at times.

As the responses below reflect, the self-critical and boundless work that we are doing is exciting, due to these tensions around our identities and identity theories. It is invigorating to be engaged in work that fervently pushes us to understand how oppression operates, as it also provides opportunities for social change. This process is what I am arguing largely constitutes the uniqueness of feminist disability studies. Carlson touches upon many of that ideas that I argue, contrary to Carlson, are guiding principles for feminist disability studies:

...So, I think from a historical standpoint there is a lot there. And, then, I think this question of voice, I guess, and membership. I mean as soon as you define a field of study, I think there are issues of power and authority, and sort of, "Who defines it? Who is a member? Who is included? Who is excluded?" And, I would hope that as a field it continues to emerge with this self-reflexive, self-reflective posture. I think it's a wonderful field that can be so rife with contestations, and with conflict. I think it's not, it's not going to be an area that has a doctrine or a theory, or even a set of principles, whether they are methodological, or...so in that sense I think the value of it is that it emerges as something that already is in flux and agonistic in a way, and I think that's a virtue. I don't see that as a downfall.<sup>51</sup>

In many ways, the reluctance or resistance to defining feminist disability studies gets precisely at the heart of feminist disability studies. As Carlson discusses, and I agree,

feminist disability studies is concerned with who is not present and the dogmatism that polices identity-related boundaries. This rich, albeit “rife with contestations,” work makes feminist disability studies into an emerging and “in flux” process. However, I would argue that these critical issues offer guiding principles for a feminist disability studies process and that the contestations and conflicts have the potential to contribute to the mosaic of theories and emerging process for doing identity-based politics.

So far we have seen that most of the participants recognize various ways in which the two fields overlap and create a unique space of “feminist disability studies.” At the same time, however, the feminist theories that inform our awareness of privilege, oppression, power, and intersectionality make us aware of, and sensitive to, the issues of essentializing an identity. Not to explore the ways in which other lived experiences of privilege and oppression impact the disability or female experience is dangerous and oppressive. Kim raised nationality as an additional layer of analysis:

I think I looked for one thing, and disability studies didn't have that, and women's studies didn't have that. And the thing that I was looking for is to understand disabled women's experience in Korea. So, that was my start, and then I came here and I had to add another layer of nationality, because I realized that I can't talk about Korean disabled women without thinking about the context of how it is going to be understood in relation to imperialism, racism. So, I actually added one more complicated identity by coming to [the] United States.<sup>52</sup>

Feminist theories of privilege, oppression, and intersectionality challenge feminist disability studies to push beyond just a dual lens of women or gender and disability and remind us that centering marginalized voices must remain an important anti-oppression tool. Doing so provides additional spaces within feminist disability studies to address such issues as nation, imperialism, and racism along with disability and gender.

The growing considerations of impairment and chronic health issues within disability studies, which are opening the door to potentially conflicting ideas of disability, impairment, and the body also resist the distillation of identity to one type of identity formation, upon which the pure social constructionist perspective of disability studies would insist. Feminist and disability studies theories create a uniquely contested space that is central to resistance to dogmatism and provide a constant inquiry into who is not present at our feminist disability studies table.

Most of the participants gave detailed statements on how they viewed women studies

and disability studies as overlapping, nearly always highlighting critical topics such as fusing a feminist intersectional analyses and anti-essentialism with a social-cultural understanding of disability. A few, however, expressed a reluctance or resistance to identifying a feminist disability studies area of study. Adrienne Asch gave a direct and thought-provoking response to being asked to define feminist disability studies:

Kristina Knoll: Do you think you could say more about the fragmentation, and the concern that you have with the fragmentation?<sup>53</sup>

Adrienne Asch: Well, I don't like identity politics, and never have. Even though I have been involved in feminism. I mean I see a value. I always have seen a value in politicalizing. (...) I see a reason for a disability rights movement. I see a reason for a feminist movement. I see a reason for a civil rights movement. Any oppressed group...or a gay rights movement. But I believe everybody ought to join all of those movements. Oppression is oppression, and we should be fighting to end it. I don't...I'm not interested in celebrating a status, or not celebrating a status. I am just interested in living my life. I don't have to have a banner that has to say, "disability is delightful." I don't have to have a banner that says, "being female is fabulous." I'm female. I'm disabled. Don't get in my way. Don't bother me. Don't deny me opportunity. That's my basic political view. So, when I read things that I don't understand. Say...I don't know anything about you. I just met you. I know that you are female. I know you have some kind of disability, but I don't know what it is. I'll get to know you by talking to you, and when it is important for you to say how old you are, or where you live, or where you grew up, or what your disability is...when it comes up in the conversation. It will come up. I don't have to have a list of your categorical memberships to have a conversation with you. I'm not interested in your categorical memberships. I'm interested in what you think about, and what you care about, and what you want. And if what you think about, and what you work on is affected by some categorical membership, then you'll tell me. What are you thinking?

KK: I completely agree. However, I also feel that sometimes the oppression is so intense that sometimes...well, maybe conversation takes a long time to get to know someone, and that is perfectly fine, but I think sometimes bringing up the conversations help bring people to feel more comfortable perhaps to speak of their experiences with privilege and oppression.

AA: Well, maybe. I mean...It depends. I mean it depends on what you are talking about, I suppose.

KK: Yeah, and each person.

AA: ...one of the reasons I have never especially liked identity politics is that I am a lot less interested in difference than I am in commonality. I'm a lot more interested in what people share, than what they don't share. And I mostly think that the

problems in human relations come because people don't see themselves as the same. They see...take some superficial thing...So, the problem with all the fragmentation is that it makes too much of difference, and it says that one particular status...If you are interested in one characteristic, then you could spend your life focusing on it, but I think that misses all the other characteristics that people have. So, I find the notion of feminist...even though, I did, you know I edited a book sixteen, seventeen...eighteen years ago, whatever it was, called "Women with Disabilities,"...But I came to doing it in a very sort of tentative way, sort of like, maybe if I do it I'll figure out if there is some particular thing to say. But it was not obvious to me until I did the work on the book that women with disabilities was a relevant category. I was a woman. I was disabled. I had things in common with women. I had things in common with disabilities. I had things in common with people who are men...

...

KK: For me, if you don't mind me saying, my experience of the book offered many missing pieces from so much of the literature that I have been reading in women studies and elsewhere, and those missing pieces are so critical, personally.

AA: Well, that's wonderful.

KK: And...I guess that's the problem. Identity politics is, if there isn't representation, then there is the need to push, to push the identities forward, to bring the voices up, if they are not already present.

The concern that Asch raises in defining feminist disability studies is that it is going to contribute to what she perceives as the negative aspects of identity politics and that insisting on a concrete definition will result in a breakdown in communication and collective action against oppressions. She may be concerned with the issue, as well, of only recapitulating the oppression by focusing on such categorical memberships. When Asch says, "I don't have to have a list of your categorical memberships to have a conversation with you," it is central to her concern about identities and, therefore, identity politics. There is a concern that identities create boundaries around our individual and group relationships and leave room for sharing how and the degree to which these identity categories are relevant to individuals. A few disability studies scholars argue that we look to commonality in order to unite, but I argue this is also what can threaten to bring us back around to universalizing concepts, even though such exclusion is precisely what we are trying to avoid.

Interestingly enough, Rosemarie Garland-Thomson said in an interview with Andrew W. Potok that "identity is a little bit like nationalism" and "a very coercive category, leading to political fragmentation and division" (Siebers, 2006, p. 13). Asch and Garland-Thomson appear to be concerned with the boundaries and limitations that can come with identities. I



think that they are concerned with “identity” from a postmodern (and sometimes strong postmodern) identity studies position. This position tends to cause worry that these theories can threaten to invalidate identity and identity politics. I argue that the fear that dogmatic theories can be used to police identity boundaries will keep individuals from sharing how potentially new and/or overlapping identities are exposing more systems of privilege and oppression.

Burch also expresses concerns over the boundaries around identities by discussing the instability of identity, which some disability theories display:

As somebody who is a self-proclaimed feminist disability studies scholar, I am reluctant to try and nail down a definition, which is not intended as an effort to avoid the question. But in deep honor and humility of the complexity of the evolution of feminist thinking and disability studies thinking, and, as you are alluding to, the combination and enhancement that happens when these two fields come together. So, the historian in me would start wanting to assert the historical changes and continuity over time and the social, political, economic, and cultural constructions that identify bodies in specific ways and the meaning that comes from that, which I think is part of the story. But I am recognizing that I am mostly a historian by training, but as a scholar and activist who crosses all sort of disciplinary and other boundaries, a recognition that there are many ways to define that, and that is part of the definition itself. I see it very much as an interdisciplinary description and assessment as bodies and relationships about bodies and experiences of bodies, and when I say bodies I don't merely mean corporal bodies...all of it...intellectual, cognitive, emotional, physical. And at the same time a very much new understanding of all of these aspects. So, that in ways that perhaps (the department) can articulate what feminism, or at least feminist theory is, in a way that feels somewhat comfortable or confident. I don't feel I'm at a place personally yet, and I'm not sure the field is at a place yet to give a concrete description of feminist disability studies. To add to that really briefly though, I think part of what...what I love about it, and which excites me...are descriptions like Lenny Davis's critique of race and gender and disability, and pointing out...you know...(in this) dismodernist discourse the instability of all of these categories, and that disability really offers exciting new ideas about the instability of identity and that lends so nicely and so fruitfully to what feminist studies has come to as well. And, so, I kind of delight in the prospect of never being able to really give a solid definition to it.

Susan Burch's response highlights what I saw develop out of my research, namely, that there is a beautiful elusiveness to this field of inquiry “feminist disability studies.” I argue that this elusiveness reflects how feminist disability studies is not only emergent, but also a continual process that employs a mosaic of theories and tools, even ones that seem to conflict at times, in order to expose the politics that are disguised in the symbols of our identities. We come to

know systems of power, privilege, and oppression by analyzing how our social and physical environments are structured for certain people. Here is the crux of the dilemma: finding commonality in sameness (or impaired or non-normal, according to Davis) or commonality through difference and allowing for marginalized and overlapping identities to emerge. If people involved in the social justice work find the necessary insights into the systems of power that oppress them (by exploring these theories), and have the means and determination to work together, opportunities for coalitions to find liberation are made possible.

We are able to share phenomena that are represented through our identities by sharing our experiences, and providing safe spaces to hear one another.<sup>54</sup> Therefore, it becomes imperative to prioritize experiences and theories that emerge from our identities. This concern over prioritizing marginalized voices and experiences was shared by participants as well when reflecting on feminist disability studies. Susan Wendell expressed this nicely:

Well...it is the study of women's experiences of being (ill) and, or disabled, and the implications of all of those experiences, what we have learned from them, on the one hand. On the other hand, it's not just the study of women's experiences, but rather the process of taking a feminist perspective on all the experiences of everyone who has a disability, or (impairment). What makes it disability studies, and not just the study of particular disabled people, is that it is a very high priority on looking on the experiences of the people themselves, who are living with the disability, rather than the perspective...say the medical practitioner's or for rehabilitation practitioners, which would be quite common. Now both rehabilitation practitioners and some medical practitioners are involved in disability studies. It doesn't preclude them, but it's a matter of perspective and how much interest you take in how people are experiencing (having) disability. I don't think that it's necessary to have a social constructionist perspective...for it to be disability studies. I mean that I would disagree with other...probably with other people who participate in disability studies. I think...I'm interested in the experiences of people who are politically naïve in that sense, or people who feel that analysis does not apply to them, as well as the experience of those who aren't quite politically sophisticated about their disability...

Wendell's argument challenges and broadens disability studies and feminist disability studies perspectives with regard to issues of impairment and chronic illness,<sup>55</sup> which do not fit neatly into a pure social constructionist perspective (e.g. as some people living with impairments or chronic illness argue that "no amount of activism" will remove the barrier that they feel as being within their body).<sup>56</sup> To resist a strong postmodernist and pure social constructionist perspective, Wendell provides a tension and space that allows new and Other experiences and identities to be explored, shaped, and challenged. While she notes the importance of

experience, and I agree that we want to provide lots of space for those who are not familiar with feminism and disability studies to explore their experiences within our coalitions, a social constructionist perspective is an important part of the disability studies and feminist disability studies process, even though it is not the end of the story and may have some of its own flaws. Social constructionist perspectives typically emerge when looking at experiences of privilege and oppression, revealing experiences of marginalization.

Eunjung Kim also argues that feminist disability studies concentrates on the experiences of women with disabilities, but she tempers this remark by adding that she does not want to prioritize certain voices over others and that the theories of marginalization and oppression that reveal systems of power are important. This includes Kim's highlighting of the importance of focusing on marginalization (and the political systems that construct it), shifting away from the focus on political boundaries around identities:

Eunjung Kim: I would define it in a way that feminist disability studies focuses on the status of disabled women in a society. I might define disabled women's issues through shared experiences among disabled women and their knowledge about the society that marginalizes them. Feminist disability studies starts from very specific issues of disabled women, but there should be a theorization that can be shared with the larger disability community, with non-disabled women's community, and with the society in general. And also it analyzes the general structures that impact non-disabled people, men and women, and disabled people as well. So, feminist disability studies analyzes the impact of gender and disability together that creates certain group as dominant, and how the assumptions about gender, sex, and disability affect categories of different bodies.

Kristina Knoll: I just want to make sure that I am getting this correct. You said something to the fact that the issues arise from the women with disabilities, or the questions and things that need to be addressed. So, it comes from the group of people who identify as women with disabilities?

EK: Yes...I'm not saying disabled women are the only one[s] who can point out the problems of the systems. I don't want to prioritize certain voice[s] over the other, because I don't think that experience comes from a certain condition of the body. But I think it is more important to have consciousness about the existence of discrimination and oppression of certain people. But without disabled women's perspectives, it is hard to recognize how gender and disability interact in day-to-day situations. So, by disabled women, I'm not really constraining that as a group with a clear boundary. Disability, here, exists as a flexible embodiment connected with marginalization. Disability-identified women might be a better term.<sup>57</sup>

Kim brings her analysis of feminist disability studies back around to the critical point of bringing in the experiences of women who are disabled, yet doing so with flexible boundaries around identity and those who can participate in the conversations. She highlights both a “consciousness” about discrimination, which I would argue is an understanding of the politics of and between our identities. We do need the experiences of those who are marginalized in order to reveal the politics. The flexibility of identity is a theme that emerges among many of the participants. For most of the participants, considerations of overlapping or intersecting identities became more and more prevalent among participant responses as the interviews progressed. What remains central to the respondents is that an individual working in feminist disability studies is familiar with and uses both critical feminist and disability studies theories, and although experiences from these groups of people are pertinent, this does not preclude perspectives from those who do not have those lived experiences from being a part of the group process.<sup>58</sup>

As Asch and Garland-Thomson, and most, if not all of the participants, seem to recognize, the political relevance of naming one’s experiences, revealing systems of privilege and oppression, and the political implications of identities being imposed and claimed in order to work toward social and political transformation is central to the feminist disability studies process. For example, following the end of Asch’s quote, she discussed how Judy Heuman pointed out to Letty Cottin that not all women are sexually harassed, and, more or less, the issue regarding how women who have physical and visible disabilities is rarely treated as sexual. The critical issue of sexual harassment does not apply to “all women.”<sup>59</sup>

Naming one’s experiences that may be contradictory to a coalition’s social justice pursuits may create important insights necessary for our continued social justice work in fighting oppression. I discussed with her how the book she co-edited with Michelle Fine, *Women with Disabilities* (1988), impacted me, and although I did not share this with Asch, I have also had students tell me that my including articles from that book in classes changed their lives and helped bring students together to fight injustices. Speaking up and presenting new perspectives, be it one-on-one or through a publication, can create a ripple effect of social change.

Similarly, Garland-Thomson, in a “postscript” to her article, “Integrating Disability, Transforming Feminist Theory” in the anthology *Feminist Disability Studies* (2011), pointed

out that writing and talking about feminist disability studies made it more real. In conclusion, the clearest “proof” we have of the reality and necessity of feminist disability studies is the social justice and liberation it provides. Our experiences, and the theories and language that we develop, are a part of the process that has the potential to change lives, as Garland-Thomson noted (Garland-Thomson, 2011, pp. 43-44). What this comes down to is the concern over whether or not the identification of feminist disability studies actually creates liberatory practices. There are countless affirmations that it does, and, in addition, I maintain that the feminist disability studies process that resists dogmatic practices by employing a continual piecing together of many and sometimes contradictory identities and identity-based theories remains central. The point is not whether one theory is right, or more right than another, but whether or not any or all of these theories provide critical information about how privilege, power, and oppression operate. Because our goal is social justice, we simply want to know the systems and structures that oppress so that we can better address them.

As the above interviews suggest, exploring experiences and identities helps reveal critical tensions (e.g. the politics) of activist and academic pursuits, which challenges and strengthens our work.<sup>60</sup> We find activism in the grassroots work that fosters a connection to emergent and marginalized voices (who are likely unfamiliar with the identity politics jargon and processes), as well as in the politics that are transformed.

A few of the participants remind us in their responses to the first interview questions that we must, therefore, keep our theories intertwined with activism. In reflecting on defining feminist disability studies, Licia Carlson, Alison Kafer, Catherine Kudlick, and Brenda Brueggemann all commented on the necessity of tying feminist disability studies scholarly work to grassroots activism. Licia Carlson hits upon what both Kim and Wendell commented on, the necessity of the embodied experience to inform the theory. To inform our interdisciplinary work we need to remain connected to lived experiences, what happens in the daily lives, in the homes, and on the streets of people with disabilities, which keeps us from a static, essentialistic doctrine about our lived experiences. We need to remain connected to our final goal: social justice.

Licia Carlson: The term “studies” is somewhat broad, and, so, I guess one question I would have, or one thing I would say to someone who is completely unfamiliar with it would be that there is this kind of theoretical, academic perspective, and, then,

there's the political, activist side of it. And that, in terms of methodology, I would say, at least in my view, feminist disability studies is, and should be committed to praxis, to bridging those two, and that it isn't exclusively theoretical. It's not exclusively an academic endeavor, and that if it were it would be somehow missing one of the vital parts of that...field, really. And I think to tell a kind of history of feminist disability studies would reveal the fact that a lot of it really has its roots in a kind of grassroots movement, as opposed to some sort of academic, scholarly term. So, again, at least, with respect to feminist philosophers, it's really been a call and a challenge that's come from women with disabilities themselves saying, "This is something that we've ignored in feminist theory." So, I think feminist disability studies, from a methodological standpoint it involves a commitment to theorizing the intersection between gender and disability, both as concepts and as embodied identities; and, then, also attending to the relationship between theory and practice, and politics, and activism. And, then, the other thing that I think is maybe unique about it, or at least promising, is that there is [a] kind of self-critical mode, or dimension of it that I find exciting because you have these two terms that are interrogating each other.

Both Alison Kafer and Brenda Brueggemann also discuss the significant focus of feminism and, thus, also feminist disability studies on activism, social justice and bridging theory and activism.<sup>61</sup> There was discussion about how feminism impacted disability studies. Perhaps much of our disability studies work has always been more feminist than we realized. The participant responses give way to the necessity of intellectual and activist spaces that are uniquely contested and uniquely feminist disability studies, with a seemingly ever-expanding topical field. Feminist disability studies is not only the rich theoretical complexities and tensions between women studies and disability studies, but it is also about who we are and how and why we come together to collaborate on academic and traditional activist projects. In doing identity-based politics, and, therefore, engaging with the contested spaces of identity politics, we are a part of a process that continually reveals opportunities for knowledge production and social justice, a point further explored in Part II. I argue that this process as a whole (which includes our working across identity or minority groups) is inherently activist.

Catherine Kudlick expressed the excitement of the challenge of working in these contested political spaces of identities, as feminist disability studies seeks to do:

I think people should open doors in scholarship, rather than nail them shut I think a feminist consciousness is really important. I think a disability consciousness is really important. You know...a queer consciousness is really important. All those things, and racial ones. I don't mean to (like) just go through the list...to be politically correct, but I think each thing brings you something. Every thinking person should be pausing to say, "What does this give me in this moment?" And to be able to be

surprised, or to be...you know, mildly corrected, or ready to say, "Wait. You didn't think about that." Rather than trying to head off all the passes and put up the barricades. I'm always kind of excited, a little embarrassed of course, when I don't get it right, but I'm always a little bit excited that somebody has challenged me and how I think about something. I mean that is what it is all about.<sup>62</sup>

The majority of participants underscored the necessity of such conflicted spaces, a politics that pushes us to explore and sharpen our theories and activism around identities and identity-based theories. The participants discussed the politics between such identities and identity-based theories, such as: to identify or not identify feminist disability studies as a field of study; to incorporate solely a social-constructionist perspective of disability versus also including illness and impairment perspectives that challenge the strict social-constructionist perspectives within disability studies; to be an able-bodied ally versus a person with disability in the field; to be an activist versus an academic; and so forth. The majority of participants discussed how feminist disability studies also includes the necessity to work on creating tools to make these contested spaces more comfortable to participate in, a disability studies repertoire from which to work, and, critically, to use the history and analyses of feminism that make marginalized voices and intersectional inquiries foundational to every project.

Although I agree with the majority of the participant reflections that there is or should be a feminist disability studies area of study, responses such as Burch's, Wendell's, and Asch's provide part of the necessary tension that helps explore the dynamics of identity politics and propel action in our theories and our working together in order to facilitate social justice. I argue that there is truth and purpose to these arguments and concerns. Disability studies and women studies should take up each other's goals (as well as other identity studies). Yet, they do not always take up each other's perspectives and concerns, and sometimes they refuse or resist, giving heed to the necessity of feminist disability studies communities and spaces to do this work. While feminist disability studies spans narratives of the experiences of women with disabilities, a mosaic of feminist and disability studies theories is developing a new political process for exploring identities, identity politics, and identity-based politics.

Within this research about feminist disability studies emerges a beautiful diversity of thoughts and actions that give heed to tensions that challenge us to think deeper, get more

involved, and work across identity boundaries and identity-based theories (e.g. identity-based politics). The range of responses by the participants in regards to both their own identities and their thoughts about identity-based theories revealed that tensions between identities and identity-based theories provide insight into the social and political facts that bind. It is a political process, and thus transformable—thereby, again, a potential support to our end goal: social justice.



## **Part II: Crippling Feminist Activism & Identity-Based Politics**

Several themes emerged in reviewing the interview transcripts, all of which highlight concerns over the following: identity issues (including the legitimacy of certain identities), our political goals, and *how* we can and should work across identity groups (e.g. identity-based politics). As soon as we start engaging with one another in the politics of our identities, opportunities emerge for working together toward social justice. Part II addresses how the overlapping, partial, and sometimes contradicting theories of feminism and disability studies that are outlined in Part I inform and help propel the feminist disability studies area of study.<sup>63</sup>

In particular, I argue that engaging in identity-based politics provides opportunities for various forms of action toward social justice (e.g. activism). While the terms “activism” and “social justice” are used in a variety of ways by many people and for different purposes (possibly even oppressive), I distinguish feminist disability studies forms of “activism” and “social justice” as fighting identity or minority based oppression.<sup>64</sup> Activism emphasizes the many ways that one may take action against oppression, and social justice is when liberation from certain oppressive actions occurs.

However, this process and the ways in which we take action also has the potential to be imperfect, sometimes even destructive. This is not a disclaimer, but rather a recognition of the potential consequences of using identity-based politics as a route to social justice. The emotional strife that can come from engaging in identity politics and identity-based politics, in addition, is a critical element, which my research does not cover in depth at this time. We need to recognize, however, that when oppression within social justice action happens, there can be an opportunity to address it, which I outline in the following chapters. This process, like our bodies, is often sticky, messy, emotional, partial, growing, and unconventional. As discussed in Part I, the politics and power systems we discover between our bodies and identities help us discover how to not only maneuver through this tricky and highly personal terrain, but how to change it.

As I and a few of the participants point out, we must guard against the ways in which we might simultaneously oppress another group of people while pursuing particular social

justice goals. Yet, the junctures where tensions and politics arise between identities help us discover the inner-workings of the politics and systems of power, privilege, and oppression. This will include: finding solidarity through sameness (e.g. all impaired, non-normal, and interdependent) versus difference (e.g. only some of us are socially situated as disabled and experiencing ableism) (Chapter 4); the legitimacy and rights of a disabled activist and scholar versus a non-disabled ally within the field (Chapter 4); the importance of traditional activism in comparison to social justice research and scholarship (Chapter 5); and arguing for risking ostracization by speaking up against oppression, but also making identity-based politics spaces feel more welcoming and accommodating for speaking up (Chapter 6). As I will show, such moments provide an instance that can help us refine our social justice tools so that we work better together against oppression.

After sorting through my interview data, I realized that there was too much critical overlap between two of the themes I had used in my sorting process: discussions around “identity and identity politics” and participant views of themselves as a “researcher, activist, and/or teacher.” While all of the interview questions provided some correlating reflections by participants, there were two, in particular, that triggered reflections that further informed my argument that identity-based politics provides opportunities for social justice and activism:

*Interview Question #2: Would you call yourself a feminist disability studies scholar and/or activist?*

*Interview Question #5: What are some of the challenges of being a feminist and/or disability studies scholar and/or activist?*

What emerged from the responses to these questions is a major theme of this study: that activism and identity politics are inseparable and that how the politics that create and sustain minority identities is a powerful social process—a process that can propel action. In contemplating their identities, all of the participants affirmed that social justice was a critical focal point. Therefore, an interesting dynamic that emerged was a passion for social justice and acting towards it, yet there was also a questioning and trying to define or break down the boundaries around both identities and activism and their place (or identities) within these debates. As Gwyn Kirk and Margo Okazawa-Rey write, “Politics is about power: What is it? Who has it? How is it used? Who does it benefit and who is disadvantaged?” (Kirk, 2001, p.

533). There is a direct connection between theorizing about who we are (e.g. our identities), and about who does and does not have power and privilege, and these theories are the first catalyst toward change. Kirk and Okazawa-Rey also write, "...doing something about an issue or a problem requires us to have a theory, an explanation, of what it is. The theory we create directly shapes what we think ought to be done about it. Thus *how* we theorize is a key first step in creating change" (Ibid, pp. 534-535).

Theorizing about ourselves and each other, and our intersecting forms of privilege and oppression, was heavily intertwined with the discussions about activism during my interviews. Thinking about, theorizing about, and perhaps even arguing about identities and intersecting forms of privilege and oppression with colleagues is the first step in developing an activist process. For example, question two of my interview questions revealed valuable tension between how the participants identified themselves and how they perceive activism (and their role, or lack of participation as an activist).

Here is a classic example of how an interviewer can intend one meaning, based on the way that a question is posed. I had tried to be all-inclusive with the terminologies of "scholar and/or activist"—but without any intention for that to be the focus. I was interested in whether or not participants would identify as being connected to "feminist disability studies." Instead, however, most of the participants spent more time on whether or not they would call themselves an activist—and why, or why not. I wanted to interview people who worked both inside and outside of academia, and, therefore, tried to shape my questions in such a way that recognized people both inside and outside of the ivory tower. Ultimately, all of those who participated work within higher education, and the discussions that emerged about being in women studies and/or disability studies, and whether or not one would consider oneself an activist, became one of the most unexpected and fruitful topics to emerge from the interview discussions. This demonstrates that the context and ways in which they work are a critical dimension for how the participants identified themselves.

An attempt to separate out the identity politics from the activism completely would be untrue and invalidating to both identity-based politics and activism. When discussing identity and identity politics, most of the participants often reflected upon how so much of their identity rests on what they do, and how they view themselves is wrapped up in creating social justice by resisting oppression, creating access, and/or being allies. The roots of

identity politics of every group stem from some form of social unrest that manifests as social justice. As Linda Martín Alcoff and Satya P. Mohanty argue,

Historically, identity politics has had both an activist and an academic existence. Activists involved in successful social movements, such as the civil rights movement and the women's movement, who self-consciously invoked the concept of identity in their struggles for social justice held at least the following two beliefs: (1) that identities are often resources of knowledge especially relevant for social change, and that; (2) oppressed groups need to be at the forefront of their own liberation. In viewing their politics as "identity politics," activists involved in these movements were trying to sum up—and deepen—the lessons they had learned from the oppressed. Crucially, these successful social movements were led, never exclusively but primarily, by the oppressed themselves. (Alcoff, 2006, p. 2)

If one is grappling with an identity concept related to a group that is socially situated as oppressed, then even the mere understanding and dissemination of such ideas helps create social justice and is thereby one inherent part of activism. Take for example, the story that Asch shared about Judy Heuman speaking up about the issue of sexual harassment and how many women with disabilities simply want to be seen and treated as sexual. Such insights have triggered multiple publications and paper presentation at conferences that grapple with, and claim sexual identities of people with disabilities.<sup>65</sup>

Participant responses revealed complex and sometimes problematic relationships with definitions of identities. There are long and oppressive histories behind labels linked to race, class, sexuality, disability, nationality, religion, and so forth. In addition, as discussed in Part I, essentializing tendencies within minority group movements that resist these oppressive labels have at times in turn also oppressed people within their own liberation movements. The conflicted responses by the participants over interview questions number two and six reflects this keen awareness of the power of labels and identities.

*Interview Question #6: How do you identify yourself (socially, culturally, etc.) and how does this influence your work?*

Multiple topics or issues emerged from the participant responses to these questions about how one does or does not identify, such as participants' resisting and/or embracing various identities related to race, class, gender, nationality, disability, and so forth, and resisting and/or embracing definitions and identities around impairment and disability. Some of the participants take more of a "dismodernist approach" when looking at identities and highlight commonality over difference, thereby imploding value systems governing bodily difference

by making us all the same. Other participant responses, on the other hand, follow more of a “Linton perspective,” where only people who experience disability oppression are disabled, and disability is thus a qualified identity or minority group that has boundaries around who belongs. As discussed in Part I, both approaches, though seemingly at odds with one another, demonstrate how our labels, and values around labels, are socially constructed, and that objective “truths” around race, sexuality, disability, and so forth are thus not bound to the materiality of our bodies.

An additional identity issue that arose among a few of the participants is just how able and active does one have to be to be an activist. What is the role of ableism and internalized ableism in some of our experiences within feminist communities? For example, can one be sick or impaired and be an activist? Who qualifies as an activist? These are some of the critical activist issues that came up for participants when thinking about how they identify themselves in relationship to debates around identity, disability and impairment. I argue that it is necessary to embrace this contradiction in our identity politics movements because both have the potential to propel us toward greater social justice. This clear resistance to identifying or not identifying with a particular cultural label is found across multiple minority groups as a strategy to resist oppression.

Similarly, a few of the participants passively or actively resisted being categorized according to race, class, disability, sexuality, and so forth, and would even say to identify them just by their name. There is a desire and need at times to disempower labels by empowering individual identification, thereby disavowing group identity labels. For groups of people who are angry about being called “that word,” or treated in accordance to a specific category, it makes sense that part of the movement of resistance is toward complicating or dissolving such labels (e.g. pathologies for many). In the participant quotes below, some do not want to even “give a nod” to any identity category because this can just reaffirm the notion that the category, and the potential oppression, is valid.

Can any single identity be static, objectively “real” and unchanging, when each person holds so many different experiences of privilege and oppression (and many intersecting identities) that constantly shift? The static, unchanging perspective of identity is explored by both questioning the socially constructed nature of singular identities and questioning theories that do not take into account intersectional analyses. Feminist

intersectional analyses help reveal that these socially constructed identities are often highly dependent on other forms of privilege and oppression. So much slippage exists even within each minority group identity. For example, even within just the disability category, there is an entire spectrum, ranging from able-bodied, to temporarily able-bodied, to passing, to impaired, to sick, to numerous other forms of disabilities and impairments. This begs the question: what are the potential implications of taking on the label and role as an “able-bodied ally”? The point is that power plays an important role in these labels, and in identity politics. The label and the value given to that label by the person with more power in any given situation can (e.g. institutional, individual, and symbolic), for example, mean the difference between a graduate studies program admitting a person with a disability versus a non-disabled person. Engaging in these conflicted discussions and roles all play a part in resisting oppression, and are thus a part of activism.

Due to the attention given to feminist intersectional analyses, along with the broad foundation of bridging activism and theory, and the awareness of a category that has had limited exposure in most identity studies (i.e. disability studies), and the fundamental challenge to bodily differences and limitations (via arguments such as Davis’ dismodernism), feminist disability studies’ theories and spaces provide perhaps one of the best locations thus far for countering oppression. The identity politics are so multidimensional and conflicted that the activism that comes from there to fight oppression is empowering. At the same time, however, as somewhat of a late-bloomer within identity politics and identity-based movements, feminist disability studies and disability studies also have a lot of catching up to do in order to engage disability studies ideas with various feminist intersectional identities and theories.

#### Chapter 4: Identity Politics: Commonality & Difference

Two participants struggled with the goals of diffusing oppression by finding commonality through impairment or non-normalcy (e.g. dismodernism) versus difference. There are some solid arguments for how focusing on the differences only reinforces the oppression by reifying the boundaries between disability and ability. Adrienne Asch spoke with me poignantly regarding this issue, and our discussion became one of the critical counterpoints in my thoughts as I worked through this topic on feminist disability studies and identity politics. To review a section of our discussion, preceded by Asch's reluctance to claim "feminist disability studies," she states that "we divide ourselves into more and more smaller categories to our detriment."<sup>66</sup> She added:

Well, I don't like identity politics, and never have. Even though I have been involved in feminism. I mean I see a value. I always have seen a value in politicalizing....Oppression is oppression, and we should be fighting to end it...I mean one of the reasons I have never especially liked identity politics is that I am a lot less interested in difference than I am in commonality....And I mostly think that the problems in human relations come because people don't see themselves as the same.

Adrienne Asch was very direct about topics regarding identity politics. Yes, "oppression is oppression," as Adrienne said, and I agree to some extent with her as well that, "problems in human relations come because people don't see themselves as the same." There is truth to Lennard Davis's argument (Davis, 2002)—in that if we are all viewed as non-normal and imperfect, we could not draw a line between the able-bodied and the disabled. We would also have common ground in pursuit of creating access for all, if we are all impaired and needing adaptations to our physical and social environments. "Common ground" is a powerful tool for breaking down oppression because all are invested in its demise. Susan Burch made a similar statement:

...community has always been really important to me, and so from very specific interactions to sort of a broad range of fortuitous relationships and experiences has taught me—whether or not I have or identify as having a disability—[that] I am a member of the disability community. In the same ways I want to see everyone, to the extent that they are willing and able, to join the feminist community, and claim that as part of who we are and what we can do in this world. I see that in exactly the same way I do...embracing disability studies and activism does. The quicker we start dismissing the boundaries that dis-empower us, the sooner we will get to a better

place.<sup>67</sup>

There is truth in the notion that bringing people together through commonality is fruitful, but I think that to get to an understanding of commonality, we first have to work through how we are falsely constructed as different, as discussed in Part I. This tension between claiming difference and claiming commonality already exists among feminist disability studies colleagues, who believe that disability is true and definable in how we are socially constructed and treated, but it is also a highly unstable category that could potentially apply to anyone at any point. Disability and disability studies are pushing feminism's embodied concepts. Licia Carlson grappled with this complex issue in our discussion as well:

Licia Carlson: Yeah, I think that being self-critical is asking, "What does it mean when we define feminist disability studies, in terms of primarily, let's say physical disability, or, for example, the focus on embodiment?" I think that one of the key concepts in feminist disability studies is the body, and what do we make of the body, and abnormal bodies, and all of that? But I think that to focus purely on embodiment and the body leaves out a whole other dimension of disabilities. There are concerns that are really distinct from lived experience of bodies, at least in the ways that it's been theorized, or representations of bodies. So, not that I think that it can be divorced from that, or that we can talk about disembodied disabilities, or persons with disabilities. But I think that the theoretical tools are there to also be consistently self-critical about who may already be excluded in this field, and that...I think that is promising, because I think that as long as that is at the forefront, I think there's hope that there will be, that it will continue to evolve as more inclusive.

Kristina Knoll: It sounds like you are talking about universalization, and...

LC: Essentialism, and some of those...challenges. And that's another thing...I would say about it...that...I think that disability raises unique challenges to feminist theory, and to feminist practice, and so it's not just kind of a new group, or new lens to add to the mix. I mean I think there are really fundamentally different dimensions that emerge, when you take disability into consideration, and thinking about feminism. ...I think that one question that emerges is really the question of identity and group identification, because, I mean I think...some people talk about disability as a permeable category, as a category, you know, anyone could eventually be a part of, if they aren't already....I think that question, with respect to disability and identity is much more salient than it might be, let's say, for race<sup>68</sup>...but I think disability adds this new dimension to questions of essentialism and identity....And...and really, again, it really comes back to this question of how to find some sort of ground for similarity or commonality, and also how to address the question of difference. And that tension there...There is a part of me that thinks that disability as a category is even more unstable, I think, in certain ways than gender or race, potentially; and that there's this really strange sort of paradox where from a political standpoint, I think,



there's this sort of continued movement to undermine it as a category in certain ways, in the terms of the ways it has been an oppressive category, and yet at the same time to value it and to develop kind of positive disability culture, disabled identity. And I guess there is something similar, if you look historically, in terms of defining women, and that tension there as well. But I think the nature of the definitions in disability; because it is such a heterogeneous category, leave even more room for that tension to emerge in different ways.<sup>69</sup>

Licia Carlson very succinctly summarized the issues of disability and impairment, including touching upon Linton's perspective, the richness in the struggle to try to find boundaries around impairment and disability and the critical insight that feminism brings to the discussion. As Carlson points out, feminism continually asks us who is present, and who is not present in this conversation. This reflects back upon our need to recognize difference, and intersecting forms of privilege and oppression. In order not to perpetuate old systems, we must be aware of those who are not present in our conversations and seek to bring in those voices, and provide means to support them.<sup>70</sup>

Lennard Davis recognizes that this is a long process, that we still need disability activism, and that it is still necessary to use identity to counter oppressive forces. As Davis writes, "While there is no race, there is still racism" (2002, 31). We may all be impaired, but we do not all experience disability oppression because not everyone is recognized and treated as impaired. The problem with dismodernist theories is that it is dangerous to say or give the impression that one is dismissing feminist analysis, intersectionality, additional identity-related studies, and identity politics in general. Feminism's critical role within feminist disability studies, and disability studies in general, is to continually try to pull to the forefront an awareness of how privilege and oppression is socially constructed, analyzable in our built and social environments, and intersecting across race, class, gender, sexuality, nationality, religion, disability, and so forth. It is not our bodies that separate us out as one person being better or having more access than another, but rather our socially situated bodies that denote this separation. Our identities and how we are separated out into a variety of categories are based on how we socially and culturally create hierarchies between groups of people.<sup>71</sup>

We need to understand how these differences are constructed and maintained in order to show that there is oppression and that there are grounds to demand change. Alison Kafer echoed some of these concerns:

Last year at SDS [2006]...I think because I was on the board, I was visible as

somebody responsible for the program, and so I had somebody come up and tell me that there was no need for any more discussion of gender or sex, that we have been doing that for years, and that it is time to stop....I think SDS and other disability studies conferences have done a lot of work. But I think that we could do a lot more in terms of sex and gender. So, that response kind of took me by surprise. That's the most explicit personal encounter I have had. Lots of people have made this comment...not just me...but Lennard Davis's book, "Bending over Backwards," where he just sort of out-of-hand dismisses feminism...that book is sort of talking about disability as being the post-identity position. And so in making that argument there's a place where he says that disability can get us out of the mire of identity politics that feminism and queer are stuck in. And, I mean, I disagree with that argument, but I can see making that argument in a responsible way, but I would still disagree. But the way he makes it...I mean I think he is doing it to be provocative, to get people talking. But the way he does it is sort of like "feminism...queer...bad. They are stuck in this place and we don't need them anymore. They are not useful." And...so I think that is the resistance piece that I feel in disability studies sometimes, sort of like, "We don't need that feminist or queer stuff anymore."<sup>72</sup>

Both arguments are necessary and the tension between the two will be a large part of the impetus that brings us toward liberatory change for people with disabilities. The tensions brought into conversation via conferences and literature about these dividing lines over identities and identity-based theories challenge us to confront our own thoughts, writings, and social actions. Furthermore, these tensions with one another and within ourselves keep the debates, movements, and social justice alive, and resist the same oppression. I do not know if we could get there without Davis' argument, but dismodernism by itself is not the answer. The dialogue between the two arguments is necessary in order to destabilize, and hopefully end disability oppression. Without dismodernism, we may still hold onto impairment (or non-normalcy) as a pathological method to separate out one body from another, a significant precursor to disability oppression.<sup>73</sup>

Is there another term that could be used to play the role for which Davis and many other post-identity politics scholars strive, that is, to create normalcy out of utter difference, non-normalcy, impairment among all? Naming some as abnormal has been used as a means to maintain the privilege of those deemed "normal." Such theories as Davis' strive to make no one capable of being privileged (i.e. by being a part of a certain group) by showing that normalcy and non-dependency do not exist. By exploring this theory we actually help unearth privilege. However, as Davis recognizes, the experiences by these groupings hold meaning. Disability may not be "real" (or a true barrier that resides within our bodies), but

ableism is real (as it is experienced and exposed through systems of power).

One method capitalizes on differences as being “real” and factual social and political experiences, while the other disempowers oppression by making the categorization a myth. I agree with Davis that we need both methods, although they are contradictory, for disarming disability oppression. They both provide insights into the politics and power at play between these identities. That said, I am not convinced that Davis is going about it in the best way because he does not fully account for how feminist theories, such as intersectionality and standpoint epistemologies, are indispensable for social justice work. Nonetheless, disability-impairment debates, from social constructionism to dismodernism, highlight such issues as non-disabled privilege and the material aspects and experiences of our individual bodies.

### **Making Alliances**

Along the same lines of this discussion of claiming or not claiming disability as a form of diversity (versus the idea that we are all impaired and non-normal) is the question of who has the authority to speak about disability. After all, if we are all impaired, do certain perspectives still hold more weight over others in terms of oppression and anti-oppression work? Standpoint epistemologies have taught us that we need to pull in voices from the margins to make our research and theories as accurate and inclusive as possible, which makes it paramount for people with disabilities to be brought to the center to speak. What role, then, do people who do not identify with disabilities play within disability studies and feminist disability studies? This is one issue that several participants raised. Catherine Kudlick pointed out this “elephant in the room.”

I’m actually surprised that there is nothing built into your study to distinguish between somebody having come out with the experience of disability, versus not. And it’s probably deliberate on your part, but it’s very interesting. Omission is too strong, because obviously you’re conscious about (what’s) going on. But it’s an interesting elephant in the room. And that’s not a criticism at all. It’s just an observation....It’s just that there’s this tension in the field, right?...between people who identify themselves as disabled and those who don’t. So there are the ones who suggest that non-disabled people don’t have a right to be doing this work even if they’re making great contributions. So, they are all terrific scholars, and terrific people. And I know that conversation comes up periodically, and...you know...people that see themselves as allies, versus those who live it...Having been somebody who can kind of pass on both sides I find myself in on some of these

conversations.<sup>74</sup>

Kudlick was right that it was deliberate on my behalf, but deliberate in that I purposefully did not want to box anyone into any identities. Mostly, I felt that trapping or forcing someone into taking on labels would contribute to the oppressive, ableistic system. I tried to make interview question six as open-ended as possible to allow participants to navigate their own path that they felt was most liberating in talking about themselves. By leaving the identification process open, participants could “claim” disability, or resist the reifying of socially constructed categories between those who are privileged and those who are oppressed by not claiming particular diversity labels. This is a research project about identity that does not ask the “elephant in the room” identity question in order to subvert the labeling that accompanies people with disabilities and to emphasize my alignment with identity-based politics rather than identity politics crudely understood.

I wanted to know how participants identified themselves. As discussed in the prior section, claiming and not claiming disability (as well as other identities), is a political act. I was curious what the participants would do with the open-ended question. It led to fruitful conversations, such as many of the ones presented above, and I anticipated that there would probably be some discussions regarding more dismodernist views of disability versus claiming disability as a diversity label.

A downside to leaving question six open-ended is that I did not get to ask the more pointed question about one’s disability identity, and so I was not able to explore the likely varied emotional and intellectual responses to such a politically charged issue. The discussion of the role of able-bodied or non-disabled allies was mostly brought up by those who identify as such. I did not ask participants who identify as disabled what they think the roles of able-bodied allies should be in academia. However, the participants who brought up the identity of being able-bodied in disability studies, or as allies, provided excellent critical self-reflective thinking about what it means to be an ally to people with disabilities. For example, Susan Schweik discussed how she, on the one hand, feels that she would never apply for a disability studies job, but, on the other hand feels that if no one else is teaching disability studies, then it is important for her to help develop that curriculum through research, publishing, and teaching.

We discussed how this is a tricky and delicate balance—between bringing in the

marginalized voices of people with disabilities and filling the disability studies academic roles within higher education (when so few people with disabilities have yet to climb up the faculty ladder). Awareness has to be raised in order to create change; allies can help open up more opportunities in many ways, including researching, publishing, and teaching in disability studies and insisting that the university be accessible and welcoming so that people with disabilities can become tenured faculty. As Susan Schweik reflected on non-disabled privilege and awareness,

What leaps out at me there, most urgently in the context of this discussion, is contingently non-disabled. I don't say able-bodied, because that is a fantasy, and I don't like temporarily able-bodied, because that seems kind of (retributive) and revengeful to me...it is always a very flexible category, right? And I have occasionally thought that maybe I had crossed over, but decided not, mainly because it is clear to me that, in terms of day to day operations in the world that, although invisible disability seriously complicates this formulation, I don't think of myself of as invisibly disabled, (in) a strikingly (pressing) kind of way. And the fact that is not strikingly (pressing), it bears on the other thing, which it is absolutely clear to me that socially, in the ordinary everyday social world I am in no way subject to the disability label. I am never subject to that, and that has just profound daily implications for my daily experience. I am not mobility impaired. The various kinds of stigma I do not have to deal with—so, the ways in which I can think about my own bodily experience, and understand the ways in which my body is limited and diverse from the abstract normal body, and all these things matter. I am socially non-disabled, and in the kind of phenomenological way I am not dealing with a level of pain, or fatigue, or impairment that, which puts me in a position of constantly having to decide whether to disclose or not. So, for these reasons, even though I don't simply claim the term, I do think it is sharp conceptually for me to identify myself as non-disabled...And, you know, yeah, that does have (bearing) on this work...I wouldn't even consider applying for a disability studies job...I can understand why other people do it, because I think there are good reasons to question those whole binary categories, but I think that for economic and social reasons, when I look around and see who is standing up in the classroom, and who isn't, and what kind of knowledge of impairment people can bring into the classroom—that is incredibly useful for people in universities to have access to. However it is brought forward or not, I cannot tell you how strongly I feel that it is inappropriate for me, personally, to consider applying for those jobs, and how strongly I feel that my main task, as somebody involved in disability studies, from my position, is to try to make sure that there are people who identify as disabled, who are scholars, experienced scholars, in authority at the front of the classroom, and that's the project that is most important for me to do. Now there has been a lot of movement for me, because originally I barely felt that I should even teach courses in this field at all, and the only reason I did it was out of the sense of looking around and no one else is doing it, and someone should, so...ok. And I was absolutely terrified that I did a bad job too. And, then, you know, I saw myself in this kind of ally position in terms of developing a curriculum, and it

took me a long time to think, “I am willing to write a book in this field.” I have no problem with that all, and it took me a long time (to) figure out a project that I felt comfortable doing that with, and I have actually (schlepped) off various drafts of the introduction. I have written kind of long treatises about my standpoint, or, as Rosemarie [Garland-Thomson] puts it, “my sit-point”...or whatever [laughter]. And I decided that, at this point, to (schlep) them off, the drama of my identification. It is ok with me not to do that, and I can see the counter argument to that, but I think that is where I stand.

Kristina Knoll: I actually think that is really key. I think it is really important to have both, both of those arguments going on at the same time. It’s almost as though they can’t be without each other.

SS: I agree. I agree, and when I was trying to write that, what I knew I didn’t want to do is that kind of generic form of it that I see a lot of, where somebody says something like the following, “Well, you know, while I was writing this book, my whole relationship to this category of disability was very fluid, and, you know, this thing happened, or I am vaguely alluding that this thing, I don’t say what it was, but that thing happened.” You know, boy, it is really a contingent category, and that’s true, but I find it really boring and also...it’s like a ritual or something. And at the same time I think it is really problematic not to think about it.<sup>75</sup>

I appreciate how Schweik struggles with the complex dynamics of claiming certain roles in resisting oppressive forces. There are multiple ways, including seemingly contradictory ones that can propel anti-oppression movements forward. At one point the best way to be an ally may be to refuse teaching a disability studies class, and to argue for why people with disabilities need to be hired instead, and, at another point, teach the disability studies class so as to raise awareness such that others start to understand why they need to hire and advocate for people with disabilities.

Again, as Schweik points out, it seems problematic to reinforce the idea that there is a strict boundary between those who are disabled and those who are not, and one’s role within disability studies and the disability rights movement. Similarly, Eunjung Kim expressed hesitation about identifying one way or another because oppression is ultimately negative for all. I agree with Kim that one does not need to identify as part of an oppressed group in order to work toward social justice for that group. In fact, I do not think that social justice can reach maturation without non-oppressed people understanding how they are situated within oppression and privilege, nor without their being a part of the liberation process.

Eunjung Kim: It depends on the context. I define myself as Korean in the United States. And I identify myself as feminist. In order to work toward social justice, one

doesn't have to identify as a certain group. And that's the reason why I was not too much confined by the fact that I'm not disabled to speak out (on) disability issues. Because I see the unjust practices happening, and that affects me as much. I have privilege, but acknowledging the existence of discriminatory systems is very important. How they impact everybody, both parties. I always felt that identity does not necessarily work toward what we believe is right.<sup>76</sup>

The key issue is how people are a part of the liberation process. Some people are suspicious of non-disabled people in disability studies as being self-serving in some of their actions (such as taking a disability studies tenure-track faculty position). Since the oppressive forces impact those being discriminated against far more, to be an ally means to be aware of this, to be self-reflective, and to work against it, such as arguing why the university needs to be more accessible, and working to recruit and support people with disabilities in their professions. What does it mean if few people with disabilities are applying or being hired? What oppressive systems are in place, keeping people with disabilities from succeeding? To not work on addressing these issues is to participate in disability oppression. Therefore, I argue that allies, who are in positions of power and privilege, should not ignore these issues. Thankfully, there are many people who are concerned about these barriers, while many people have varying ideas and positions regarding our "identities." Eunjung Kim, interestingly, does not identify as an ally because she views such a label as "assum[ing] [that] there is an inside and outside to activism."<sup>77</sup>

While sometimes taking different approaches, most made a point to touch upon how it is critical to recognize privilege and to use that knowledge to advance those who have perhaps not had those privileges. Susan Burch spoke to being self-reflective about positions of privilege in terms of her understanding of being an ally as well:

Susan Burch: I'm frequently reminded of the privileges that I have. You know, one of the obvious ones is that I am white. And so, I move through the world not having to deal with many things that my friends and peers of color likely do have to negotiate on a daily basis, or people I don't know of color have to negotiate on a daily basis. And that I am more or less temporarily able-bodied, and certainly read as temporarily able-bodied, gives me phenomenal privilege. You know, that I have education, at least middle class status, and so forth...these kinds of things...I live in America. You know, it affords me opportunities and power that my peers in the world, which I mean everybody else, may or may not have, or may have in different ways, and so the role of ally is also really important to me. And I'm fascinated and frequently disturbed by the boundaries that come up of, "What does it mean to be an ally?" As an example,

in the Deaf cultural world, “Can a hearing person be of the ‘Deaf world’?”...and who decides that, and what context and what does that mean; versus, being an ally of...or being...you know, being straight, but being deeply committed to LGBT activism. Can a straight person be of the LGBT community, and/or an ally, and what is the role of, “ally” in that?...It’s a complicated territory, I think, in that on the one side of it, it calls to an autobiographical experience, or at least an understanding that you are not necessarily of the subject under discussion, or advocacy. At the same time, why are those boundaries present? You know...and to what extent, I don’t mean to be dismissive of this...I mean...quite rigorously...to what extent does the gender or sex difference affect one’s ability to claim an identity, or participate in the movement? And who decides that I think is [a] really important issue.

Kristina Knoll: The power dynamics there...

SB: Absolutely. I certainly don’t have any answer [laughter] as to who should or...or even...I don’t think I’m even comfortable trying to make the judgment myself, which again is not intended to be an avoidance technique, because I do think it is an important...on many, many levels to actually have people of communities, underrepresented communities, be in positions of recognition and power. At the same time, as somebody who is not herself Deaf, who works in the Deaf cultural world, has friends and relationships, and studies, and would like to think I have something to contribute to the way this topic is studied...I bridle at the suggestion that I am inherently limited because I am hearing. I absolutely accept that I am a hearing person, and I don’t live as a Deaf person, but...and that does affect my ability to fully grasp, or present. That said, I also studied Russia, and early nineteenth century America, and I am not in fact Russian, nor two hundred years old. I (throw that out) a little quickly. But what I mean is that I think...it’s really important to also acknowledge the disciplinary training that we have...that our commitment as scholars, hopefully, really does seek the ideal of recognizing our limitations as scholars, but also what we can offer. And I hope that we will...we, as a community of scholars and activists, not dismiss a person’s contribution based on his or her bodies, which...I’m really keen on that point...that I bridle when I feel that my body...my personhood is being judged by the way that it is represented in the world, whether that’s gender, or race, or age, ability, orientation....<sup>78</sup>

This is a complicated situation for those who are non-disabled in disability studies. The ally role is extremely important; our ally-colleagues contribute critical and insight into the field. As Susan Burch highlights, who decides the boundaries around disability, impairment, and ally roles within disability studies? Disciplinary training matters, as does the informative



personal experience and liberation from oppressive forces for people who are disabled.

There is an uncomfortable sense of policing and self-policing that takes place, but perhaps this is not completely bad. Sometimes we need more than critical self-reflection. Sometimes we need challenging conversations with our colleagues. We need to grow more comfortable with, and trusting in our ally and colleague roles by having uncomfortable discussions, and we need to respect those who continually open themselves up to such dialogues. *How* we do this is critical, however, as oppression tends to silence and disempower. As will be discussed in Chapter 6, we need to be concerned about who is and is not present, why that is so, and bringing in and supporting marginalized voices. At the same time, we need to have additional theorizing about respect and the space that people need to be wrong, to be corrected, and to learn.<sup>79</sup> We need to grow more comfortable with making mistakes, owning up to those mistakes, and using those mistakes to learn and teach each other.<sup>80</sup>

These tensions over “Who is inside and who is outside?” expose power systems that create boundaries, both imposed and claimed, around our identities. Understanding these power structures can help us address, for example, why minority groups tend to focus on “talking to the center” versus talking to each other (and participating in identity-based politics). The ally role is not only important on an individual level, but also on a group level. Information and learning is enhanced. The overlapping and intertwining of identity perspectives on all sorts of intersectional levels will provide insights that monologues and dialogues around identities have not been able to sufficiently address. Ally tensions occur as well between various groups related to identity studies, such as women studies, queer studies, American ethnic studies, deaf studies, and disability studies. As Eunjung Kim and I discussed, recognizing and working with these “inter-group minority politics” can enhance our studies and our movements by creating language and theories to work together that may subvert those in the center or the top (e.g. those in power). This is how Kim responded when I asked question number nine, “How can we, or do we support each other as feminist disability studies scholars and/or activists?”

I think to say a lot of criticism out loud is a great way to do it. We need to disagree more often, and not worry about feeling safe too much. Like not worry about, “I’m not feeling safe.” I’m not a very expressive person. It takes a lot of courage for me to say things in front of people, so I am trying to encourage myself to do it, and trying

to feel good about it. I try to think of people who can inspire me, who show those strengths without worrying too much, but still respectful of other people. I think we should have a great friendship, great feminists around each other, so that we don't get isolated, and don't expect certain things, because that person says that she is a feminist. That has been my struggle. I expect certain things because they claim that they are feminists, and it doesn't fit into my expectation and sometimes people can be unaware of racism while being feminists. I feel betrayed, and it affects me a lot. People can get hurt by someone who one thinks (is) in one's own category, I think. We just can't assume those things, even if one belongs to one minority category. We need to recognize inter-minority group politics. It's easy to talk to the mainstream, but it is harder to talk to other minority groups. So, it's not always between the center and the margin. It's among groups in the margins. Inter-minority group tension and conflicts, all of those politics need to be addressed more often.<sup>81</sup>

One of the positive aspects about being involved in identity studies is that it is highly interdisciplinary, including across various identity studies.

Gloria E. Anzaldúa speaks to the trust-building exercise of creating allies, as well as the risk and hurt of betrayal, in a 1993 interview published under a section titled "Allies" in *Readings for Diversity and Social Justice: An Anthology on Racism, Antisemitism, Sexism, Heterosexism, Ableism, and Classism*. Anzaldúa reflected, "Allies might challenge some of your positions as a first step in finding out whether or not you are a real potential ally. Then you can get a sense of whether you can trust this person or not. And you go with your gut feeling" (Anzaldúa, 2000, p. 475).

Anzaldúa also commented on the pain from being betrayed by people you think are allies: "The biggest risk in forming alliances is betrayal. When you are betrayed you feel shitty. When I have been betrayed I have felt stupid, like, Why did I trust this person and allow this person to stab me in the back, it's all my fault—you know, the victim syndrome" (Anzaldúa, 2000, p. 476). Anzaldúa speaks to how much it hurts to feel betrayed by those we feel are, or should be allies, which Kim also addressed. I too have felt this sting. Anzaldúa writes about feeling tokenized by being brought in by people who are supposed to be allies, yet then finds herself the lone spokesperson at events such as conferences. Sometimes one feels like a checkmark, as in, "Check...one disability person just arrived through the door. Our job is done." It is not an ally relationship when the tough issue, our oppression, is not addressed or we are tokenized. We speak up, we write letters, and we call up the people who we believe are our allies to try and hold them accountable.

Although oppression operates on individual levels, oppressive systems and

institutions largely enforce and maintain largely it. For example, although my workshop at a National Women Studies Association conference in New Orleans was, I believe, the only disability pride related session, it was scheduled in one of the worst time slots, and, worse yet, it was held in an inaccessible room. Participants worked with me to write a letter of protest to the National Women's Studies Association (NWSA) president. The letter and the president's thoughtful response were published in 2003 in the *NWSAction* Newsletter (Castagnetto, 2003), and I heard that at later conferences there was more of an effort to include disability.

Despite this, I believe that oppressive systems still operate within NWSA on various levels because disability was absent from a central and critical faculty workshop regarding civic engagement and pedagogy for the NWSA 2010 conference. I sent an email to NWSA to inquire about why they did not include disability, and I was impressed that someone high up in NWSA responded promptly. She encouraged me to apply to be a faculty participant.<sup>82</sup> My first reaction was frustration that she would ask me to apply to do a workshop to educate the rest of the participants, rather than having disability fully incorporated into the faculty workshop. Then, I calmed myself down and mustered up my ally-spirit in order to write a follow up email to offer to help out in any way that I could to incorporate disability studies, despite my not yet being a faculty person. I did not hear back from her.

I know that the this person is surely busier than one can imagine, but I felt deflated—more by NWSA as a whole, rather than by the individual lack of response. I believe that the system and institution of NWSA failed in this instance. As Allan G. Johnson wrote in “Shame, Guilt, and Responsibility,” “[F]ighting social oppression with blame and guilt psychologizes and individualizes something that's rooted in *systems*. The individualistic model relies on the false notion that systems produce bad consequences solely because bad people with bad motives participate in them” (Johnson, 2004, p. 53).<sup>83</sup>

I believe that there is something wrong with the organization when many people have raised concerns about the lack of disability representation since before our letter was published in *NWSAction*, and yet now we face the same issue six years later. I went from simply feeling tokenized to feeling like even offering my free labor as an ally against oppression was not good enough. That experience at the NWSA conference in New Orleans was a hurtful one. Yet we take risks and find alliances, amidst these tensions, with people

who do take up our causes, such as the workshop participants who wrote the letter to NWSA regarding the lack of accessibility and disability representation during the New Orleans conference.<sup>84</sup>

We work across identity issues, and finding and working through struggles with our allies is central to creating social justice. It is not easy work, not by any means. As Bernice Johnson Reagon writes, “Most of the time you feel threatened to the core and if you don’t, you’re not really doing no coalescing” (Reagon, 2001, p. 540). Alliance building is perhaps the hardest, yet also perhaps the most critical part of our activism.

While systems and institutions perpetuate oppressive forces, we as individuals can continue to work against those systems and institutions by engaging the communities within them. The individuals creating alliances, one by one, have the power to change these systems and institutions. Jennifer Baumgardner and Amy Richards call this “autokeonomy” in their chapter on “What is Activism?”: “To practice ‘autokeonomy’ (‘self in community’): to see activism not as a choice between self and community but as a link between them that creates balance” (Baumgardner, 2000, p. 280).

Brenda Brueggemann discussed the advancement of working across identities in her own research and writing when I asked her question number six, “How do you identify yourself (socially, culturally, etc.) and how does this influence your work?” Her alliance between fields is at the core of what propels her work: her activism.

It’s funny. It is located here kind of in the center of your questions, and for me it is the center. Because I have a hard time identifying myself, and I think that’s very much what’s influenced my work. So, people tell me, especially the book that I just sent off to NYU press, and the reviewers come back and say, “Is it true that you are one of the few people who is trying to do a deaf studies book?”...And very proud to be doing a deaf studies work, and, then, also doing disability studies work. I’m very proud to be doing that. And, then, also working really hard to try and to keep a conversation up between those two fields. And a conversation that is ethical, in the sense that it illuminates what is very different, and different and distant about these two, and probably always will be, and that’s to be valued. But, then, what they also really have in common...<sup>85</sup>

It is impressive to me how important the ally role was to the participants, both to those who identified as non-disabled and those who identified as disabled. Dialogues and multilogues across axes of privilege and oppression seem to be the cornerstone of feminist disability studies methods and methodologies. Understanding one’s access to privilege, such as that

available to our non-disabled allies, and working across the politics between inter-minority-group tensions is the feminism of our feminist disability studies work. Feminist anti-oppression work is ever-shifting and amorphous, as it is in motion across many experiences, perspectives, dialogues, and multilogues. In our discussion, Licia Carlson echoed such beliefs—that being self-reflective, considering historical stand-points, learning through conflict, and so forth, are vital components of feminist and feminist disability studies.<sup>86</sup> This was her response when reflecting on the questions related to interview question number one, “If someone were to ask you what ‘feminist disability studies’ is, how would you define it (topically)?”:

Some broad concepts would include the issue[s] of embodiment, identity, identity politics, standpoint epistemology...praxis...theorizing oppression...I think also the arena of bioethics really is significant in that, because I think you have this tradition of both pathologizing and medicalizing women’s bodies, and disability. So, I think that would certainly fall under the purview of feminist disability studies. And I think also resistance and political representation, and the questions, both meta questions and specific questions about activism and politics. And I think history is a really important component to that. I guess the thing that I have written that’s probably most true to the label of “feminist disability studies” is a[n] article that I wrote about sort of a gendered history of mental retardation, and looking at different roles that women played in the history of this concept as it emerged in the late nineteenth century. And, so, I think revisiting the history of “the disabled” as a group, broadly speaking in the context of women’s history, and, then, looking at the intersections there. I think it becomes really, really interesting. So, I think from a historical standpoint there is a lot there. And, then, I think this question of voice, I guess, and membership. I mean as soon as you define a field of study, I think there are issues of power and authority, and sort of, “Who defines it? Who is a member? Who is included? Who is excluded?” And, I would hope that as a field it continues to emerge with this self-reflexive, self-reflective posture.<sup>87</sup>

The role of the ally in feminist disability studies surfaced without any direct questions about ally work in my interview questions, or in any questions regarding being non-disabled in disability studies or doing inter-minority-group-work. Out of eleven interviews, three people actually used the word ally or alliance, and an additional three talked about ally work in terms of when, how, and why to advocate with people with disabilities and Other oppressed groups. Four of these six participants identified themselves as able-bodied or non-disabled at some point during our discussion.

One of the critical identity politics roles that non-disabled people can play in shaping feminist disability studies activism includes engaging and theorizing about the role of being

allies with people with disabilities.<sup>88</sup> These debates and tensions between people with disabilities and non-disabled allies have the potential to map out the power structures, such as institutional, that may keep people with disabilities from being recruited, hired, and retained in academia and in various professions. What allies do with this knowledge is key, as they are the ones with able-bodied privilege. The knowledge of the systems of power between us is just one of the critical steps, and can provide an impetus toward a liberatory action.

I argue that any conversation that incorporates intersectional analyses is a part of doing ally work and contributes to a social justice process. All of the participants, to one degree or another, revealed within their interviews that they participate in identity-based politics. Because there are systems of power that contribute to various forms of privilege and oppression, of which we may be unaware, to participate in the unearthing of positions of privilege and oppression requires actions toward social justice. For example, considerations and use of intersectional analyses were present in every interview. These moments reveal many opportunities for potentially shedding light on the critical tensions that can emerge when the overlapping of identities and minority issues converge and this process is central to feminist disability studies. Feminist disability studies maintains that we need to bring in marginalized voices, which is ultimately a call to be an ally, to do identity-based politics, and this is one way to contribute to feminist disability studies activism. The tensions and contradictions that can occur in this process between identity groups and theories, and how we respond in those moments, can provide the opportunities and mortar from which coalitions are built.

## Chapter 5: Diversifying Activism

Intersectional work is at the core of feminism, and requires working across identities and identity-based groups. We must constantly challenge and enhance our ally tools not only to ask, “Who is not here?” but also, “Will you work with me to create a more just world, and how can we best do this work together?” This sharing of experiences and theories across identities contributes to an identity-based politics and activist process.<sup>89</sup> Participant considerations over what is and is not activism, or “activist enough,” caused me to start forming a feminist disability studies definition of activism.

Insightful reflections by participants demonstrate tensions over whether or not they do enough traditional activism. I am using the words “traditional” and “non-traditional” to speak of what is sometimes referred to as mainstream activism, grassroots activism, or street activism. I prefer the word traditional because traditions celebrate something great that occurred, indicating a desire to remember, honor, and replicate and/or uphold those moments in the present time. Since rights movements often start from this type of activism, the terminology “traditional activism” carries a feeling of legacy and respect for our roots.<sup>90</sup>

This tension over whether or not one feels that one is contributing enough toward activist pursuits, which I call “activist-guilt,” exposes potential ableistic underpinnings of traditional activism. Because the work that the respondents are doing is intersectional, across disciplines and identities, it is not surprising that some participants clearly articulated their research, writing, and/or teaching as forms of activism. This is not unique to feminist disability studies scholarship, but it is a leading and critical component of feminist disability studies. Addressing ableism within activism and making identity-based politics central to every project are central components of feminist disability studies activism.

In response to the following question:

*Interview Question #7: Do you have activist components to your teaching, research, and/or work outside of academia?*

Catherine Kudlick explained that just being in disability studies at this time is a form of activism.

I think right now it is really easy to be an activist in disability studies. I mean the very fact that you do it at all is a pretty activist act...you know...to stand up in front of a classroom, and say, “Look we are going to use disability as a category of analysis

on a par with race, class, gender, ethnicity, sexuality...whatever.” That’s pretty activist right there.<sup>91</sup>

Kudlick’s response also highlights the importance of intersectional analyses in our work, and how being a minority and teaching is a form of activism. Simply being a part of disability studies is a form of social justice work because there is often resistance to incorporating disability studies perspectives into any discipline, including women studies. Disability studies perspectives are oppositional to the medical-model norms of western culture, and with disability studies being so new to higher education, it is not surprising that Kudlick recognizes that just taking part in these disciplines is a form of activism. It is bold to say something new that is highly counter-cultural. University campuses currently have a wealth of activism, and that needs to continue.

Alison Kafer identified herself as a scholar and activist, but also commented that she is unsure why she sometimes feels like what she is doing is insufficient:

Yes. Yes, on both counts. Sometimes I feel more like a scholar than an activist. Although, when I say that...I think of all these reasons why that is not true, and why it goes against everything I think. But sometimes I feel like I am not much of an activist, like I don’t do enough, or am not “active” enough. I’m not sure what that is about.<sup>92</sup>

Kafer refers to what I call “activist-guilt.” This is when one questions whether or not what one is doing is creating enough social justice, or is active enough in physical terms (e.g. being out on the streets protesting) to be called activism. Those who protest out on the streets, chain themselves to inaccessible buses, and get arrested make powerful public statements that confront people about their privilege and oppression (people who otherwise may never have been confronted). This kind of activism also rarely pays or pays minimally, and sometimes comes with high risks, such as incarceration or even death. Much activist-guilt comes from the high regard for this type of activism and the activists who do it—as well as from the recognition of the lack of support for traditional activism within many academic institutions.

In “Challenging the ‘Academic/Real World’ Divide,” Catherine Orr also grapples with the issue of activist-guilt when she encounters the reaction of her women studies students after they became aware of how higher education reproduces privilege (and often



fosters and reinforces oppression by the lack of access for minority groups). Students struggled when they realized how much of the intersectional analyses, and the voices that could offer more perspectives, were not present. They felt like they were a part of the problem, and were disconnected from communities who are often barred from academia. Orr writes,

In other words, higher education is not a neutral space that exists outside of “real world” interests or that just happens to attract certain kinds of people. Rather, the academy is heavily invested in promoting difference. It is no wonder, I assured them, that their participation in this institution makes them feel isolated. The university was and is, then, intricately woven into the needs of for-profit corporations and expanding state bureaucracies. Thus, I attempted to recast the students’ personal feelings of longing and failure into a political context and reconnect them to the “real world” from which they felt so sequestered.

With this history in place, the students and I then could begin talking about these feelings of separateness from “the community” as more than just personal failures to be “activist enough.” (Orr, 2002, 45)

It is important to acknowledge and address how universities are set up in such a way that activism—especially traditional activism—is not well-supported. Acknowledging this is a first step toward addressing the barriers that restrict those in academia from participating in various forms of activism. With the scholastic pressure to obtain a Ph.D., gain tenure, and so forth, it is not surprising that participant responses focused more on academic-based-activism and their conflicted feelings over this.

Scholarly activism, such as conducting a research project that includes talking with teenagers with disabilities about accommodations issues and social life in high school, is not supported either. Universities deter researchers from projects that include subjects deemed too “vulnerable,” perhaps because ableism keeps some programs and departments from appreciating the need for this type of project. However, research, theory, and publishing all contribute to social justice and expand upon our definition of activism. Whereas every participant discussed abundant activism within either their research and scholarship, their teaching, conferences, or campus activism, only a few of the participants clearly discussed involvement in traditional activism outside of academia.

Asch talked about involvement in anti-Vietnam war and civil rights work in the

1970s, meeting Judy Heuman and working toward disability rights, joining the National Federation for the Blind, and participating in, demonstrating, and/or lobbying around a few critical issues, such as Section 504.<sup>93</sup> Eunjung Kim was heavily involved in working with a disabled women's group in Korea. Licia Carlson talked about her involvement in political rallies for issues such as pro-choice and reproductive rights. She was also involved with the People First Movement in Toronto, and her reflection on this again highlights our questioning of what activism is, or what is significant enough to be called activism:

I would call myself both, but I think that defining myself as an activist is probably more problematic, or would be perceived more problematic maybe from the outside, than defining myself as a scholar. And what I mean by that...is that...I think my involvement in...the political side of disability, in particular in terms of cognitive disability I would say has been peripheral, and yet it has informed my scholarly work, but I wouldn't say that I have been as involved as I would like to be. And, so, I feel like there have been many sort of points of resistance that I have engaged in, and sort of at very small levels. So, I would say not as part of this large movement that personally both, you know, as a teacher, as an academic, as just a person involved in that. So, I feel like, insofar those political acts, I guess, of resistance count. They count. But I would say, in terms of, if you define activism in terms of ones sort of participation in larger movements....Yeah, so I view myself as both. But I think that...I think in terms of the kind of the division of labor, if I think about, the attention that I have given this area, and I think definitely it is more representative of my work, in an academic context...This is where my Foucauldian bias comes in. I think resistance is such (a) broad term, and I think there are so many sites of resistance that can take place. But at the same time, I have to be honest that I feel like (it) also can be a bit of a cop-out answer; and, so, I am aware of that...I think it's also very easy to say, "Oh, yes, well, I am an activist because I practice these, you know, I've had these moments of resistance in certain ways." I think that is something to ask myself, you know, how involved I've been and in what ways....when I was in Toronto as a graduate student I was, you know, involved some people in the People First Movement, and the self-advocacy. And, unfortunately, when I went to Seattle, (with) my first job, I just...I didn't pursue that.<sup>94</sup>

While the participants considered myriad ways in which they create social justice, as Carlson also discusses, there is still an understanding that there is a need for traditional activism, and a bridging between theory and activism. Although it is unclear how much participants have been involved in traditional activism, reflections do make it clear that there is a theme of some scholars feeling as though what they are doing is not activist enough. Discussions around this subject help reveal the importance of traditional activism, ableistic barriers to traditional activism, and therefore the critical need to value additional forms of social justice

work as a means to resist ableistic systems that disempower people with disabilities who do social justice work.

An extremely critical point, which I would argue still does not get enough attention in women studies or disability studies, is that there is risk of contributing to oppression, and perhaps even to unethical work, when we are not connected to the diverse communities we are theorizing about. The more we connect to the communities we theorize about and the more we ask, “Who is not here?” the more we are “further from falsehood” in our theories.<sup>95</sup> This is an identity-based intersectional approach—to ask constantly who is not present and seek out more diverse identities across various forms of privilege and oppression. This method unravels the sources of privilege and oppression, and thus makes it clearer how to target areas needing social justice. This should make “traditional activism” a priority for all identity-related studies because we need to seek out more voices—voices that may not be within academia. Our feminist work calls us to go beyond our sheltered communities to more complex and politically charged interactions with additional identity-based groups. We can become sheltered, and perhaps privileged in our academic worlds.

Eunjung Kim articulated this concern about the academic-activist divide within feminism as well:

Feminist disability studies can get detached from what I consider as feminist. There can be a separation between how people live and how they do their scholarship. Two different things.<sup>96</sup>

Kim’s point remains central and critical to the feminist disability studies activist process, that is, to strive to remain connected to the daily, lived experiences of people with disabilities. There is a variety of ways in which we can address the gaps between our scholarly work and lived experiences, remain connected to multiple identity-based groups, and broaden our understanding of privilege and oppression.

Approximately half of the participants talked about conferences as a hot-bed for activism, a place to experience personal radical social justice and to impact others toward more liberating views of gender and disability. Conferences also provide a space for more activist projects that are often outside academia, thereby helping create a critical informative bridge to various coalition building needs. It is a strong theme and important consideration

for how to build and support coalitions and identity-based politics.

Words and theories can create a radical new framework with which one can counter oppression. Simply standing and speaking about feminist disability studies is a form of activism, as is even the simple act of wearing a “disability pride” T-shirt. Such actions spur questions and conversations. Some forms of activism take more time and/or physical effort, from conducting research and/or writing a book to planning a protest at the capitol steps. All are extremely critical and worthy of pride and honor.

With all of the “activist-guilt” I heard in some of the discussions with the participants in mind, I subconsciously started feeling defensive about the work they were doing and wanted to uplift it and celebrate all of their work as activism.<sup>97</sup> Discussions with a couple of the participants also revealed how there are often ableistic underpinnings to traditional activism. Thus I argue that all of the elements that contribute to social justice are a form of activism. There can be limits as to what one can do each day and even within a lifetime. Extrapolating from Susan Wendell’s thoughts about chronic health issues and traditional activism, expectations of traditional activism can even go so far as to contribute to ableistic belief systems, if we have certain expectations, such as having to be out and about on the streets. We only have so much time in the day, and there are many forms of activism, all of which contribute to social justice. There are also many coalitions, from campus to local and global. It is not feasible for each of us to do all of it.

Susan Wendell reflected upon feminist activist stereotypes, and how this has been a painful process for her, to come to a place where she could recognize and appreciate herself as an activist:

And, yes, we admired older feminists, but the terms of admiration were, “She’s still so energetic. She’s still so active. She is still at every demonstration, and so on and so forth.” Those were the terms of admiration, and if you were a feminist who had become too ill in old age, and so no one saw you, then there was a lot less interest in talking about reclaiming (you). There were exceptions to that, but, by in large, I was very...shocked (...) at how ignorant...my own conception of the female body [was]. And even though the analysis is very complex, and deals with many issues...how left out women with disabilities (and illness is) from feminism. Now the other side of that, and even more practical one, and that is that the image of a good feminist. In my mind, and I think in minds of most feminists I knew, was of a very energetic woman, and...and ironically, a very extroverted woman. And I say ironically because I am not an extrovert. I am quite introverted. And so this is always a clash with my own nature, and something I beat myself up about, was that I hate meetings. I hate phone

calls. I hate demonstrations. I hate [laughter] (...) contact. I want to be quiet, thinking, reading, writing. It took many years to give myself any permission to do that as a feminist. And it was a painful journey. But clearly that also clashes with the life of any woman who has to accommodate a disability or a chronic illness.<sup>98</sup>

Wendell's response was in reaction to the interview questions about whether or not disability studies had informed her feminist thinking, and it helps us thread together how internalized sexist and ableistic beliefs have made many feminists want to counter the sexist female perspective that women are weak (in hand with the ableistic belief that weakness is bad). To counter this sexist and ableistic stereotype there have been feminist responses that squelch stereotypes, which includes all of us who are fatigued, in pain, and so forth. This helped spur on the iconic radical feminist activists, who contribute to this day toward ableistic and internalized ableistic beliefs that being a good feminist requires being a physically active one. Therefore, feminist disability studies works to round out and celebrate all forms of activism and shows the need for all of the various components of activism that help create social justice.

Wendell further argued her point later in our discussion, talking about how scholarship and teaching is a form of activism:

...in the conception of what activism is, of what feminist progress is. It's very extroverted. Despite the fact that it is perfectly obvious that feminist theory has an enormous (reader)ship, and an enormous effect [sic] on many, many women's lives. Still, it was...it...the activism...reading, writing, publishing, speaking, were not really ever, and still to this day, considered the prototype of the...a way of being a feminist activist. You're either an activist, or a scholar. Scholarship is not considered a kind of activism. Whereas I would argue, "Of course it is." I mean even teaching women studies, you are teaching the future professionals of your society, the social workers, the psychologists, the doctors and nurses, the teachers at every level. You are teaching the future of professionals of your society to have a feminist outlook. And frankly I have my doubts about whether marching in the streets can have as much effect [sic] on a group of thirty of people, as teaching over a semester.<sup>99</sup>

There seems to be a tension here, which Eunjung Kim and I touched upon in our discussion as well:

Kristina Knoll: ...Dare I say this...but is activism maybe more feminine? ...and...I've never thought about this before, but...I am starting to wonder...like the academic field is more masculine. It has more power. It has more respect. And activism has often had this feminine...

Eunjung Kim: ...informal...yeah...yeah...unstructured...

KK: I don't know if it is true or not, but I think it is worth exploring.

EK: In Korea, activism is very, very militant. So, that would be a reason why disabled women weren't accepted. But disabled women's organization[s] ha[ve] to collaborate with other organizations and their causes. Because they employ all kinds of militant and extreme tactics that push the body to its limit and are often met with militant suppression tactics by police, such as hunger strikes, going down to the railroad to stop the traffic, protests can get very dangerous in Korea. Some women felt uncomfortable about that. But a lot of women participated in protests anyway, and I was not in favor of it because of the safety reason. A lot of disabled women wanted to do it. Because there were so many police, things got violent. The protests were about transportation access in 2001. The protests lasted more than a year. And some people died during the protests. The disabled women's movement was always a part of it.<sup>100</sup>

It is important to discuss the complex dynamics that emerge here. There are internalized sexist beliefs that propel feminists to do everything in their power to counter Western stereotypes of weakness, which Othered those who are weak or are stereotyped as weak (e.g. people with disabilities and/or chronic health issues). This creation of the non-disabled, physically active activist has been oppressive for feminist disability studies scholars and activists.

It is interesting that higher education does not often hold traditional activism in high regard, yet many identity studies disciplines largely stem from such traditional activism. We want recognition for our work as feminist disability studies activists, but, like our non-disabled activist allies, we struggle to fold traditional activism into academia. There is a double-Othering that feminist disability studies scholars and activists are beginning to realize and counter-theorize, against the able-bodied prototype of feminist activism and the stigma or dismissiveness of traditional activism in academia.

Activist-guilt calls attention to two things that traditional activism can sometimes limit: the participation of certain types of people (i.e. people with disabilities and impairments) and the recognition of social justice work. In this sense, limits on what counts as activism can be oppressive. This type of oppression can occur within our identity studies related disciplines, and can occur between individuals. While traditional activism plays a critical role in creating social justice, most higher academic institutions are not supportive of it. Not to participate in activism goes against many of our feminist methodologies to seek

out intersectionality and be connected to our communities.

Catherine Kudlick advocates for various forms of activism, while separating out many forms of social justice work (e.g. research, teaching, advising, publishing, and so forth) from traditional activism:

I'm president of the Disability History Association, so I'm using that a lot to...get disability recognized by the AHA and the broader community of historians. It's that kind of activism. It's not the activism where I am camping out at the independent living center trying to get benefits for people. I figure the movement is so big, and it's so much work that we all have something to offer. You know...we each work according to our abilities, and strength and desires, and all that stuff.<sup>101</sup>

I reiterate that I believe that this activist-guilt or defensiveness that academics sometimes have about their activism points to the respect and need for traditional activism.<sup>102</sup>

Susan Schweik brought up a similar point, that she holds activism in high regard and that there needs to be more traditional activism in disability studies:

I personally think that [the] disability studies program I am involved in needs to be much more thoroughly informed by ongoing, immediate disability activism (...). But when things come up I try to make people aware. And, you know, in some ways more than others, and in a pretty low-key way. Yeah, you know, I would identify, I didn't say it as a word (...), but I don't know if I would identify myself as an activist, which I would have a higher standard for what that word would mean than what I am doing by a long shot. But engaging in activism is something that I certainly value, and it's important. I do it when it seems right and possible. Sometimes there are different forms, like there is campus activism that has to do with issues, that have to do with issues very immediate to my work place, and those I think I engage in more frequently... I mean it depends on what's going on in the world, how shaken out of my complacency or how (revved up) [I am], or it depends sometimes on when structures for activism kind of become very clear in my mind, sometimes more than others.<sup>103</sup>

The need for collective thought and action to address all of the intersecting forms of privilege and oppression demands that we find ways to work collectively, that we learn from one another—from our students participating in internships and practicums to conferences that encourage bridging between traditional activism and academic activism.<sup>104</sup> This collective need also supports the need for theorizing and sharing thoughts via email and publishing in books and journals. Theorizing, writing papers, and speaking on these subjects within feminist and feminist disability studies circles are all part of the collective and intersectional approach. We seek to pull in ideas and theories from our colleagues who are

working with various communities.

All of this is part of a social justice chain reaction. All of the components are critical and needed, and deserving of high esteem. We, as individuals, cannot do it all, and to espouse such can even contribute to oppression, but we, as a collective, can contribute many elements of activism that will help create knowledge production and social justice transformation. The points made above support the claim for the necessity of both traditional activism and feminist scholarship activism. We all play a critical role. Some areas are segregated, unpaid or underpaid, and desperately need more support, traditional activism in particular. I believe that we need more and new scholarly activism that fights for more bridging with and support of traditional activists and also support for people within feminist and disability studies disciplines to participate in traditional activism. We also need to ensure that traditional activists have ways to bridge into academic, theoretical, and pedagogic activism. We need to recognize and counter the internalized sexist and ableistic beliefs that have created the feminist activist icon.

More scholars are discussing and theorizing about the importance of exploring and expanding upon our notions of activism, and working toward an understanding of how activism can bridge in and out of theory. As a couple of participants stated above, just being a part of the disability studies discipline is a form of activism and pushes the movement forward.

### **Bridging Theory & Activism**

Here I will look briefly at the various ways in which participants enact social justice via their scholarship, teaching, and/or campus activism in particular, and highlight the vast array of examples of activism. As Catherine Orr suggests, I am doing so to help us bridge our theoretical selves with our already activist selves. Examples such as Georgina Kleege's autobiographical writing, which she discussed in our interview, provide a new feminist and disability studies lens from which to read and write oneself into liberation, demonstrating how there are many ways that each of the participants is helping break down ableism.

Catherine Orr writes about the dangers of separating out our theoretical selves from our activist selves in our theories and teachings, as it can leave students feeling



disempowered and frustrated with their ability to enact social justice:

Nevertheless, I always cringe a bit when the academic/real world divide is evoked, whether in the classroom, in journals, at conferences, or even in casual conversation. It is not that I disagree with the need to demand that students think about how what we do inside the classroom has effects outside the classroom; nor do I think that there are not important differences between the academy and other institutions and locations in our society. Rather, the cringing comes from my discomfort with the dichotomy itself, our tendency to see activism as, in Sonita Sarker's words, the "constructed Other" of our theoretical selves (cited in Bart et al. 1999). Like any act of "othering," separating our activist selves from our theoretical selves endangers our abilities to see connections and promotes the importance of gaps. It emphasizes difference as a fact rather than encouraging investigation into its inception. And it invites oversimplified ideas where subtle and complex perceptions would serve us better. If our disciplinary mandate of making positive changes in women's (and men's) lives is to be advanced, then the othering of our activism needs to be investigated. (2002, p. 36)

In the prior section, I discussed the issues of activist-guilt among some feminist disability studies scholars in academia, and how this points both toward our respect of traditional activism, as well as some problematic sexist and ableistic roots that promote the "Othering" of traditional activism from additional forms of enacting social justice. While my research does not include the traditional activist perspective, it is also important to acknowledge the beneficial slippage between academia and activism evident in all of the participants. It is beneficial because the "slippage" provides more and necessary information for fighting oppression.

Another form of rich activism is scholarship, and the impact reading someone's work can have on a person. Reading Simi Linton's book, *Claiming Disability: Knowledge and Identity* radically changed my self-perception and my framework from which to fight oppressive systems within the university (Linton, 1998). If it were not for Linton's book, in hand with meeting inspiring mentors, I would have left the university during my first year in graduate school. During a time in which I was experiencing discrimination for having a learning disability, Linton's book as well as mentorship altered the way in which I viewed myself and the world.

Extrapolating from my personal experience, books and mentorship can be transformative, and trigger a wave of activism. Disability studies theories are informing feminist notions and values around activism, and raising awareness about how valuing some

forms of activism, such as traditional activism, over other forms of activism, such as writing and publishing, can contribute to disability-based oppression. Alison Kafer also reflected on how theoretical texts in feminist disability studies inspired her activism:

Alison Kafer: Well, this is sort of a good beginning of my becoming a feminist disability studies person, but I sort of discovered disability studies as something I could do....I mean I discovered it as a field, and then as something that I wanted to do, by reading feminist theory. So, although I had been thinking some about disability, I didn't really get that it was this thing that people could do, or that it was a whole lens of analysis, or...that there is this whole other way of looking at experience or looking at the world. I was reading people like Judith Butler, who didn't really talk about disability at all in her earlier work, not explicitly anyway. But reading her and reading Susan Bordo was just...so all these feminists were writing about body...I was like, "Oh...disability." And, then, I read Rosemarie's book...Rosemarie and Susan Wendell....A whole new world opened up for me. So, it was a feminist theory class that introduced me to disability studies—not to the disability studies texts, because of course we didn't read those in there. But I did that course, and then the next semester I did an independent study on feminist theory and the body. And those two courses were...what started me where I am now. And in some ways I think that goes back to the activist question, because I became politicized around disability by reading these theoretical texts, and became a disability activist in some ways, because of reading those texts.

Kristina Knoll: How do you feel you became an activist from reading the texts?

AK: Because they were talking about the politics of bodies, and they were talking about how certain bodies get valued and others don't, and talking about that in terms of an ideology that gets passed down, and passed on, and perpetuated, and...and I think particularly Butler, in this sense, in that...that it becomes self-evident. So, it just comes to seem natural...and we have no awareness that we are actually taught to think these ways about bodies, and actually taught *to be* bodies in these ways. And I think that opens me up to those sort of...you know...disability rights ideas that we could construct our environments in completely different ways to become completely different bodies.<sup>105</sup>

Kafer provides a powerful analysis of how reading someone's theoretical text can lead to action.

Susan Wendell also brought up how reading other people's works can greatly impact new ways of resisting oppressive forces inside and outside the classroom:

...I feel very connected to people when I read what they write. So, for example, Irving Kenneth Zola, was, you know, a hero of mine, I never met him, but I felt his presence, in a way, in the classroom sometimes. I felt that he was encouraging me, with his own writing. I...there were very few philosophers talking about disability at that time that I started writing about it. I [laughter]...right...oh...I (sub)scribed...I

am a member of the American Philosophical Association, so they send a fairly big newsletter three or four times a year....[One] issue contained a letter to the editor...in which he told the editors of the American Philosophical Newsletter...he gave a piece of his mind about the patronizing attitude towards people with disabilities. And I had looked for anything written by a philosopher about disability, more or less in vain. But I pounced on Ron Amundson cause he had written this letter, which I thought, "Whoa! There's a philosopher who knows something about disability." And I wrote to him, and he wrote back, and said, "Oh my god, another philosopher!" [laughter]... "in disability." He's a philosopher of science, with post-polio syndrome, and he had just barely recently begun getting interested in disability activism, and disability studies. So, we, then, had a correspondence about that....some of the people in the women studies department were very encouraging. And by the time I taught the course, I think I published, "Toward a Feminist Theory of Disability," which was my first...sort of...coming out as a philosopher with a disability. And, so, my colleagues knew roughly what I was thinking about...and some of them were very encouraging about the possibility of my creating a course. But, no, I didn't...I had no other syllabi. I had nothing. This came out of my head, and there were certain issues that I saw, that people wrote about, and a few written things that I had to work with. And things I had thought about that were going on in my head (space, in that) first article. So, it (...) but as I say, I feel like I have a lot of...connections, intellectual, but also spiritual connections to other people, people like Jenny Morris, whom I've never met. But I feel...she was wonderful, (support in)...her writing.<sup>106</sup>

As Wendell's experience demonstrates, reading other people's writings and epistolary mentoring can become incredible support systems of enacting inward and outward social justice. Not only reading people's books, but having these interviews and listening and re-listening to the transcripts of each participant provides tremendous motivation for me to work on this doctoral task that is definitely not structured for someone with a visual processing disorder and reactions to trauma. The participants' thoughts remind me of how the world is structured for the non-disabled, and spur me on toward wanting to create social justice.

It is virtually impossible to be removed from the activist reaction of being involved in feminist and disability studies. Eunjung Kim discusses how she shapes her classes in such a way that there are not only activist projects, but that the class structure in and of itself is part of activism, by providing new theoretical tools to potentially change one's world:

I think...I put this in my syllabus too, and I say, "All courses are guided by certain perspective." And it's not like I have an academic part and an activist part, but the whole structure of the class is an activist effort to change how they learned before. So, I state it in my syllabus and say that I am open to other perspectives as well, and I don't feel too comfortable not allowing other types of prejudice coming into the classroom. Because I think there should be a lot of freedom in this setting to

express...I'm open to what students bring to the classroom. I try to bring in some of the documentaries made by NGOs and other organizations, bringing activist writings into the teaching, bringing assignments that they can think about so that they can do something about the issues that they felt strongly about.<sup>107</sup>

Not only is the way we structure our classes capable of being a part of the social justice aspect of feminism and disability studies, if one is a teacher with a disability, our sheer presence and interaction within an environment structured for the non-disabled becomes a rich learning moment that can greatly alter people's understandings of their bodies and their environments. The friction between an inaccessible space and the need and demand for change can trigger insights, discussions, and movement toward social change.

As an instructor with a visual learning disorder, reactions to trauma, and chronic health issues, my students are quickly challenged the moment I "out myself" with my mostly invisible disabilities and impairments. They have to wrestle with their ideas of who a competent professor is. Cultural and university norms of what it means to be intelligent and rational, as well as one's worth within society, and how those abilities are supposed to be demonstrated and judged, makes my mere presence destabilizing in the classroom. Students have to reconsider their understanding of who a university instructor is supposed to be (e.g. the epitome of socially constructed notions of rationality and intelligence).

Similarly, Catherine Kudlick discussed her experiences of being an instructor with a disability, and how that can become an activist space:

I do think that it is an activist act to label myself in different contexts such as when I do or don't use a white cane. I don't use it at school except at night when I actually need it. But I use it at conferences, and that is a form of activism, and I use it partly because...conferences are a visual nightmare for me, and hotels and all that stuff. And at school I am on very familiar ground. So there are practical considerations. But in this weird way I become an activist instantly when I pull out my cane in public, just because of the way that I talk about it, or hold it, or get students to think about it as transgressive rather than pathetic. When you force people to wake up about something, that can be activist. There's intentional and then there is unintentional activism, like when I stand up in a classroom, and I say, "Look, you can't raise your hand, because I won't see you in the back of the room. You've got to shout out." Well, that is a form of activism. It's a form of teaching people to think about accommodation in a different way. To think about using slides in my classes, when I can't see what the bleep is going on in the slides, that's activist. They don't know that it is activist, but I know that pedagogically when I walk into the classroom and say, "You know something...I want you to describe that slide to me, because I can't see it." Probably they aren't thinking about it as being activist, but I hope that

sometime in the future when they are in a situation where...you know they are thinking about a visual image...they are learning to access it for themselves, but they are also learning to figure out what it is to describe it (...) I'm not necessarily saying that activism, in my own case, is going and being in a barricade, or, you know, being in a march. I've done a little bit of that, but not nearly as much as most people believe is necessary to earn the activist label. If there was anything that I felt a little bit, kind of...I don't know...embarrassed is too strong, but, you know, I haven't quite earned my stripes yet. I haven't been arrested for sleeping overnight on a cold floor. You know...I'm a spoiled brat. [laughter]. That said, I think I would be willing at this point to do it, if it came to that, and if it was something that I felt strongly about.<sup>108</sup>

Here, Kudlick highlights what some of the other participants have said, and many of us feel. She moves from talking about how just her presence alone is a form of activism (and how her activism goes beyond that) to talking about perhaps not having done enough to have earned her activist "stripes." Many of us, feminist and disability studies scholars, feel that our work is not activist enough, and yet a lot of what we do is directly tied toward challenging cultural norms and creating social justice. We need to be aware of, embrace, and work on the variety of ways that we can contribute to social justice.

When I asked Susan Burch whether or not her academic work has activist components she responded:

Heck yeah. Yeah, I try to not to mask that, but be upfront with my students, because I think it is important to own when you are being manipulative. But I absolutely believe that with education comes responsibility and activism. That there is not a boundary. That is not to say that students must acquire my belief system and act the way I believe an activist should be, and so forth. But part of what I do as a scholar and educator, I hope, in its best sense, is work with others on obtaining or enhancing tools of empowerment so that they can seek their own path in a really effective way. And if that is a path antithetical to my own values, I would rather have that happen and have that person feel like they have tools and that they are aware of it, and that they got it from ...from like me than to have students who agree with me but who don't do anything about it. I'm a true believer in democracy in that way. But, yeah, I think it's essential, again as a person with privilege, and having worked in the sanctuary of an academic setting to build programs like Women's Leadership Training Institutes and disability empowerment organizations, and to keep asking, "Who's not here, and why?" I think that's the question for both feminists and disability studies folks, to be asking, "Who's not here, and why?"—and to chase after the answer.<sup>109</sup>

Even though so many of us struggle with the feeling that we are not doing enough, when we look at the work we do it is impossible to deny the activism in our intersectional work across

identities and minority groups, including in academia. Doing intersectional analyses requires connecting with additional minority groups, and this process, I argue, creates moments between people and groups that have the potential to teach us about privilege and oppression. This is a part of the activist process, and can include research, writing, and theory development as a part of it. As Burch's statement reveals, part of what we have learned and teach is that we need to keep asking who is not present. By questioning boundaries between activism and academia, feminist disability studies has the potential to point out the oppressive elements of having a boundary between academia and activism.

After discussing and reflecting upon the academic side of the activist spectrum, it is appropriate to end this section with a nod of admiration toward the more traditional side of the activist spectrum by highlighting both a disability rights group that bridged academia and activism, and one of the many feminist disability rights activists, CeCe Weeks. Even teaching and publishing on historical activist moments can trigger activism. Therefore, to celebrate the traditional side of the activist spectrum, I want to highlight both the group who established the first Center for Independent Living, and Weeks, in particular.

The creation of the first Center for Independent Living stemmed from campus activism, and further demonstrates the beauty, the need, and perhaps the inevitability of intermingling between academia, identity politics, and activism.

The first Center for Independent Living (CIL) was founded that same year of 1972 in Berkeley, California, by a group of disabled activists. As students in the late 1960s, they had persuaded the University of California to establish a disabled-student services program. It had included personal assistance to significantly disabled students, enabling them to live in campus housing. Transferring their ideas and strategies to the off-campus community, the group helped to launch the Independent Living Movement that would soon emerge also in Los Angeles, Houston, Boston, and the rest of the country. Their central goal, self-directed living in the community supported by centers like CIL, was adopted by Congress in the vocational rehabilitation act. (Senator Alan Cranston of California was a coauthor.) (Longmore, 2003, p. 103)

A student collective action on campus had a ripple effect on communities beyond Berkeley, probably more than one can fathom today. Using such activist stories in our teaching and mentoring reminds us of the interdependency between academia and activism, and for the potential that we have—especially as collectives working toward social justice together.

In 2006, CeCe Weeks was featured on the front of the *Radical History Review*:

*Disability and History* (Meade, 2006). Weeks participated in civil disobedience, including chaining herself, along with others, to an inaccessible theatre in Berkeley, California. She also participated in the movement to secure Section 504, which facilitated disability rights as a civil rights issue. A couple of her fellow protestors recalled the incident:

That's when CeCe Weeks and I were left in charge of the group....Sleeping on floors every night, no showers, never knowing when the Feds might charge in and bust us....But we held our own and finally, we were victorious. (Stein, 1997, p. 43)<sup>110</sup>

One of the reasons the 504 demonstrators were able to pull off the longest sit-in in US history is that we were well fed.

...

I don't know who got the bright idea first, but it was not many days after we marched into the building that the Black Panthers started delivering one or two wonderful meals every day for all the demonstrators in the building. (Stein, 1997, p. 43)<sup>111</sup>

We owe to Weeks, her fellow protestors, and many others, the enfolding of traditional activism and the whole spectrum of activism into academia, be it through historical accounts or philosophical reflections—as well as the unfolding of our disciplinary work into social justice action. It is due to disability rights activists that I am writing this dissertation. Feminist disability studies activism will bring increased liberation, because it seeks out people with disabilities and additional marginalized and silenced minority voices. Past activism enables us to take our work further and with greater ease. There are many ways that this can and will happen when we work together on a collective level to be as attentive as possible to all communities and the intersecting forms of privilege and oppression.

### **The Activist Process of Identity-Based Politics**

Asking the participants interview question two, “Would you call yourself a feminist disability studies scholar and/or activist?” revealed both the tensions and the excitement among the scholars in doing and defining activism, but also raised interesting insights as to why the participants did or did not identify as feminist disability studies scholars or activists. Six of the eleven scholars gave very clear replies of, “Yes,” while three gave answers that were what I would call hesitant “Yeses.” Only one clearly declined to identify herself as such. Several of the participants seemed to completely accept or gloss over the question about being connected to the term “feminist disability studies,” and focused, rather, on the

terms “scholar and/or activist.”

A few discussed whether or not they would identify with “feminist disability studies.” Alison Kafer, Eunjung Kim, Catherine Kudlick, Susan Burch, and Licia Carlson identified themselves clearly and quickly as feminist disability studies scholars and/or activists. And as discussed in the previous section, many of the participants struggled to try and define if and how their work is a form of activism, and if so, to what degree. However, their critical role as researcher and teacher as positions of helping create social justice was abundantly clear in their discussions with me.

Those who said that they identify themselves as feminist disability studies scholars, but with a bit of hesitation, also seemed to have meaningful or respectful timidity around this identification. A couple of the participants’ reactions may have been out of holding the position of “feminist disability studies scholar and/or activist” in high regard or wondering if their work qualifies enough as “activist” or “feminist.” However, most did come around to claiming the identities pretty quickly. I argue that, while we respect, need, and celebrate traditional activism, these feminist disability studies discussions demonstrate that claiming a variety of social justice projects as “activism” is in and of itself contributing to social justice (by refusing to reify compulsory-able-bodied stereotypes). We need to be proud of and claim our “activisms.”

Georgina Kleege affirmed her role as a feminist disability studies scholar, and, then, also came to identify herself as a feminist disability studies activist via her autobiographical writing and teaching. At first, it seemed as though she was unsure whether or not she could claim the activist title, but she shifted and affirmed her social justice role in her scholarship and teaching on autobiographical writing and in challenging “cultural scripts”:

I guess so...I mean certainly in terms of my writing, my research. You know...I would fall into the category in terms of scholarship. In terms of activism, I mean...as an autobiographical writer myself...I think that writing can be a form of activism, in that it can challenge cultural scripts about being a disabled woman. So, yeah, I think I would define myself as...yes to both of those terms.<sup>112</sup>

Brenda Brueggemann struggled with claiming the “feminist” identity, but realized that this identity was significant in the way that others saw her in relationship to the work that she has done, and continues to do. This identity of “feminist” also clung to her because of the work she is passionate about and is called upon by others to do, and in the way her family



perceived her. This is how Brueggemann responded when I asked her if she would call herself a “feminist disability studies scholar and/or activist”:

You know...I guess I have to at this point. But like I said, when I told that story about (Andrea) it wasn't something that I would have thought was going to be...(holding) an associate faculty position in women's studies, I teach a course for them now on gender and disability, and the new chair has been even more interested in disability studies, and I am working with three graduate students. So...yeah...three of them...two Ph.D.s and one M.A., who...they are all definitely doing disability studies projects, so I think even if the influence...back...and the students that I've had...I think I've got to say, although, it's so funny, as a girl from western Kansas, to call myself a feminist...it's like such a hard thing to do. It's hard. It's programmed so deeply into me that...you know, although, you know, my family would tell you the first thing I say is pretty much feminist. [laughter] And when I go back to Kansas they'll say that...they'll call me, “the raging feminist.” [laughter] But I haven't thought about myself that way. So, I guess so. I guess...yeah...you'll just have to put that identity on me [laughter].<sup>113</sup>

Brueggemann recognized the significance of the feminist and disability studies labels by how others identified her, and she said that this is the work that she is doing and values.

Susan Wendell gave a quick “yes” to the question of whether or not she identified as a feminist disability studies scholar and activist. However, she also said, “Yes, scholar...not enough energy to be an activist. I'm connected to activis(m), but remotely.” So, in addition to how we are identified as an activist, by ourselves and/or others, Wendell brings in the question of impairment and/or chronic illness within activism. Does being an activist mean being a certain amount of “active”? Although she identified herself as not being an activist at first, she followed up in our discussion with outlining how so many of the things she has done via scholarship, teaching, or mentoring create critical social justice for other people.

I was taken aback by Adrienne Asch's clear “No” response. Asch said that she would not identify with feminist disability studies, and that she was even “hostile” toward the idea of feminist disability studies. As articulated in Chapter 3, however, there are some good reasons to be uneasy with the creation of more and more identity groups and studies, which can lead to a splintering of ideas and goals. It was also clear throughout the interview that Asch used and appreciated both feminist and disability studies and rights movements. This is how Asch responded when I asked her how she would define feminist disability studies:

Since I haven't read Rosemarie Garland-Thomson's book, or article rather, I can't tell you how she defines it, and I don't think I would. In fact, I am a little hostile to it as a further fragmentation, of already fragmented things. I think women studies and

disability studies is enough. I don't think we need feminist disability studies. I think we divide ourselves into more and more smaller categories to our detriment.<sup>114</sup>

It is fascinating and insightful for me that Asch seemed to have such a strong reaction to the idea of “feminist disability studies” when she has written so much related to feminism, women, and disabilities. Asch even co-edited one of the discipline's pivotal, foundational books, *Women with Disabilities: Essays in Psychology, Culture, and Politics* (Fine and Asch, 1988). Many of the classes she taught at Wellesley were listed as women studies, and she put some disability topics into them. It is not that she does not believe or use feminist and disability studies ideas, however, but that she believes that these topics or issues should not be relegated to smaller and smaller classifications. Rather, she argues that “oppression is oppression” and should be everyone's issue.

As we saw in the “disability and impairment” section, a few of the other participants were concerned with this fragmentation within identity politics as well. As outlined in this earlier section, balancing the more dismodernist approaches (e.g. we are all impaired or all the same, and washing away difference) with the opposite claiming of identities to further identify how privilege and oppression operates on individual, institutional, and symbolic levels creates great discussions and movements in our pursuit for social justice.

Susan Schweik's slight hesitation in claiming the feminist disability studies title was because she humbly felt that perhaps she is not doing enough intersectional work, which she perceives as central to the feminist part of feminist disability studies. Contrary to her self-perception, she does an exceptional job of bringing intersectional analyses into her scholarship and teaching, including talking to the University of Washington's Disability Studies Curriculum Transformation Project in April 2006. I admire, however, this feminist struggle of hers that she inserts into feminist disability studies, because there are always more layers of intersecting forms of privilege and oppression that we need to continue to seek out. This is how Schweik responded when I asked her if she would identify herself as a feminist disability studies scholar and/or activist:

Yeah, the only hesitation at all in my voice, is that I don't feel that I have...let's say in the book I am just finishing utterly fore-grounded the kinds of intersection I would see there. But, on the other hand, I would really hope that my perspective as a feminist, which, my education as a feminist preceded my disability consciousness by a long shot, and, you know, to some extent, I think informed it and paved the way for it. I think from something as simple as the fact that way before they were common in

other cultural phenomena at women's culture events, in the eighties, say women's music concerts, there were ASL interpreters, to the general set of paradigms that you take from feminism, which are usable in related arenas. I think that I do everything that I do from my (grounding) as a feminist scholar. At the same time, I don't feel that I have exactly, in terms of what I spend my time thinking about really squarely and solidly stayed in place in thinking about gender, and that is partially a historical phenomenon. I think that a lot of women, at about my age, who cut our critical academic teeth on feminist work, (f)or whatever complex set of reasons didn't just stay there, in the last ten years, but I don't think it gets left behind in any way. However, I don't think of myself, like some other people I can think of who are really doing work that I think of as at the forefront of feminist disability studies scholarship, as opposed to, you know, there are a bunch of people I can think of who I think are doing nothing that is in the slightest way counter to feminist work in disability studies, and is knowledgeable by it, and is informed by it, but isn't shaping that particular conjunction very clearly, the way Rosemarie Garland-Thomson is, or Alison Kafer, or Adrienne Asch is a good example, Marsha Saxton, Corbett O'Toole. I think Tanis was really working right there in a very different way that wouldn't be reducible simply to feminism, Eli Clare, because there is a whole issue too of how queer theory and gender studies intervene historically and, you know, and still complicates the field when you are talking about this.<sup>115</sup>

I continue to ponder the fact that Schweik identifies Adrienne Asch as one of the central feminist and disability studies scholars, when Asch does not identify herself with feminist disability studies (while acknowledging that she works in and across both areas). It leaves me wondering who has the right to define what our disciplinary and activist roles or identities are: ourselves, others, or perhaps both? I agree with Schweik that Asch is one of the foundational feminist disability studies scholars and activists, and I would also argue that Schweik is great at incorporating feminist intersectional analyses in her discussions with other people. Brueggemann similarly recognized that her identity was shaped by the reaction of others to her work. She was labeled as a feminist and has been asked to do more feminist and disability studies type of work by colleagues and students. Identity is important not only when it comes to the power of self-claiming, but also in the political power of communication between people about who can be depended upon to uphold both of the value systems that come with feminism and disability studies.

Our identities are fluid, and, as pointed out throughout this section, they are influenced by our interactions with others. Resistance to labels and claiming the way we are identified is a big part of the power of identity politics. The interactions and discussions around identity claims create awareness, and even the tensions move us to think, speak, and

act differently. There is significance to the way we identify ourselves, and I am grateful for the insight that each participant gave in their interactions with me and others. It makes us think, and move toward liberation, albeit by different ideologies.

However, there is also significance in the way that others identify us. There are certain expectations in being called a feminist and disability studies scholar, and although we would like to think that everyone has the same values in working toward social justice, that is not the case. There may not be clear boundaries around who can claim or be called a feminist and disability studies scholar and/or activist, but there are certain expectations or hopes. When I am told that someone is a feminist and disability studies scholar, I expect them to have general values and goals related to those schools of thoughts. It is very different from saying that someone is doing just disability studies, or just feminist activism.

Feminist studies and activism are still greatly lagging behind in embracing disability studies and disability rights. Disability studies and disability rights activism, although heavily informed by feminism (being post-origination of women studies and infiltrated by feminists), desperately needs to infuse more feminist theories around privilege, oppression, and intersectionality. I believe that the two are intertwining, due to those of us who are bridging the disciplinary and identity politics divides. There is something unique and special occurring in this bridging between the two arenas, and it is important to be able to identify where that is happening.

When speaking to the theory of disability in disability studies, Susan Wendell writes in "Toward a Feminist Theory of Disability,"

This theory should be feminist, because more than half of disabled people are women and approximately 16 percent of women are disabled (Fine and Asch 1988), and because feminist thinkers have raised the most radical issues about cultural attitudes to the body. Some of the same attitudes about the body which contribute to women's oppression generally also contribute to the social and psychological disablement of people who have physical disabilities. In addition, feminists are grappling with issues that disabled people also face in a different context: Whether to stress sameness or difference in relation to the dominant group and in relation to each other; whether to place great value on independence from the help of other people, as the dominant culture does, or to question a value-system which distrusts and devalues dependence on other people and vulnerability in general; whether to take full integration into male dominated/able-bodied society as the goal, seeking equal power with men/able-bodied people in that society, or whether to preserve some degree of separate culture, in which the abilities, knowledge and values of women/the disabled are specifically honoured and developed. (2006, p. 243)

The intertwining and bridging between these two disciplines or schools of thought addresses issues that may not be addressed otherwise, or brings us there faster. Some of the issues that disability studies grapples with stem from or have already been discussed within feminism and can greatly inform disability studies. One of the first feminist disability studies articles I read that really highlighted the uniqueness of these two fields merging was “Smashing Icons: Disabled Women and the Disability and Women’s Movements” (Blackwell-Stratton, 1988), from the book that Michelle Fine and Adrienne Asch edited, *Women with Disabilities: Essays in Psychology, Culture, and Politics* (1988). This article pointed out the clear need for looking at the intersections of women and disability, such as looking at prenatal testing, disability, and abortion, cultural perceptions of beauty and expected roles of women in relationship to being a woman with a disability, and so forth.

There is a need to understand the history and theories that have emerged from these two different areas, giving birth to new ideas from these conceptions. Second and third waves of feminism have pushed us forward to realize the necessity of complicating these additional intersectional analyses with race, class, nationality, sexuality, religion, and so forth. And disability studies provides radical new ways for feminists to think about our bodies, normalcy, and health in relationship to the complex webs of intersecting forms of privilege and oppression.

Alison Kafer encapsulates well how the process of women studies and feminist activism intertwining with disability studies and disability rights activism is critical, and how feminist disability studies creates a ripe space for discovering new challenges—and tackling those challenges. I believe that our discussion, excerpted below, also highlights the necessity of, and inevitable connections between, identity politics and activism.<sup>116</sup>

Alison Kafer: So, having conversations about what personhood means, and what kinds of fears that reproductive rights and reproductive justice activists have about personhood, such as, you know, anti-choice groups wanting to get fetuses declared as people so that abortion can eventually be made illegal. And then getting disability activists talking about how we have not been seen as people, and that’s how all these abusive attitudes and practices toward disabled people have been justified...I just think there’s all this space to actually have those really hard conversations where in some ways we find connections between movements, and other times I think we are going to find connections really hard, if not impossible. But...I don’t know, there is something really exciting to me about making those conversations happen, and I think feminist disability studies is a place where those kinds of things can happen.

Kristina Knoll: What do you think makes those kinds of spaces happen?

AK: Because, ideally, feminist disability studies is actually thinking about all these things together, and has been wanting to...you know, feminism has this long history of theorists talking about why we can't rank oppressions, or what happens when you pit one marginalized group against another. Both...both a long history of sort of theorizing why doing that is bad, or how it is ineffective, but also people trying really hard not to do those things. So, I think those histories are important, and I think that they help create different kinds of spaces. And because, you know, ideally, and of course none of us do this all the time...or if we are lucky we do it once or twice. But because I think feminist disability studies is a place where people are thinking about disability writ large and gender writ large, and sexuality, race, and nation, and how those things come together. And I think to have those kinds of hard conversations...you have to be juggling all of those balls at the same time, which is really hard, and which is why we need lots of people involved in those conversations, and lots of people deciding what conversations to have in the first place.<sup>117</sup>

Kafer offers an example of how difficult dialogues between one identity group and another are really exciting and insightful, and how feminist disability studies can be a great place to theorize and enact social justice together. Because feminist disability studies scholars and activists are working hard to incorporate intersectional analyses with disability and impairment. This is one space where excellent social justice and multiculturalism is able to take shape.

We do have work to do, because we have become aware that it is through our difficult dialogues, multilogues and ally work that we come to this understanding. We need ally work between disciplines, identities, and between the identities of non-disabled and disabled. As Kafer pointed out, feminist disability studies provides a prime space for doing so because it is so keenly aware of intersectional analyses of various forms of privilege and oppression. Susan Burch also reminds us of the critical role of intersectional analyses in her response regarding what topics or issues feminist disability studies scholars need to pursue further:

Certainly developing countries, and...and just...countries and cultures outside of America and Western Europe. We have a lot more to learn about the rest of the world. Illness versus disability; cognitive... developmental disability; psychiatric disabilities. I think there's a lot more, selfishly I say, about historical studies. One of the frustrations that I have with disability (studies) generally, and gender history is that scholars frequently use just one or maybe two frames to examine something. And in the ways I was talking about Junius Wilson I was not capable of separating out where his race versus gender versus age versus disability versus geographic location, time chronologically speaking, was more or less important, though some

may be perceived as more important. But that all of these things are being enacted in our present and meaningful at all times. And so thinking methodologically and theoretically, I think we have a lot more to do. And we have to, in terms of theory, move through the social model and into these more kind of intersectional discussions. And again, I am not a theorist. I don't claim theory as my expertise. So, I am hopeful that those who have that kind of gift will pursue that. At this point as a practitioner, I am just finding the boundaries to be constraining.<sup>118</sup>

Burch reminds us that identity and intersectional analyses are critical for the feminist disability studies movement and the activist process.

To conclude with the person who had the most staunch counter-point position to identity politics among the participants, Adrienne Asch offered an exciting example of how identity politics lead to activism, demonstrating resistance to ableistic and sexist beliefs. This is what she had to say when I told her how powerful it was for me personally to read the book she co-edited with Michelle Fine, *Women with Disabilities: Essays in Psychology, Culture, and Politics* (1988):

Kristina Knoll: For me, if you don't mind me saying, my experience of the book offered many missing pieces from so much of the literature that I have been reading in women studies and elsewhere, and those missing pieces are so critical, personally.

Adrienne Asch: Well, that's wonderful.

KK: And...to...I guess that's the problem. Identity politics is, if there isn't representation, then there is the need to push, to push the identities forward, to bring the voices up, if they are not already present.

AA: Well, yeah, there was a great moment at some feminist conference where Judy Heuman and (Letty Cottin Pogrebin) had this kind of (interchange)...(Letty Cottin) says something like how awful it is for woman to go down the street and be whistled at, stared at, ogled at, and treated like sexual objects, and how that's everyone's experience. And Judy Heuman said from her seat at the table...."It's not everyone's experience." You live your life using a wheelchair, and I'll tell you how little you are looked at, noticed, treated as a sexual object. Well, that was a very useful corrective for (Letty Cottin). I'm glad that she heard that, and I think that she was made quite uncomfortable by it. So, you know, that was a nice example, of a voice that hadn't been in the conversation about women's experience, being in the experience.<sup>119</sup>

Judy Heuman used her disability rights perspective and altered feminist politics about ideas of rights for women. From a feminist disability studies perspective, it is oppressive not to be seen as sexual, due to disability being socially constructed as unattractive and often asexual. Feminist disability studies seeks to find the liberating space where all have the right to be

viewed and treated as sexual beings without being harassed in a way that creates fear and perpetuates gender violence. This great activist moment that Asch shared demonstrates how intersecting identities can inform and create shifts in identity politics and movements.

This critical mixture of feminist and disability studies ideas is one of the leading arenas for the politics of identity, which so thoroughly fuels activism. Activist moments, such as the one that Asch shared, spring up everywhere when the politics of our identities are challenged or oppressed, and we create resistance and insight. The politics of our identities cannot help but provide opportunities for activism, and this is the originating catalyst toward social justice.

In addition, understanding the tensions that come from the identities associated with traditional activism versus more scholarly work can expose institutional power structures within the university (e.g. how and why traditional activism and feminism often face a lack of support by the university), and also reveal ableistic components of traditional activism within feminism. These moments can teach us that traditional activism needs more support within academia, and that respect and opportunity for a variety of forms of activism is important for non-oppressive social justice practices.

Not to address the ableistic components of activism breaks down an identity-based politics because it can prohibit participation by people with disabilities in every minority group and coalition. Feminist disability studies activism insists that activism be accessible and that we always work toward an identity-based politics, and that this *process* of identity based-politics is inherently activist.<sup>120</sup>



## Chapter 6: Toward an Identity-Based Politics

Part II is about the specifics of how we already have enacted, presently are enacting, and still want to enact social justice in the future through the politics of our identities, so that we can live in a less oppressive world. From quiet and covert activism to painful and blatant resistance, participants shared innovative ways in which they have resisted oppressive forces in their lives, giving us blueprints for future social justice actions.<sup>121</sup> A movement occurs when a group of people comes together to work toward some form of social justice, resisting some form of oppression or layering of oppressions. A movement is formed through working with other people, that is, coalescing. A movement's presupposition is coalition work; coalition work comes about through brave acts and is sustained through a willingness to work with others through a multitude of differences. This is where the identity politics of a movement can transform into identity-based politics, that is, when we allow for opportunities of knowledge production from the tensions that will arise. Part of what we need to do is to theorize and teach more about *how* we work across differences and identity groups, and to show how sustaining a space for tension and difference helps inspire identity-based politics.

My research participants give details of what they feel creates barriers to identity-based politics, as well as ways we can improve and encourage working across identity or minority groups among feminist and disability studies colleagues (and beyond). Participants, however, nearly always used the term "community" instead of "coalition" in their discussions with me, including sometimes when they discussed how and when we choose to work on social justice issues together. My phrasing of the interview questions also surely swayed the way in which they discussed their ideas with me, since I used phrases such as "feminist circles." The term "identity-based politics" was never brought up, and is likely an unfamiliar term, which I outlined in Part I.

I am going to predominantly use the terms "coalition" and "coalition building," because coalescing highlights more of a choice to converge diverse ideas and people toward a certain, joint action (rather than ending up in a "community" where one may or may not be engaged in that community toward any particular end goal).<sup>122</sup> Through working across differences, privilege, and oppression (e.g. identities and identity politics), we are coalescing

and participating in identity-based politics, whereas a community could be doing no coalescing or identity-based politics whatsoever. However, by the actions and behaviors denoted by participants when using the term “community” in their conversations with me, I infer that they were frequently referring to coalescing and identity-based politics types of work. Therefore, I use the terms somewhat interchangeably, but use the terms coalition, coalition building, and coalescing more in order to highlight the shift toward working across identities and minority groups (i.e. identity-based politics).

This chapter of my dissertation is the “how to” of what participants and I feel helps create and maintain feminist disability studies coalitions. In talking about *how* we have enacted social justice, such as coalescing across identity groups, we pinpoint some of the key events and people in the risk-taking, collaboration and mentoring that has led to the impetus of the feminist disability studies movement. Coalition building has often developed out of bold statements and brazen acts, be it speaking up in front of others, such as presenting a paper at an Modern Language Association (MLA) conference or at a meeting in one’s department, or speaking up in written form, such as online or via a peer-reviewed journal article. The boldness involves writing on a subject that some deem not academic, or not academic enough, such as emotions and activism. It is often at these points of contestation that a person is inspired and connects with another person because of the first individual’s brave acts. It takes such activism to pull people together over similar causes and build coalitions, where people, for example, decide to create a sub-committee on disability, organize a conference, gather together to protest Peter Singer’s ableistic theories, or decide to collaborate on writing an article or book on a topic that is highly contested.

This chapter also celebrates how these connections have occurred, and why. Many of the reflections discuss how conferences have played a pivotal role in creating coalitions, both as a site where interdisciplinary people have come together and have met new people with transformative ideas and as a site where people have created new conference spaces to specifically fuse different ideas (such as feminism and disability studies). In discussing the ways in which we have created encouraging spaces or struggled with barriers to coalition building within feminist and disability studies circles, key arenas in which these spaces and struggles have occurred have often been through some sort of face-to-face encounter (especially conferences) and writing and reading radical new works.<sup>123</sup>

Not only did the participants share their rich and sometimes deeply passionate thoughts about the strengths and weaknesses of coalition building among our disability studies, women studies, and feminist disability studies communities, they also shared a few amusing and remarkable stories about their first encounters with other feminist disability studies colleagues. Many of the participants were and are covertly and overtly challenging norms, ableism, internalized ableism, sexism, and academic professionalism and orthodoxy together—all of which create barriers to building a coalition. From the intersections of women studies and disability studies theoretical frameworks, feminist disability studies scholars and activists are sketching out and trying new techniques for better coalition building. Individuals who work in coalition, seek to fight oppression and create social justice, while considering all forms of privilege and oppression and keeping a social-cultural analysis of disability at the center. The heartache, friendship, fun, love, and collaboration described in this chapter are too rich not to take note.

The interviews revealed a few key points in the evolution of the feminist disability studies movement, many of which are related to conferences or publications. It is impossible to identify the beginning of feminist disability studies. However, it is fun to try to explore when people first started mixing feminism and disability studies theories and activism. I argue that it emerged simultaneously among many people, such as when civil rights was on the horizon and individual people with disabilities started identifying how they too were oppressed in similar ways. I read Judy Heuman and Adrienne Asch's meeting as playing a big role in the initial development of feminist disability studies. Asch, however, as I interpret her responses, also believes that there is not, or should not be a feminist disability studies field.<sup>124</sup> because she is more interested in finding commonality, and less interested in creating the fragmentation across differences that comes with creating more forms of identity studies.

Nonetheless, one of the first identifiable critical academic points that I was able to find in our feminist disability studies movement was when Michelle Fine approached Adrienne Asch, who was a graduate student in social psychology at Columbia, about possibly co-writing an article about the double discrimination of women with disabilities, and then, later, an article regarding abortion, the women's movement, and disability rights. After writing the article together in 1981, "Disabled Women: Sexism without the Pedestal" in the *Journal of Sociology and Social Welfare*, Fine encouraged Asch to work on creating a book

on women and disabilities with her. As Asch reflects as well, many of the pivotal moments came about through enthusiastic collaboration with mentors, colleagues, and the friendships that were being developed amidst scholarly activism:

So, we did an article that was published in 1981 in a journal that looked at a lot of the literature, and confirmed that, at least if you read that literature, it looks as though there is, that women with disabilities are more discriminated against than women without, and that women with disabilities were more discriminated against than men with disabilities. So, we kind of...put that stamp on that. And, from that, Michelle said, 'let's do a book.' So, more because it just seemed like fun to hang out with Michelle, I said, 'ok.'<sup>125</sup>

The interviews confirmed that many pivotal movements, such as the ones between Fine and Asch, came about from people approaching others who were pursuing similar issues to work together, and how the budding friendships can create indispensable colleagues and catalysts toward social justice. Michelle Fine and Adrienne Asch did edit a very well-known book for feminist disability studies scholars and activists, *Women with Disabilities: Essays in Psychology, Culture, and Politics* (1988). In the introduction they identify a few key scholarly pieces that overlap feminist and disability rights issues. Although their article, "Disabled Women: Sexism without the Pedestal" may be one of the first feminist and disability studies articles written in the United States, they identify a couple of other scholars who published around the same time on topics of feminism, women, and disability.

Yvonne Duffy, who published a book around the same time in 1981 called "...all things are possible" (1981), discusses "sexuality as a key arena of both oppression and expression for women with disabilities" (Fine and Asch, 1988, p. 2). Around that same time, Fine and Asch also recognized how Canadian and British scholars were tackling similar topics, and influencing scholars whose work overlaps women studies and disability studies in the United States. As Fine and Asch wrote in *Women with Disabilities*, "Jo Campling (1981) brought to public discourse the private lives and stories of British women with disabilities; her book was hailed here, too, because it spoke for long-silent U.S. women" (p. 2). When access to publication is possible, as a couple of interview participants discuss, it is one of the most powerful ways to help support other women with disabilities—and create and sustain coalitions.

From reaching out to friends and colleagues to address personal and big issues in life, and finally reaching a more public domain by publishing, Fine and Asch kick-started those

whose interests overlapped women studies and disability studies. Perhaps one of the most jarring earlier articles for feminist scholars and activists was Fine and Asch's "The Question of Disability: No Easy Answers for the Women's Movement" in the *Reproductive Rights Newsletter* (1982). As a few of the interview participants discussed, one of the difficult, but critical, factors of building a coalition and creating change is making bold moves and showing a willingness to possibly be ostracized by colleagues.

This article by Fine and Asch was a huge wake-up call for the women's movement and disability rights, creating a key moment. "The Question of Disability" challenged feminists to see how they were oppressing others by using ableism to fuel their cause. This quote from the article beautifully illustrates the tension between a major part of the women's rights movement and the disability rights movement:

The politics of disability and reproductive rights share a tradition and a commitment to women's control over their bodies and access to resources to live full, sexual and meaningful lives. Men can not control women's bodies, and one's level of disability, conflated by social class, race and gender, can not be manipulated to deny disabled individuals control over their lives. These struggles are intertwined. Feminists can not alienate, much less exploit, the disabled for the aims of reproductive rights. One battle can not be won without the other. (p. 20)

Therefore, in addition to the fun and beauty of friendship and collaboration, there also came the often difficult task of confronting large numbers of colleagues, friends, and family members about their oppressive ways. These difficult tasks, such as confrontation and the risk of being ostracized, are teased out further later in this chapter. Sometimes our most difficult moments become the most noteworthy moments in a movement's history. Fine and Asch wrote a letter to the feminist journal *Off Our Backs* in the fall of 1981 to counter the idea within the reproductive rights movement that no woman would want to raise a disabled child. Asch recalled the incident in her interview:

Michelle and I wrote a letter to "Off Our Backs," objecting to the article, and "Off Our Backs" refused to print the article. They said we were, "guilt tripping their readers." I just about, we just about flipped. I was livid. So, we sent the article, as written, to a different reproductive rights newsletter, called, "Reproductive Rights National Newsletter." And they agreed to print it, and it was printed in 1982 as, "The Question of Disability: No Easy Answer for the Women's Movement." And it is, to my knowledge, the first iteration of the points I have been making on the prenatal testing topics ever since. Well, you would have thought we had dropped some kind of atomic bomb on feminism. We distributed the article in 1982 in (June) conference 1982, and people were furious...just furious, and it made me realize that yet again,

there was a disability perspective that feminists weren't getting.<sup>126</sup>

These types of moments help identify those working together on similar and pertinent topics of concern (and/or those in transition and “gnawing” on the issues), creating a coalition of people working on overlapping and often very personal issues. These daring moves into the public domain help create coalitions.

Conferences have also been a critical component in how feminist and disability studies scholars and activists have spoken up, found each other, and then worked together in some way to counter sexism and ableism (e.g. creating boards or committees, publications, organizing conferences, etc.). Conferences bring together people who would possibly never encounter each other otherwise, and provide opportunities for exploration of ideas and feelings with similarly-minded people. They also play a critical role in the feminist disability studies genealogy, noting who, how, and when people met and possibly started collaborating in some form.

I loved and related to Susan Wendell's reflections on the importance of how conferences, such as the “Society for Women in Philosophy,” can restore, refresh, and create new movement toward social justice, especially when the conference represents minority issues:

When I was young, before I became disabled, as you may know, there were very few women philosophers (...) in graduate school. There were about eleven percent Ph.D.s in Canada, and I think it is comparable percentage to the United States. And we used to joke, I mean, there was one woman in most of the philosophy departments in Canada. There was one woman, and we saw each other one week, once a year at [laughter] at the, “Society for Women in Philosophy” conference—rather we got together once a year. And we used to say after a couple of days of that conference, there were muscles...there were certain muscles in our bodies that had not relaxed since last year [laughter]. Can you understand what I mean? [laughter] [KK: Yeah.] [laughter] And the same thing is true for me in being around non-disabled people for a long time, that, then, you feel like the exception—you have to draw attention to your needs. It depends on the kind of day I am having, and so on. And there are certain muscles in my body that don't relax, except around other people who are sick and disabled, who are disabled. And...and that makes me realize that our experiences are different. Our experiences of the non-disabled world and our experiences of ourselves are quite different in many ways, from non-disabled experiences. And that means that if you get too far from our connection, our daily connection to people who have disabilities or illnesses. Then, our work loses something, because our perspective loses something. It's possible to go on writing about the same issues, and those are the key issues of your time, without realizing that people are facing (...)

new issues. And, so, you do have to remain connected to (this group of) people you are speaking about, even if you don't see yourself as trying to serve that community. And I always saw myself as a feminis(t) who is trying to serve women, (at least serving) women. And as a disability studies scholar, I try to serve people with disabilities. So, I need some kind of a connection.<sup>127</sup>

Conferences can be that community space where muscles can relax that have not relaxed in a long time, and, on the other hand, when a conference causes more muscles to become tense, sometimes people will find each other and create a new group or conference space to socialize, theorize, and create social justice. It is in these interactions, by speaking up within written publications or in face-to-face conversations, such as within conferences, that we can counter potential barriers and encourage spaces for coalition building and creating social justice. There are a variety of reasons as to why we face conflict within such spaces as conferences: some people want to focus on one identity issue, while others argue that you must consider all intersecting identity studies simultaneously; some want to focus on one college or school of thought, such as the humanities, while others believe that we must remain interdisciplinary; some believe that just looking at disability from an academic standpoint is sufficient, while others believe that we are not being true to social justice causes if we are not including and bridging with traditional activism. Some believe that we need to look at all of the ways we are different, while others argue that we are all the same, or that we need to focus on commonality and not reify socially constructed differences.

In this part of my dissertation, I discuss how supporting various identity-based voices and theories to come into conversation and perhaps conflict with one another plays a critical role in propelling a social justice movement forward. Although identity-based perspectives may seem contradictory at times, I argue that there is value to these dialectical spaces. I believe this is true about all of the conflicting stances taken within our communities. I believe that these tensions between people and coalitions can be fruitful and necessary for the movements, and that we need to be more attentive to the richness that can come from contradictions. Perhaps most poignantly felt are those tensions that emerge in a place where an individual believes she or he is safe from oppression, such as at particular conferences. Therefore, I work to bring into conversation those things that participants felt were barriers, those things that they felt encouraged coalition building within their social justice communities, and consideration of the usefulness of the contradictions and tensions.

### **Barriers to Coalition Building**

Information summarized within the following section is in response to various interview questions. However, I asked a few key interview questions that opened up conversation with participants about those things that break down coalitions, and those things that uplift community. A few of the interview questions that probed these issues include:

5. What are some of the challenges of being a feminist and/or disability studies scholar, and/or activist?
  - a. Have you experienced resistance to women studies, or feminist perspectives in disability studies circles?
  - b. Have you experienced resistance to disability studies in feminist, or women studies circles?
9. How do we, and/or can we support each other, as disability studies scholars and activists?<sup>128</sup>

The most notable barrier to feminist disability studies circles discussed by participants was ableism, mostly in more implicit and covert ways within academia and among colleagues. Internalized ableism, although on a lesser scale, was also discussed as having a negative impact. Equally of concern, and interrelated with covert ableism, participants discussed how identity politics, competition for resources, and oppression ranking within academia have impeded individuals and coalition building. Licia Carlson, for example, discussed how various identity groups use “distancing discourses” from other identity groups by highlighting their normalcy and another’s Otherness, thereby reinforcing oppression.

Another significant issue raised by participants was a critique of the diminishing spaces for traditional activists and activism. About half raised this concern, and one addressed a potentially critical counter-argument as to why activism should—for example, within Society for Disability Studies (SDS) conferences—be diminished or excluded, and why the conference should remain academically centered. A few of the participants also addressed how they have felt like “outsiders” in feminist and/or disability studies coalitions due to feeling either not academic enough or not disabled enough within such circles as SDS.

Although it is not of any lesser value, only a couple of participants discussed the problem of there being limited resources and not having access to a community space, which



ties into covert and/or unaware ableism. The other issue raised was the concern that disability studies or feminist disability studies was too radical or “out there” for Other identity groups (including some deaf studies colleagues).

Often the places where we face barriers, and an opportunity to either build or break down coalition building, are the ripe locations for these critical contradictions and tensions to emerge—that is, where there are competing goals that are both striving for social justice. Both in women studies and disability studies there are explicit and implicit forms of resistance to the other’s school of thought and social justice projects. There is a range of reasons for this resistance, the foremost being a long history of able-bodied privilege and ingrained sexist and anti-feminist perspectives. The participants noted ableism as one of the biggest barriers to disability studies within women studies; for the most part, it operated on an unaware and unintentional basis.

Ableism is of course not unique to women studies, but for the focus of this project, I concentrate on feminism and disability studies. We live in a medical-model, ableistic society, where being disabled is not desired, and is sometimes even hated, which can feed into many women studies programs, and individuals within those programs. We are all subject to societal influences, however, and I admit that even I, though thoroughly entrenched in and embracing both disciplines, catch myself struggling with internalized forms of sexism and ableism. We have to pursue a constant unraveling of various forms of oppression, including internalized.

Sometimes there is also discomfort because some feminists may know that disability oppression exists, but they do not quite understand it, and fear falling into ableistic traps and having their students and colleagues recognize that they are possibly being oppressive. I believe that we sometimes fear being oppressive so much that we can become frozen and hesitant in our social justice work.<sup>129</sup> Perhaps subconsciously we feel that if we do not move or take action in any way that we will not be oppressive. This, of course, backfires because doing nothing also contributes to an oppressive system. We become unaware and implicit in the functioning of the oppressive system. Resistance to social justice often comes in the form of passive non-involvement.

Other reasons that participants feel that there is often unintentional or covert resistance to disability studies is fear that it will possibly infringe upon limited resources.

This is something that I discuss more later in this chapter. Catherine Kudlick discusses some of these discomforts and ableism within women studies and of sexism within disability studies:

I think feminists are nervous about disability. I think they are uncomfortable with the topic a lot of times. Not everyone of course, but there's definitely some resistance, maybe more passive than active. And there is also a group within feminist circles that feels disability is going to take away from the feminist agenda, or it's going to dilute the pool. And I find it also in humor. It is interesting. I mean...feminists are just not supposed to have a sense of humor anyway, but there's a way that some feminists use disability in their humor or dismissiveness of people they view with contempt. You know, it's ok to make fun of George Bush being "so lame," deaf to this, blind to that, crazy...or whatever, and I find myself in situations where I am trying to work with people that should know about the politics of language a little better, and they don't...And often they just don't see that there's a direct relationship between disability and feminism. I've had a number of times where I will propose a speaker or something on disability to the feminist group, and they will basically glaze over. They just haven't thought of it. It's not on their radar. I see a lot more resistance on that side of things...on the women's studies side...I can't think of a time when I had to explain to someone in disability studies why feminism needed to be included. Things have come a long ways from the early days of the disability rights struggle when women's issues were put on the back burner.

Kudlick, Susan Schweik, and Alison Kafer all expressed concern over the resistance to disability studies within women studies, and described resistance that was more overt or explicit. Eunjung Kim, Susan Wendell, Susan Burch, Brenda Brueggemann, and Licia Carlson described the resistance they experienced as more covert, unintentional, or unaware. However, what is covert or overt is a matter of degrees, as often what others describe as covert resistance feels rather explicit and overt to me. Kim described how people would address the disability topic by asking *her* to do more work by coming and giving a guest lecture, rather than them informing themselves. Susan Wendell described her experience with resistance through the ways that ableism operated on a more covert level with some colleagues. She described how some colleagues expected her to keep up with certain able-bodied standards, such as sitting for all day work retreats:

When we had all day retreats, which I refused to allow them to call, "retreat"...I said, "Look, the fashion is to have all day meetings. A retreat, historically, is a time for spiritual and mental, and physical refreshment of the body..." "It is not a day long, a twelve hour work day!"...So, they called it, ("Advances"). And it was always the joke.

...“We all (understand) that Sue doesn’t want this called a retreat. That’s fine.” That was another way of my educating...But I said, “If I’m coming, and I’m not coming for twelve hours, I have to have a place to lie down and rest.”...So, when the first retreat where I demanded accommodations, they wheeled in...a hospital bed...So, when I got tired, I lay down on the hospital bed, and to my surprise later somebody said, “Do you need the bed Sue?” And I said, “No.” And she said, “I have got to have a rest”...So, she lay down in the hospital bed for a while, and people started to admit...that this is exhausting. And, so, a demand arose to reduce the amount of time, the length of retreats from nine or ten hours to something that didn’t exhaust everyone. Cause non-disabled feminists were pretending to be stronger than they are.

Licia Carlson addressed the resistance as not blatant, but rather in the form of omission of the subject. Brenda Brueggemann described the more implicit resistance as often stemming from a sense of competition for resources. As demonstrated by the participants, there are many different ways that resistance can be experienced.

That said, eight of the eleven participants described some form of resistance to disability studies on some level within women studies circles, be it overt, covert, intentional, or unintentional resistance. Georgina Kleege, however, explicitly addressed how she felt that women studies was a much more open field, and likely to embrace disability studies. Kleege also gave examples of how there have been a few feminist journals that have done special issues on feminism and disability, thereby demonstrating support. I believe that this is true as well, because women studies focuses on addressing privilege, oppression, and intersectionality. It is a matter of breaking through heavily engrained ableistic ideas, however, as well as colleagues taking the time and making the effort to understand how disability oppression operates.

One of the barriers within disability studies is an outright dismissal of or resistance to feminist theory, its usefulness for, and historical and theoretical connection to, disability studies. A couple of the participants gave the sense that disability studies resists feminism because some think that we should be beyond the focus on sex and gender, or reifying differences as a whole, or possibly because they want to believe that the tools to fight disability oppression are unique, which could be true to some extent. Alison Kafer remarked that there is some of this resistance to feminist thought within disability studies:

Last year at SDS [2006]...I wasn’t the program chair last year, but I was on the program committee, and I think because I was on the board, I was visible as somebody responsible for the program, and so I had somebody come up and tell me

that there was no need for any more discussion of gender or sex, that we have been doing that for years, and that it is time to stop. I mean he just sort of walked up and was like, “So, blah...blah...blah.” I mean I think SDS and other disability studies conferences have done a lot of work. But I think that we could do a lot more in terms of sex and gender. So, that response kind of took me by surprise. That’s the most explicit personal encounter I have had.

One of the core theories or frameworks of analysis from feminism is the study of the many intersections of various forms of privilege and oppression. This ties in directly with what I discuss in this section of my dissertation regarding activism and identity politics, and the desire by some to move away from analyses that focus on diversity and difference, as they believe that it fragments coalition building and reinforces the false notion that there are these divisions by ability and pathology. What I propose, however, is that contradictions and tensions are the mortar from which coalitions are built; what is needed is a way to handle such tensions in a collegial, respectful manner, with an understanding that this tension can propel our theories forward.

These tensions come about, in part, due to conflicting goals, such as believing that looking at gender or sex will dilute the work and progress toward dealing with disability oppression. The monist approach to a social justice process, however, is counterproductive, and even destructive at times, when we realize how different we are within our diversity groups. Nonetheless, these processes and goals bring about the tensions and contradictions that call attention to ways to address oppression more fully.

Another way that resistance to feminism can be felt is by the undercurrents of sexism within the coalition.<sup>130</sup> There are theories that sexism and machismo are rampant in some disability studies communities because of how people with disabilities are asexualized or treated as non-sexual. There is a belief that some disabled men go to the extreme of machismo, sexism, and womanizing to try and reclaim their identity as virile heterosexual men. Susan Wendell, who has also worked on issues of pornography, discussed how she has even received hateful and threatening mail about her work. There has been some strong resistance at times, when feminism has threatened a reclaiming of sexual identity through sexism and machismo.

Eunjung Kim and Catherine Kudlick described the resistance as being even more covert. They described it as coming in the form of colleagues not addressing disability in

their own work, because someone else is doing it. That is resistance by omission and tokenism. People say things like, “Oh, I don’t do that. I’m glad you do, and will you prepare and give a guest lecture to my class?” Brenda Brueggemann discussed how people like Rosemarie Garland-Thomson would encourage disability studies people to look at feminist models for working through various forms of oppression, but there still has been some resistance to looking into feminist analyses.

Susan Schweik and Georgina Kleege, on the other hand, both felt that they were not aware of resistance to feminism and women studies within disability studies. There was definitely a sense among the participants that there was a lot more resistance to disability studies within women studies, and that disability studies is a lot more receptive and incorporates feminist perspectives on a more regular basis. In addition, I estimate that over half of the participants have participated on an organizational level with the Society for Disability Studies at some point. Thus, feminists have been and are very involved in the disability studies movement on the national level. Also, disability studies is in its infancy compared to women studies, so disability studies did not get to shape women studies from its onset. Therefore, it probably makes sense that resistance might be stronger within women studies.

Although we are making strides in connecting the two fields, the overt and covert forms of resistance break down coalition building at times within women studies and disability studies, while also fueling motivation to work with other feminist disability studies colleagues. We need feminist disability studies outlets to bridge the two fields that are sometimes at great and oppressive odds with one another. Finding one another in these contradictory and tense spaces has helped fuel feminist disability studies.

Ableism and internalized ableism come in many different forms, and they also create barriers to coalition building. Ableism within academic departments can manifest itself through physical barriers to one’s education or work, social barriers that isolate and stigmatize, and a devaluing and lack of support for one’s work. Ableism and sexism, as discussed earlier, may appear in more covert forms, where people tokenize, do not take responsibility for educating themselves, or fear that supporting other identity studies may diminish or damage their work in their field, or their movement.

Internalized ableism can create barriers to building coalitions as well because one

may feel not disabled enough or not academic enough to participate. One of the major forms of ableism and internalized ableism that is rarely discussed or acknowledged is emotional and psychological ableism within academia. In a space that is presumably about “rationality” and “intelligence,” to be Other is dangerous. I enjoyed discussing and even joking with Amy Vidali about this problem in general, but particularly within academia:

Kristina Knoll: I have dealt with that, but in terms of emotions. I am far too emotional, and academia is not a space for emotions.

Amy Vidali: Oh no...you can't have that. We are all supposed to go to our offices and cry [laughter]. And everybody knows that everybody does it...you know.<sup>131</sup>

Sometimes it is refreshing to joke about the oppression we face with those who understand these barriers, and this was one of those instances. Amy and I shared laughter over how ridiculous, albeit painful, ableism and internalized ableism can be. It was liberating and refreshing for me to have someone else recognize this form of oppression in such a poignant manner. Somehow, laughter with the right people about these matters feels like resistance to oppression because we both understand the ridiculous profundity of it all and no longer feel alone under the pressure to be the socially constructed “normals” of academia.

Similarly, Amy Vidali discussed how she shared humor with a few other disability studies scholars, such as Brenda Brueggemann. Humor can be a subversive way to acknowledge a mutual understanding of a form of oppression. The quote above illustrates that we feel the need to work too much so as to not appear “weak” or less qualified for our field, and the humor helps illuminate how these feelings might be fueled by internalized ableism and sexism.<sup>132</sup> The professionalism and academia-ism in which we are mired may be rooted in oppression, and sometimes humor helps bring the issues to the surface. Amy Vidali hints at a similar feeling:

We were doing the CFP for the DSQ [Disability Studies Quarterly] thing I was telling you about. It was me and Margaret, and Cindy, and, then, also Brenda... of course we send it to each other like four hundred times, and by the end...I forget what Brenda called it. She was like, “I can see...you know...when I was in graduate school we had a club like...you know, ‘women who must control the world and work all the time,’” and she had a funny acronym. She was like, “I’m glad to see you’re all card-carrying members.” Cause there we are all on Memorial Day, you know, emailing each other the whole day. It’s sort of sad. Yeah...you can throw that under

my social and cultural affiliation.<sup>133</sup>

Sometimes we push ourselves too hard to try and prove that we belong, and to prove that our discipline, disability studies, belongs in academia. Professionalism/Academia-ism can alienate and oppress people. This can cause our work to be diminished or questioned in our home departments and universities, as noted by Catherine Kudlick. This can appear in forms such as being accused that our work within identity politics is really about us being too self-absorbed, and that one cannot be objective about one's lived experiences.<sup>134</sup>

Another way in which a couple of participants identified how some movements lose people is by diminishing spaces for various forms of activism, especially traditional or grassroots activism. Our work often gets slanted away from activism, and this impacts our research, publications, and the foci of conferences (and, of course, our participation in traditional activism).<sup>135</sup> Alison Kafer touched upon how she wishes that the Society for Disability Studies supported traditional activists more:

It feels academic in the sense that...it gives me an opportunity to see where the field is going, like being on the program committee I get to see what all these different people are doing. But also in terms of thinking about what SDS can do, or can be. But that is also where it starts to feel like activist work. Activist work in the sense that you are doing organizing work and getting people together. But activist work also in that I would like SDS to be more welcoming of activists, and not just activists who present themselves in an academic way.<sup>136</sup>

As previously discussed, many of the participants struggled with what qualifies as activism, identified a variety of forms of activism, and felt as though traditional activism needs to be supported.

At least five participants noted their concern over the diminishing spaces for traditional activism. Amy Vidali discussed briefly how one conference with a disability studies focus felt inhospitable to activism. Susan Burch argued that our disability studies work needs to transcend the classroom more. Eunjung Kim expressed a specific concern with the disconnection from everyday lived experience in feminist disability studies and how this has been a barrier for her:

A lot of scholars who have done feminist disability studies didn't give me a lot of strengths or empowerment to expand my energy....I think feminist disability studies theories are adopted as a framework of theories, not as a way of living, not from the experience of frustration, not from the experience of being an activist, as a woman.<sup>137</sup>

As Kim expressed her frustration with the disconnect between the lived experience and theory, and how this has been a barrier for her, Susan Wendell expressed concern about this disconnect being damaging as well:

...Disability Studies has certainly gotten going. But I would hate to see it become...so mainstream that it lose(s) its...it won't lose the radical edge, because scholars are always looking for a way to be the latest thing...that's how you get a career started, how you get a job, and how you keep (a) career going [laughter]. So, that won't happen, but it's a...if disability studies gets too far ahead of the progress of people with disabilities in society, then there will be such a disconnect. And I think that would be (sad).<sup>138</sup>

Traditional activism is grassroots activism, street activism, an activism that is connected to the everyday lives of people, and is concerned with hands-on social justice. Participants expressed both concerns about a lack of support for traditional activists in our academic communities and about the fact that our academic communities have become too driven by theory and disconnected from the everyday concerns of people with disabilities. The large disconnect between feminism, traditional activism, and disability studies raises enough concerns that nearly half of the participants noted it to one degree or another as a potential barrier to coalition building. This is why I propose a specifically feminist disability studies definition of activism that addresses these concerns, which is a central concept that I flesh out throughout this dissertation.

I witnessed this resistance to traditional activism and feeling “not disabled enough” with a good friend and colleague at the first Society for Disability Studies (SDS) conference, which I discussed with Amy Vidali. It was a fascinating experience, because this woman is a very good friend of mine, so we were almost always together at the conference. She uses a wheelchair, and she is a brilliant and brazen disability rights activist—and was, at that time, not a traditional academic scholar. When we met new people they would often talk to her and completely ignore me, or ask her who her assistant was (referring to me) or ask if I could be borrowed to help assist them in some manner. I believe in interdependence and in being a part of providing any kind of accessibility for anyone at any point (to the best of my ability, but in consideration of my own barriers as well). My friend would often quickly correct them, however, and tell them that I was not her assistant but rather a doctoral student attending the conference. Then, the conversation would frequently shift into questions about what I was studying or researching. At this point, the attention would usually be on me, and



my activist-centered colleague and friend would feel ignored. It seemed they would acknowledge her because she was visibly and physically disabled, or they would concentrate on me because I was an “academic.” It was so consistent and blatant that my friend and I discussed it throughout the conference.

We shared tears and frustration over it. We had been excited about the conference and theorizing about disability rights. Yet, we both felt heavily dismissed or disregarded multiple times throughout the conference, and in juxtaposition to one another. It was wonderful to go through the experience with someone I was close to, however, and to discuss it and support each other during the conference. Not feeling disabled enough, or not feeling academic enough (e.g. not knowing the literature, the politically correct language, or the professional connections that people seek to promote themselves) has been a barrier to coalition building at various times. These forms of internalized ableism can deter people from attending conferences again and creating bridges across disabilities, institutions, disciplines, and, as critically highlighted here, can impede enacting social justice.

Susan Burch touched upon the frustration of some within disability studies communities that their work is limited if they are not disabled, or not disabled enough, when she noted, “I bridle at the suggestion that I am inherently limited because I am hearing.” On one hand, a person can feel excluded from the disability studies community for not being disabled enough, not being disabled, or not being academic enough. On the other hand, not feeling academic enough may come about from being more involved in traditional activism, being new to the discipline, or, as Susan Wendell mentioned, that the theory and academic side of disability has become or could become too disconnected from the everyday experiences of people living with disabilities and impairments. This can happen when we are too wrapped up in our complex theories, when we should also be noting and discussing our differences across inter-minority group dialogues and our various lived experiences as individuals. It is a problem if we become detached from the minority group’s experiences.

The ways in which we distance ourselves from each other can contribute to ableism, as well as other forms of oppression. A common issue that came up among several of the participants was the tension between wanting to find one’s coalition, hoping that there would be a safe or comfortable space, and possibly being so disappointed by those in your coalition that one might leave. It seems, however, as though the manner in which we view and harness

this tension, as well as, of course, how we treat each other in this process, can make or break coalition building.

There is always inter-minority group politics within each frame of analysis or school of thought around a study of identity (e.g. women studies, queer studies, disability studies, black studies, deaf studies, etc.).<sup>139</sup> There are always multiple and intersecting forms of identity and power within each group, which will nearly always make us vulnerable to covert, overt, intentional, and unintentional forms of oppression by other people we view to be like us or similar to us. These tensions can also be greatly ignited and fueled when we are, or feel we are, in competition with one another for resources or academic prestige. Brenda Brueggemann raised a couple of these concerns as well, and discussed how resistance and barriers to our work (and inter-minority group work) can create competitiveness, as well as fear or stigma over one group's type of work being too radical.

Yeah...I'm trying to think of the best way to say it. It comes from two angles. One is that...all of the, not all of the, but pretty much all of the leaders of the first kind of disability studies (material) in the United States, in particular, all of the original policies, laws, acts, organizations, have been founded by men. And I don't think they resisted that, in not wanting women, but it is just there. And I sensed in the years earlier, even a decade ago, when Rosemarie would run around saying, "Well, this is all wonderful in Disability Studies, but we are reinventing the wheel. Women Studies has already talked about all of this." That would actually only piss people off even more, which is understandable, nobody likes to be told that, you know, you've already, but she would say it in a pleasant way, but that's just it, you know, we were just discovering this, and you know then (you) have to learn that it already has been discovered, and (they) say, "No it hasn't." ...and, then, I think also because their fear, and understandably so, if that we say that it is also about feminist studies, or women studies, that means we're limiting it to only gendered issues. And I have been at many conferences several times at SDS, where I have literally experienced first hand male members of the conference stand up and be very upset about that. Because they assume that when we talk about feminist studies or women studies that we are only talking about women. And that's actually our fault. We have not articulated that well enough. So, that's been a recent piece as well. And the fourth one is the way is the way in which that they put people, like Deaf people, and some (ways wanted to) just be mainstreamed, and, ...if we (trot) ourselves with being a part of feminist studies or women studies, (we) just (sound) kind of radical, and, we just want to be normal...not normal...but we want to be mainstreamed. We want to fit in. You know, we want to do good, be good, and be productive. And that's especially (when I get out) in the community, which outside the university and with people who work out in the community. You know, "I just want a good job. I just want a good job, and transportation to that job, and I don't want all this feminist, radical...gotta have my rights stuff. I just want a job. I want to be able to vote, or (write), and be able to get

into my own house.” (They are asking for very little.) And they don’t see those things connected, so (you’re right). Those are just a few. Kind of like the mainstream resistance. They see it as a radical, as that it is somehow radical.—And on the flip side, women studies, African American studies, (are strongly), I’ll just say it, you know, on tape here, have resisted disability studies. I guess, I don’t know, it’s like it fragments the picture (for them). It’s like even more that they have to deal with, and that is hard. And there’s this thing, you know, when you are in an environment, particularly (in America), (where) we compete for these resources. So, and African American Studies Program and a Disability Studies Program, those are both small programs within the whole university picture. They are competing for resources, and it [is] happening right here in Ohio State. They have an Asian American Studies Program. We have Latino Studies...we’re all competing for the same (goods). So, we end up...I had a colleague say to me a couple of weeks ago at a meeting, he turned to me and he said, “Isn’t it interesting, don’t you think, that students are now avoiding dealing with racial issues and taking courses in Native American Studies or African American Studies by taking Disability Studies courses.” ...And, you know, he meant it. You know, he wasn’t meaning to be snide or...I mean...that was just really what they thought. He just really thought that they wanted to avoid those issues, and so somehow going to disability studies...(I said), “Now I don’t doubt, I really don’t doubt that there aren’t students who don’t think that.” I mean they don’t think it consciously, that somehow they have had enough of African American Studies, so they just going to, you know, pick up the diversity thing...Cause in identity studies we put ourselves out in all these little areas, and, then, we have to compete (...).

These inter-minority or identity politics tensions and concerns are of course not a new topic or point of contention for any form of identity and diversity studies. However, the reflections by participants on this subject were heartfelt, passionate, complex, and desiring. They wished for better understanding of and respect for the tensions and discomforts that occur when doing any kind of identity politics activism or scholarship. Considering that it remains a persistent and critical topic of discussion, we need to continue to talk about how to make this process of working together as effective as possible. It can be a barrier to an individual and possibly the whole movement if these issues shut down communication, or make one individual leave the movement (or their form of activism)—due to the discomfort, discrimination, internalized oppression, and external oppression faced within a group, or amongst identity studies groups. We need to grapple with how one group can potentially further oppress another group with distancing discourses and the issues that come with wanting to find a great big, warm “melting pot” in which to soak and wash our differences away.

Amy Vidali discussed this tension, of wanting and seeking out camaraderie via

commonality, and how this expectation can prohibit a movement from progressing at times:

You know...that we all kind of have defined what is in common...you know...it's all very kind of one love multiculturalism. I think Disability Studies can be that way. I understand, because I need that...right? I need to come here and see other people who do what I do, but I'm hoping that we can maybe move toward talking about the differences. You know...how our work is not all alike...how the kind of papers I give, that I consider disability studies papers, at my national conference are nothing like the papers I give here. You know...and just to talk through that a little bit, and I think that is just where the field is at, but I'm excited to see a little bit more that. And I think we all come here and to some degree think...we're maybe a little bit more alike than we are. And that is very comforting, and I love it, but it can't go on forever.<sup>140</sup>

Just as Susan Wendell talked about how certain muscles would not relax in her body until she went to a conference with people who were facing similar issues, Amy also recognized this desire and need to connect with other people and to work together toward social justice. However, it becomes dangerous to the movements when we essentialize a perspective, or even ourselves, and do not allow for the complex and often contentious intersections of privilege and oppression to be discussed, confronted, and potentially lead to change from the process—and do not allow for disciplinary or varying activist perspectives. It becomes a barrier when we go to a place where we expect to find one another on common ground, only to find, for example that the other person is intentionally or unintentionally xenophobic, albeit a disability and women's rights activist.

Eunjung Kim also grappled with this issue about how she is trying to grow more comfortable with not expecting to feel at “home” in women studies, disability studies, or feminist disability studies (i.e. places where everyone understands and is pursuing social justice in the way an individual perceives or expects) so that she can remain in such spaces to work with others toward social justice. Here is how she answered the question, “What are some of the challenges of being a scholar and/or activist?”:

Um...every day experience [laughter]. Having to disagree with a lot of communities, having to be in either or. Either in this one or that one. And, then, not having a real home. I got stronger to deal with that better though. I don't think there is a true home as an intellectual, and as an activist. So, I don't feel too bad about that. And in disability studies at UIC, I would talk about feminism, and people were like, “Oh, ok.” And in gender and women studies when I talk about disability they are like, “Oh, that's great. Let's get together.” They don't try to put it in their own works. It's something you can address.

Kristina Knoll: Yeah, “Come give a guest lecture.”

EK: Right. Yeah...yeah totally...and then adding Korean nationality to that [laughter]. Yeah, I think those are challenges. Negotiating hierarchies among colleagues based on racism, I didn't really feel like I am in a feminist community, while I was here in the U.S.

Oppressed individuals often face this kind of tokenism. Unfortunately, in responding to problems of essentialistic drives within a coalition, some coalitions tend to respond by only inviting one or two Others to speak on the missing issues. The Others are expected to “fill in the gaps” for everything that falls under the category of their identity/s, be it doing the research, teaching, publishing on disability, or expecting, for example, the people with disabilities to figure out how to make a conference, department, or party accessible. This can also feel like covert ableism, because the designated token/s often become targeted for all of the information and issues related to that minority group. This is not to say that we should not be doing these things, such as hiring people with new perspectives, but that we would like to believe that if people understand oppression that they would actively work to understand and unravel all forms of oppression. Tokenism can happen at a larger university, on a departmental, or on an individual level. We need to be aware of it and work collectively to resist these tokenizing tendencies.

Georgina Kleege also discussed with me her frustrations with faculty within the university not taking up disability issues:

Well, the biggest challenge is that the culture is still resistant to these ideas. You know...it's still my experience that when people ask me what I teach and I say, “disability studies,” there is still kind of that moment of, “What does that mean?” So, I find myself still having to explain it. And so that kind of points to a certain resistance. On the other hand, one thing I have been observing lately, because there is a disability studies presence on this campus, and there is a minor and there are various courses and course listings and so forth, I find that there is feeling that, “Oh, they do that. That is taken care of by them. I don't really need to worry about that.” Whereas what I would like to see happen is that...you know...sort of a more general informing of specifically literary studies, since that is what I am doing, with these ideas, so that, for instance, anybody who was teaching, “Moby Dick,” would have to talk about disability. And that sort of doesn't happen now. You know...it's like you want to talk about disability...you take a disability studies course. You know...so it's as if we made a niche for ourselves, and, then, we can be ignored. Whereas I would prefer

to see it...Well, it's like one of the things that happened when women studies became a field was that suddenly when you do a survey of American literature...it's unthinkable that you would not have texts by women authors...you know...to a point that there is kind of a canon...But I don't think that's happened with disability studies. And that's something I'd like to see happen in the future.

From not making any effort to understand a disability studies perspective at all to alleviating responsibility by placing the work and responsibility on someone else, tokenism can often make one feel isolated and frustrated. Tokenism is particularly hard when it happens within women studies or other identity studies circles, in which there is usually, or hopefully, ample attention given to understanding privilege, oppression, and intersectionality. This painful situation can alert us that a change needs to occur.

Susan Burch noted discouragement around feminist and disability studies colleagues not understanding either disability discrimination and oppression or feminist issues, and how this can disappoint us when we expect people to “get it” because of their focus on another form of oppression/s:

I have certainly experienced lots of resistance to disability studies. To be fair...less so in feminist circles. Although in different academic situations, I did feel that I had to explain disability studies to an extreme lack...to demonstrate again the validity in an environment where there were self-proclaimed feminists. I have a very sad memory at the (Berkshire) Conference for Women's History of spending some time with some prominent, superb women's historians who said things that were not merely obliquely ableist, but outright bigoted against disability. And I think there is a lot more that feminist organizations, conferences, activists can do to make an environment inclusive...and just witnessing that, whether I've been the target or a person involved in addressing it...just witnessing it is difficult for me. In disability studies, I think there is a ton of sexism and discomfort around gender issues. I think there are a lot of fine people working on it, studying it, engaged in it.

Kristina Knoll: [Have you experienced resistance to disability studies in feminist or women studies circles?]

SB: In similar ways, I think the idealism of highly educated feminists would naturally take to disability studies, because so many of the ideas really reflect common values. And similarly, the educated, informed, committed disability studies people would naturally embrace feminist ideology, and I think the life lesson that I am learning is that one shouldn't make assumptions about how other people will approach the world, identify it, and so forth.

Similarly, Susan Wendell discusses the inter-minority group resistance and frustrations of

women's studies colleagues not understanding or supporting another form of marginalization (i.e. disability and chronic illness):

...I'm not always sure what is being reacted to. Is it...attention to disability issues? Is it my being disabled, and becoming disabled? I'm just trying to think that, for example, with classes... 'cause I taught the most of the upper undergraduate and the graduate course on research methods in women studies for almost the (whole time I was there). So, I had students there who worked with me on disability issues, and I would rise (...). I don't remember resistance from students...no. The thing is that in feminist academic circles (there is) resistance to a particular kind of analysis, or, especially an analysis of a marginalized group of people within feminism, is going to be mostly hidden and not overt. What I experienced was the expectation that I perform like everybody else, regardless of what was going on with me physically. And...that's (...) disabled female, feminist academic I'm talking...about it. It's very, very...it's painful, and difficult, because you expect them to understand the nature of marginalization, the nature of normalization, and expectations, and so on. And I expected them to get it after maybe the second or third round. But, and, so, when you say, "resistance," that's...you're not just talking about ignorance, you're talking about, "I don't want to get this." Right? [KK: Yeah]. And, yes, I did experience, "I don't want to get this." in the form of having to remind people. And in some cases fight for accommodation...yes. So, that's the kind of resistance I have experienced. But, well, but also the assumption, the underlying assumptions, and the not wanting to...the unspoken assumption that, "We can accept and work with all of this while you are at the margins, but do not imagine in any way typical of the women that we are talking about." Do you understand what I mean? [K: Yeah, right.] "So, don't bring it to the center of the analysis." So, let me give you an example. In...when did I do that? ...In the late nineteen-nineties, I created the second year course on feminism and disability, and I did not use most of the classics of feminist theory. I said, "Ok, we now know that we need an interactionist narrative. We are going to start with that. We are going to learn what that means, and we are going to learn from marginalized women." Women with multiple vectors [of] marginalization ...it was very well received by the students, but my colleagues, some of my colleagues were hurt and upset that I didn't use feminist (names...), and that I didn't...I wasn't teaching them a history of liberal, socialist and radical feminism...So, that...(within that) I ran into some resistance.

Wendell reminds us that individuals can find disability oppression among the academic elite, including those whom we would expect to "get it" (e.g. especially people working within identity and diversity studies). The professional norms around academic work are built on socially constructed ideas of the "right" ways to obtain information, produce work, and normative ways to be around colleagues and students. A lot of these norms are based on ableism and sexism, where the white, heterosexual, American, good-looking, able-bodied male is the most productive, desired, and "good" human being. This type of ableism and

sexism often functions on a covert level, but can also be overtly expressed and experienced. This is also how internalized ableism can get the better of us, whether we are aware of it or not. We try to meet the standards that are socially constructed to benefit certain people and certain types of bodies.

Some identity groups can even work hard to prove themselves as just as capable, just as strong, and just as rational and intelligent as this socially constructed ideal human. This has created ableistic barriers within women studies and even between groups of individuals who have been pathologized and deemed less-than because of their pathology. This can happen within disability movements as well. People with disabilities can be ableistic toward one another. Some people with disabilities have worked hard to prove, “the ‘they’ that we are not.”<sup>141</sup> For example, someone might say, “We may be women, but we are just as smart and capable as men. We are not disabled.” Or someone might say, “We are Deaf, but we are just as smart and family oriented as hearing people. We are not disabled.” Such maneuvers to prove legitimacy, to try and work against stigma and power and privilege in society, might oppress other members of that same group or another minority group. This can also greatly impede our work as feminists, disability studies, feminist disability studies scholars, and other identity groups. Licia Carlson touched upon this struggle and how it can be a barrier for our coalition building and work:

One thing that I also think is a hurdle and is something to work towards is to acknowledge these distancing discourses and struggles, in terms of not wanting to be associated with another kind of disability or another group. One thing that was really interesting in this NEH seminar that I was in, there was a woman who teaches at Gallaudet and one question that kept coming up for her was whether people who are capital “D” Deaf view themselves as having, wanting any part of disability studies, because they don’t view themselves as disabled. And, so, she was talking about the extent to which there [is] a place for disability studies there. In terms of my interests in terms of intellectual disability, what does it mean to not be able to bridge that gap?

Licia Carlson highlights the critical issue of “distancing discourses,” and how we hold other people and groups at bay by not trying to understand a form of oppression, and passing responsibility off onto Others. I appreciate how Wendell uses feminist tools to bring in the disability experience and experiences of chronic illness and impairment into the sometimes contentious space of addressing these issues within women studies. Both Kim and Wendell address the implicit, “We don’t want to get it” kind of resistance to issues of race, disability,



and so forth. It can be a very isolating and painful situation to be the only one or one of few working on a particular issue within a group. It can particularly feel like a “slap in the face” when you are working hard to incorporate all forms of oppression, including issues that are pertinent to colleagues who do not even attempt to understand disability issues.

Intersectional methods bind people who are working toward an identity-based politics through a common, yet also very different experience of being pushed and pulled across various axes of privilege and oppression. Those working toward identity-based politics find commonality through our working to understand how and why differences and similarities impact us. Working across identities and minority groups can be particularly hard to synthesize when systems and institutions are inaccessible, discriminatory, or make us compete with one another for material means to continue our research, teaching, and activism. Susan Burch addressed this issue in our conversation regarding some of the challenges of being a feminist and disability studies scholar and/or activist:

I'd say...convincing colleagues, administrators, widespread society of the legitimacy of what we do, and why we do it. I think there is still a lot of educating that is required, and sometimes that is great and empowering, and a good contribution, and sometimes that is just hard, or frustrating, or exhausting...to be in a situation where one feels they have to make that contribution. Another are resources. In very practical terms, (there) are not ways to find granting institutions that offer opportunities to do research or other kinds of work, when you are doing disability feminist stuff. And that is partly about educating organizations, but it's also partly about the way policies are created. So, they are interrelated (in that sense). Actual access is problematic. You know I study Russia, which is a country which is deeply inaccessible, as are many places in America, still. And my interest in institutionalized people has taught me of the power of both policy and systemic barriers to try and learn about people on the inside, and what that means. So, I think there are very practical barriers, as well as kind attitudinal ones. That's a pretty common story, I think, for both feminist and disability studies.<sup>142</sup>

As most of the participants, including Susan Burch, pointed out, there are a lot of barriers that we, feminist disability studies scholars, are facing in our communities. From having to prove our legitimacy to colleagues and institutions (professionalism), to facing overt and covert racism, to the sexist roots within disability studies, to diminishing spaces for traditional activism and activists, to not feeling disabled enough, to not feeling academic enough, to competing for resources, to distancing discourses between minority groups, we cannot avoid the tensions and contradictions that arise within the social justice process to

make us aware of inter-minority-group-oppressions. We must take risks to address these barriers and be at odds with other people, and, simultaneously, work to find and create comfort in this discomfort in our coalition building and in doing identity-based politics.

### **Encouraging Coalition Building**

As Susan Burch and Eunjung Kim point out, one of the most difficult, but also most encouraging, contributions that any of us who work on identity politics issues can make can include the brave move of speaking up and not shying away from conflict. In this section, we will observe how some tensions have contributed to illuminations and possible transformations, creating more encouraging spaces for doing identity-based politics. Although it is reprehensible to tokenize, when we are in that position we also have the opportunity to possibly shift people's thoughts around disability, sexuality, nationality, religion, and so forth by confronting one another. Licia Carlson also addressed how as part of these fields of study and activism we should not shy away from tension, although it is difficult and painful at times. I agree with her, even to the extent that I find it disconcerting when there is no tension.

Licia Carlson: I think another thing is to not shy away from conflict or tension. I mean I think that, I mean...sadly...or not sadly...I think that is just a part of it...

Kristina Knoll: It has to be there. It's frightening if it is not happening, in my opinion.

LC: Yeah. And as somebody who just, you know, has grown up incredibly averse to conflict, it is difficult at times. I think third wave feminists, dealing with issues of race and post-colonialism...have a lot to say about that and have been crucial in addressing and exposing tensions within feminism.<sup>143</sup>

Considering how diverse our experiences are, and how complicated our work is in unraveling the intersections of privilege and oppression, not to have tensions surfacing would be a warning to me that we are probably not doing the work that we need to do.<sup>144</sup> However, no one who has experienced any form of oppression is so naïve as to think that speaking up about oppression does not come without possibly grave risks, and that one needs to weigh the options. However, if we do not speak up, the tension and opportunity for possible transformation and liberation may not occur. Within academia, for example, there can be a huge difference in risk for a graduate student, versus someone who has obtained their Ph.D.

or, more significantly, someone who has gained tenure. Layers of intersecting forms of privilege and oppression can also play a role in how much risk is involved in speaking up.

While I understand the risk and hold no judgment against those who go the less risky route, I also celebrate and feel encouraged by those who do dare to stand up and speak their minds in bold ways on issues they know will create conflict with other people. I agree with Eunjung Kim that if we could work toward not having the expectation from one another to always get along, understanding that we often have different perspectives, this might provide an environment that feels less isolating and scary.<sup>145</sup> It would place us all in the same boat, and hopefully would encourage and celebrate differing perspectives and accept tensions within the group.

Kim also expresses, however, that it is painful to feel let down by those whom you expect to understand you or your struggle against oppression/s. I also have learned from this type of letdown, and I too have grown to find comfort in knowing that my feminist colleagues can be good friends and colleagues even though we might not always agree and that we most likely will make mistakes in our interactions and work with one another. As Susan Wendell points out, it is difficult when someone does not take up a non-oppressive analysis of disability in their work even after being told multiple times that they are perpetuating an oppressive perspective through research, writing, teaching, or activism. When we can find those who do work to understand and address how they are contributing to oppressive systems, I think we can find some feeling of safety and comfort. Yet, when we cannot or do not feel this way, Susan Wendell also points out that we should not shy away from conflict and even be willing to be ostracized from our academic circles:

I think that we have a pretty good idea of how we can support each other. And I think it is very important to listen. That's probably the most important thing. It's also important to be willing to be ostracized from people, to be willing to say, "There is something to what she says," or, "I believe her." (...) The willingness to accept the ostracism of standing up and saying, "I am not one of you. I am one of them." [KK: Yeah.] I think that is very important, especially with the culture in academia, where there is (such)... constant pressure to be recognized as one of you. You spend most of your career being recognized as, "one of you."

Again, one's comfort level with doing this can depend upon various forms of support, such as class privilege and academic ranking. One's livelihood may depend upon not taking the bigger risks, but perhaps some smaller risks instead. Keeping this in mind, we must also

attend to the fact that oppression may contribute to who feels safe enough to be ostracized. The topic of feeling “safe” within struggles against oppression has been a complex one within feminism. Most of us come to realize that this is complicated, uncomfortable, and often even painful work.

The work that demands “being in tension” requires us also to take breaks away from tension. In some ways, this is what I believe Bernice Johnson Reagon would call going “home” to our safe spaces to get re-energized, so that we can keep going on and doing the tough work (Reagon, 2001). It is within these “home” spaces that Reagon says we find support in order to go back to the spaces that are uncomfortable, in which we work with others to create social justice. “Homes” are where she says we find the comfort, support, and rejuvenation that we need in order to return to the often conflicted and tense spaces where coalescing takes place. We return to these coalitions so that we can work to counter oppression. Reagon tells us not to confuse home with coalition, that we should not expect to feel comfortable when doing coalition building, and that this is counter-intuitive. “Most of the time you feel threatened to the core and if you don’t, you’re not really doing no coalescing” (p. 540), argues Reagon. To those that do not differentiate between the terms “safety” and “comfort,” Reagon is saying we should feel physically safe doing this work, but we should all expect to feel uncomfortable.

One big difference, however, that I see with the conversation of finding comfort and rejuvenation at home, as Reagon articulates, as opposed to the uncomfortable coalescing of social justice work and identity-based politics, is that I believe for many people with disabilities, and likely those who identify as LGBTQ, we frequently have no safe space into which to retreat, that is, no “home” such as Reagon describes. Sometimes traditional, family-of-origin homes are the most oppressive spaces of all. Many of us are not raised in disability or queer pride homes, nor with people who are like us. In fact, we might even be hated in our own homes.

Granted, some people are in homes and/or with families that have been chosen. For people with disabilities this may be an independent living home,<sup>146</sup> but this lifestyle usually occurs as an adult. Many have also been forced into institutions or schools, from nursing homes to mental institutions, which were (and sometimes still are) notoriously oppressive, to schools for the Blind or Deaf, and so forth. Many institutions have contributed to disability

oppression, but some provided a unique space from which a “home” was created and fostered through a shared culture. Some of these unique spaces also helped trigger activism against certain forms of disability oppression, and may mark the first known activist collectives against disability oppression.<sup>147</sup>

For the most part, however, many of us typically do not have a culture of pride wrapped around us from a long history of developing a common bond, and sometimes it is our homes that need the most radical intervention for fighting ableism, homophobia, and so forth. In comparing a womb to a home, Reagon writes:

Inside the womb you generally are very soft and unshelled. You have no covering. And you have no ability to handle what happens if you start to let folks in who are not like you.

Coalition work is not work done in your home. Coalition work has to be done in the streets. And it is some of the most dangerous work you can do. And you shouldn't look for comfort. Some people will come to a coalition and they rate the success of the coalition on whether or not they feel good when they get there. They're not looking for a coalition; they're looking for a home! They're looking for a bottle with some milk in it and a nipple, which does not happen in a coalition. You don't get a lot of food in a coalition. You don't get fed a lot in a coalition. In a coalition you have to give, and it is different from your home. You can't stay there all the time. You go to the coalition for a few hours and then you go back and take your bottle wherever it is, and then you go back and coalesce some more.

It is very important not to confuse them—home and coalition. (Reagon, 2001, p. 543)

It seems as though we ought to work on ways to balance this with respect for the process and those who place themselves in this often downright painful and uncomfortable work. Perhaps we can find comfort in each other in knowing and respecting that we are in this together, even if we are conflicted and unsure of each other. Perhaps we need to literally take breaks and make “homes” for those who feel antagonistic to our causes, but are working hard toward social justice. We do need times of rest and peace to keep doing social justice work, and we may not have a place to do that.

To make identity-based politics and feminist disability studies accessible and accommodating, we need to create and theorize about the need for spaces of retreat, relaxation, and de-stressing while doing this critical and complicated work that requires the emergence of tension—and we need the voices of women with disabilities to help us flesh out the tensions and opportunities for liberation. As Eunjung Kim expressed, we need to “rely on disabled women's perspectives, because they... they are caught in the middle, and

their voices are lost in the middle.” We need to discuss this process more: that coalition work is inherently uncomfortable, exhausting and sometimes downright painful; that perhaps we can find comfort in the collective process of discomfort and critique; and that we do need to be brave enough to create non-oppressive homes, food, and so forth for people in this process with us—even when they (and we) perhaps have a lot more learning to do about how they (and we) are being oppressive in a particular way. I anticipate that feminist disability studies will continue to provide more insights into embodiment and impairment perspectives, and how and why embodiment and impairment theories apply in making identity-based politics accessible and accommodating.

Our main common goal is to fight oppression, although we have many varying ideas as to how this should be done, and what should take priority. Eunjung Kim and I discussed these issues, and she voiced her concerns and promoted the idea that we should be less concerned about feeling “safe.” She also encourages, within the framework of not assuming camaraderie, methods for working together toward social justice in less oppressive ways. One critical tool she offers is her analysis of how and why we should be keeping inter-minority group politics and communication central to our social justice movements. Kim also addresses important points regarding the difficulties of finding places of comfort:

I think to say a lot of criticism out loud is a great way to do it. We need to disagree more often, and not worry about feeling safe too much. Like not worry about, “I’m not feeling safe.” I’m not a very expressive person. It takes a lot of courage for me to say things in front of people, so I am trying to encourage myself to do it, and trying to feel good about it. I try to think of people who can inspire me, who show those strengths without worrying too much, but still respectful of other people. I think we should have a great friendship, great feminists around each other, so that we don’t get isolated, and don’t expect certain things, because that person says that she is a feminist. That has been my struggle. I expect certain things because they claim that they are feminists, and it doesn’t fit into my expectation and sometimes people can be unaware of racism while being feminists. I feel betrayed, and it affects me a lot. People can get hurt by someone who one thinks in one’s own category, I think. We just can’t assume those things, even if one belongs to one minority category. We need to recognize inter-minority group politics. It’s easy to talk to the mainstream, but it is harder to talk to other minority groups. So, it’s not always between the center and the margin. It’s among groups in the margins. Inter-minority group tension and conflicts, all of those politics need to be addressed more often.

Kristina Knoll: Do you have any ideas how that can maybe happen?

EK: I think to find people, who have both categories, both identities are the perfect

start. Let's say...when we want to resolve the conflict between feminism and disability studies...we have to rely on disabled women's perspectives, because they...they are caught in the middle, and their voices are lost in the middle.

KK: This came up in a...in a feminist research methodologies class, calling it, "further from falsehood."...It's not about obtaining the ultimate truth, but we are just getting further from the ultimate wrong. I like that idea...it's a continual process.<sup>148</sup>

EK: Right...without falling into the trap of, "the truth."

KK: Yeah.

EK: Yeah, not only, you know, disability and women. But it can be applied to many other different categories, like queerness and ethnicity and nationality. We have to go back to the people who share those categorizations. When the category comes up...there's always an erasure of difference in the category, and usually the dominant one inside of the minority category takes it over. So, let's say we have international people's caucus. We have people of color's caucus. At SDS we have queer caucus, and whenever those things come up, we have to keep in mind that a space for international, queer person of color caucus should exist, because being international (usually foreigners to the US) does not mean that they are persons of color. When we talk about people of color, I never thought of myself as a person [of] color in my country.

KK: Right...right.

EK: So, "people of color" has a connotation that it only applies in relation to white people. But as a political term, as it was developed to include Latina women and other races in the U.S. I think that when we say people of color, it often addresses an American context. My point has always been...we need to look at how we don't have any language to talk to other minority groups. We have a lot of language to talk to the dominant group, and everyone can talk to the dominant group. Everyone is talking toward the dominant group to get more power, to get more rights, but we don't talk to the other minority and minority within ourselves. We assume that we are allies to other minorities, which is not the case in many situations. And it hurts more when we assume other minorities are allies automatically, but they're not. And their fight for justice and the goal of activism shouldn't be just about to achieve power. It should be about deconstructing the power system itself, so that other minority groups can benefit together...Without really having the sense of social justice, I don't think singular identity politics is a very tangible concept. That's why we have to look at other minority groups and how one's activism is affecting other minority, and to be very conscious of the overall impact. Does it contribute to the general equality, or does it replace you into the center?...Conflict among minorities, and the activism's role of creating more marginalization of other groups. One's group activism promoting [an]other group's oppression. And activism, meaning anti-stigma movement, more specifically, and whenever they resist certain type of stigma, and

that stigma doesn't exist alone. Stigma always exists in relation to other images. When you fight that stigma of women being deformed, you end up naturalizing deformity as inferior, preexisting condition that women have to separate themselves from. So, whenever people try to break away from existing stigma, people have a tendency to strengthen the referred group consisting that stigma. Does this make sense? [KK: Yeah]. Disabled people can say, you know, "I have a physical disability, but I don't have mental retardation," which may be true, but, "I'm not those retards," kind of thing that was in *Murder Ball*—like, "We are not those retards." So, which is important to say, because they don't have developmental disability, but at the same time they despise the other disabled person. It ends up promoting other group's stigma as acceptable status of being marginalized.<sup>149</sup>

As Eunjung Kim explains, we must always remain in conversation with people from additional oppressed groups and identities in order to make sure that we are not further oppressing each other by speaking only/mainly to the center. We need as many diverse perspectives as we can get, and at the same time, we should take up responsibility by reading theories from that area, making sure people from various groups are hired for jobs in our departments or organizations, and making sure that we are working with people to interweave discussions among minority groups. This work is not comfortable work, but we do need to work together so that it feels safe and/or maintainable. We do not want to lose people due to hostility or isolation, and yet we must at the same time discuss openly the potential necessity to feel this way at times. We should hold those who place themselves in the middle of this difficult task in high regard and respect each other for the work done, even when it is difficult and fraught with criticisms and tensions.

The issue of feeling safe and/or comfortable can be particularly complicated when something is not yet even viewed as discrimination and oppression. I think this is a particularly tough topic for disability issues, as many of us are in departments working with supervisors, mentors, and colleagues who operate from a medical-model frame of reference, which is often oppressive to people with disabilities.<sup>150</sup> Therefore, a reoccurring concern among the participants (and myself) is the issue of how we can provide space for conflicts and tension when speaking to other oppressed groups, as well as allies who are in "the center" (e.g. people within a certain privileged group who use that privileged group's language and concepts).

Catherine Kudlick touched upon the difficulty of creating spaces for doing this contentious work, emphasizing that there are many different ways that we can do it, and that



the easing of the pressure to do it correctly from the beginning will help create a feeling of safety in acknowledging that there is not “a right way” to go about it.

I think they can help each other create a safe place to talk about complex issues. Of course “safe” is a loaded, and dangerous word actually. It can be authoritarian. And I don’t mean just in the post-September 11<sup>th</sup> context of everybody wanting to be safe. But I think this call for safety all the time doesn’t do people much good. You’ve got to have a place where people feel that different points of view can co-exist in a productive way. And I think some people interpret safe as only creating an environment where only certain kinds of voices get heard. It’s hard to pull off, but I think that’s how we can support each other...is to let people know that, “there are many roads to Rome,” and that there isn’t necessarily orthodoxy and that disability studies, just like feminist studies, is a work in progress, and there’s lots of entry points. And people are at different points in the process. I think we can as scholars and teachers and colleagues, and whatever...create a sense that there’s different ways to be doing this work, and that it’s ok. And that’s really helpful.

Catherine Kudlick points out that although many of us have the common understanding of working against disability oppression, we may be coming at it from different perspectives—such as grappling with various forms of oppression via activism from a different discipline, or being newer to the disability studies or feminist scene. I have been doing feminist work for probably about fifteen years now, and I know that I have just “scratched the surface.” We must provide room to learn, and create and encourage methods that support and promote such learning.

Susan Burch and I discussed this dilemma as well, and how we might model or teach how to be receptive to conflict, tension, and criticism, recognizing that this is inherently a part of doing this kind of work. We are always both students and teachers. Susan Burch does an excellent job of explaining that we need to take it beyond our traditional places of teaching as well:

...That is one that I will be deeply judgmental about. I think to be true to feminism and disability scholarship, and then enhanced when you bring both together, we live interdependent lives, and in order for the movements and the movement to move forward, we have to embrace our relationship as a community, especially those of us with privileges, you know, who are (in) mentor positions or positions of influence, or with resources. I would hope...would respond to the obligation that they have...that we have to share in that, and to cultivate, and within that to really embrace the issue of empowerment. I think we mentioned before that one of the things that I really hope will come to be a distinguishing feature of feminist disability studies is the intergenerational engagement that goes on in ways that encourage newer generations of activist-scholars to truly be themselves, and to take the movement where they also

believe it can go...that not to have to replicate earlier models...that it's really infused with (life) and energy and creativity...in that way. And (moving for) as much egalitarianism as much as possible, particularly in academic environments. I think it is easy to slip into a traditional power dynamic, and speaking for myself as a professor who enjoys being in front of a classroom and sharing information and imparting it, it certainly feeds the ego, and I appreciate the prestige and all the egotistical stuff that goes with that. I'd like to think that we all at the same time, work to be mindful of that dynamic and the power that professors have over students, even over other colleagues, and staff, and others in the world. And to undermine that as quickly and early as possible, so that we are actually being equally human, and honoring the dignity of everybody.

Kristina Knoll: ...When I teach I make it really clear to students that it is a good thing if you criticize me. I'm not perfect. None of your faculty members are perfect. Every person has things to learn, so challenge me. Point it out.

SB: Right. That's important modeling to learn to do that, and to learn to do that respectfully. You know...at least my experience in graduate school; it was very easy for people just to say critical things...I mean negative, critical things in an effort to seem powerful or smart, or whatever. And there is so much more that we can do to be critical in an analytical way, or even challenging. But to do it in a respectful way is a tougher...tougher process, and one that I think we have to (do).

As Susan Burch discussed, we want to embrace tensions, and discuss ideas about better ways that we can be critical and have tensions among us, and to do it respectfully, in a way that supports coalition building. I struggled over where to place this section regarding balancing "speaking up" and possibly being ostracized and trying to create spaces where people can speak up and be supported. It is encouraging to me that this was a topic about which several of the participants felt passionate, and yet the process itself can feel very difficult and can easily become a barrier as well. *How* we handle these situations and work together is key.

At least nine of the eleven participants explicitly addressed various components of this concern and the goal of balancing these tensions with self-care and care for one another.<sup>151</sup> In summary, most of the participants recognized a need to challenge one another, to criticize one another, to not be overly concerned with feeling "safe," and to be willing to risk ostracization by speaking up for what one believes, and, yet, a need for all of us to work on ways to do this in a manner that is respectful and allows space to make mistakes, learn, grow, and not be made an outcast. This means that we should strive for not making mistakes, knowing full well that we can and will do so, and that we will be challenged on it. We need to recognize that this is personal and emotional and that there is an expectation for

us to learn how to engage in this uncomfortable process with one another respectfully. While the experiences of these tense moments are often difficult, and can easily become barriers to coalition building, they also provide opportunities for transformation. I suggest a shift in our focus toward why such spaces are important, *how* we can best manage these moments in respectful ways, and viewing such interactions as opportunities for liberation, and thus possibly even encouraging and exciting. Therefore, I decided to put this section on balancing the tense moments, where potentially different outcomes of “speaking up” present themselves, in the “Encouraging Coalition Building” section of this part of my dissertation on “Toward an Identity-Based Politics.”

It is a big and encouraging step to put these issues of tensions and discomfort within the coalition out there and to discuss our shared desire to respect and support each other in this process that allows us to be different, to be at different stages in our learning, and to make mistakes without being ostracized. We need to work through the conflict and understand how various forms of oppression function, and how they are interlocked or co-dependent on each other. We need to accept our varying emotional and intellectual reactions in order to begin understanding and dialogue about the process and benefits of this often intense interactional and intersectional learning. We should give credence to those who put themselves in that vulnerable spot of possibly being misunderstood or misunderstanding, causing embarrassment at how wrong one can be at times, yet remain open and working hard at expanding their emotional and intellectual knowledge of privilege and oppression.

At least seven of the eleven participants articulated aspects of coalition building that they considered highly important and encouraging, yet also hard and painful to do at times. Susan Schweik and Licia Carlson both encourage us not to be afraid of or shy away from conflict within feminist disability studies. Susan Burch and Catherine Kudlick talk about how it is important and good to critique and challenge one another. Kudlick discussed how this can even be exciting at times, and perhaps embarrassing. Eunjung Kim discussed that we should be better at criticizing one another, and Susan Wendell believes that we need to be willing to speak up and be willing to be ostracized.<sup>152</sup>

Trying to figure out how to manage such contentious spaces within coalition building is not a new concept, but one with which Black feminists within feminism have grappled. These Black feminist theories emphasize the need to always incorporate differences, and to

not submerge ourselves deeply into discourses and practices that utilize vulgar social constructionism, an anti-essentialism that questions categories or identities altogether and erases differences (Crenshaw, 1991, p. 1297). Crenshaw also highlights the criticalness and fruitfulness of these conflicted spaces of intersectionality and identity politics in “Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color” (1991):

With identity thus reconceptualized, it may be easier to understand the need for and to summon the courage to challenge groups that are after all, in one sense, “home” to us, in the name of the parts of us that are not made at home. This takes a great deal of energy and arouses intense anxiety. The most one could expect is that we will dare to speak against internal exclusions and marginalizations, that we might call attention to how the identity of “the group” has been centered on the intersectional identities of a few. Recognizing that identity politics takes place at the site where categories intersect thus seems more fruitful than challenging the possibility of talking about categories at all. Through an awareness of intersectionality, we can better acknowledge and ground the differences among us and negotiate the means by which these differences will find expression in constructing group politics. (p. 1299)

These brave moves of speaking up and challenging the group politics encourage discussion, and often trigger individuals meeting each other to discuss their common and uncommon grounds. Taking risks, such as speaking up against injustices, brings impetus to part of the necessary tension in the feminist disability studies community, and the tensions that come from doing identity-based politics. It is this conflicted process that brings us together because it allows for difference, but the varying ideas, opinions, privilege, and various forms of oppression that bleed into a coalition also cause wear and tear on that coalition. It threatens to disenchant us with other coalition members, and even the coalition at large, because we may both want to ostracize someone, and we may have experienced being ostracized or demonized for speaking up or not acting in accordance with the coalition’s expectations and norms built up within that coalition.<sup>153</sup>

I respect my women studies colleagues, not because they are all-knowing and perfect feminists, but because most are hardworking and feeling people who want to and do fight oppression. I say this even though in my first quarter of my graduate program, I was discriminated against by a faculty person, which forced me to teach everyone about disability oppression and disability studies. I decided not to pursue any formal repercussions against the person who discriminated against me. She was very upset and crying when she realized

how she had been oppressive. She apologized to me, and, most importantly to me, she was the first to incorporate disability studies articles into her large women studies lecture class—with my guidance. This learning moment for her (because she was open to it) had a ripple effect that educated hundreds if not thousands about ableism, even though she did not fully understand or agree with it at first. This does not exonerate her or others from future exhibitions of oppression, but it does build confidence in me that she is willing to work hard to understand oppression and create liberation. It would be a different story if a person did not try, did not care, and continued to be oppressive. Someone might be relentlessly oppressive in another manner as well, and not change over multiple opportunities to learn and grow. Then, I agree that we should be tougher in our reactions and choices with how to handle each situation. However, we are setting ourselves up for failure if we do not provide space to make mistakes, learn, and change oppressive ways. Otherwise, all are afraid to move—and movements require movement.

Feminists typically know well that we are often unaware of how we are privileged and how we are contributing to oppression. This provides an excellent location for exploring and creating change in ourselves and in each other. Not expecting perfection in the individual, but rather perfection in the desire and work of the *process* of the movement, and our roles within it, helps to create sustenance and hope for our movements of liberation to flourish. I really think we do not appreciate this enough, because it can be so tiring and even oppressive at times. As my participants remind me, we are also at different stages and levels in our learning, and in different stages in various areas. We should not expect near perfection in the process; rather, we should nearly always be open to exploring the depths of often deeply painful ways of living with one another in this world. The process is important, and something to celebrate. The fact that it is difficult and uncomfortable is part of what denotes that the process is working.

Many of the barriers to coalition building discussed by participants were often in relationship to conferences (particularly those of Society for Disability Studies, SDS).<sup>154</sup> Tools that were identified as helping encourage coalition building were: speaking up and risking being ostracized, which often led to people approaching the speaker and developing friendships and the possibility of becoming colleagues; mentoring; collaborating; creating humor to decompress pains of oppression; the unique ways that women studies and disability

studies have supported the other discipline and movement; a willingness to make mistakes and talk across identity groups; and to always keep asking, “Who is not here yet, and how can we get them here and involved?”

Women studies as a discipline has been pushing the inquiries of who is missing from our conversations and is trying to bring the margins into the center. Thus there is an intellectual space in women studies that lends itself to being more prepared to grapple with disability studies from a social, cultural, and political framework, and to understand how culture socially constructs certain people to be outside the norm and privilege. Susan Schweik recognized how women studies is more apt to be able to enfold disability studies:

I think there is a lot of structural support that can be given by women studies to disability studies, and you can see that happening. And (Ellen Samuels) who is getting hired at Wisconsin for her disability studies job is being hired in the women studies department. Mark Sherry, when Toledo hired its disability studies job, was placed in the women studies department. As much as you want to talk about ableism in women studies historically, I do strongly believe that that field is by a long shot, scholars in that field by a long shot are better prepared for dealing with disability issues than anywhere else on campus, and have a better tool kit for approaching an understanding of what is at stake, and I think it's no accident that very often women studies is the closest thing to a stronghold of support for disability studies. And so I see this happening on my campus that women studies, however at risk at any given point, is quite a bit more institutionalized, and structurally stable, and powerful. Faculty members there can and do things as simple as finding money for courses, writing letters of support for the hiring of faculty, being on advisory boards, and doing whatever work that entails. So, that can happen, should happen, and is happening—sometimes.<sup>155</sup>

Schweik recognizes the ways in which women studies departments have and can be supportive to disability studies. I have witnessed this as well within my department. Work has been done to encourage affiliations and adjunct recognition with faculty who have a feminist and disability studies perspective, financial support for bringing in disability studies guest lecturers, and a lot of moral support for people who pursue feminist disability studies topics. As noted in the prior section “Barriers to Coalition Building,” however, the competition for resources limits progress. It is encouraging to hear that women studies departments are seeing the critical intersections of disability studies with additional forms of oppression, and seeking out that scholarly expertise by hiring people with a strong disability studies background.

Georgina Kleege and Susan Schweik reflected on how they felt encouraged by the

support they have seen within women studies toward disability studies, such as collaborative projects with journals, including the special issues of *NWSA* and *Hypatia*.<sup>156</sup>

...I am encouraged by, as I say...the fact that so many women's studies programs have embraced the disability studies perspective. And that's something that I perceive as ongoing. And, so, I mean...I think there are a lot of institutional alliances that can take place. You know...within particular university structures. That women's studies programs can help launch, or...foster...you know disability studies courses, programs, or minors, or whatever the deal is. And, then, I think there has been a lot of collaborative work...you know...different journals that have published disability and women type special issues. People attending conferences back and forth. So, I think that is all very generative. One thing...I was talking to somebody at SDS, who pointed this out to me, and I knew this, but it hadn't really struck me was that one of the national women studies conferences is always scheduled the same weekend as SDS.<sup>157</sup>

While there are definite barriers that feminist disability studies scholars face in women's studies, there has also been a lot of support, and a lot of hope on the part of feminist disability studies scholars for more collaboration. Also, as discussed in Parts I and II, the intersectional analyses of privilege and oppression that come from feminist theorists are an intrinsic part of feminist disability studies, and feminism. Therefore, feminism, being the forerunner of the necessity of such intersectional considerations, must take up disability studies analyses.

Although disability studies fits right into feminist theories and tools to understand and fight oppression, as noted in the prior section on "Barriers to Coalition Building," women's studies has been fairly resistant to disability studies theories for multiple reasons, including our general culture being entrenched in able-bodied privilege, ableism, and a medical-model perspective of disability. Most feminists are keenly aware of just how ingrained privilege and oppression can be and that we can even be completely unaware of it, but it is still a long process to unravel oppression, such as ableism. Disability studies concepts are still fairly new for many feminists. For example, feminist disability studies scholars often feel that they have to explain and re-explain feminist disability studies theories. As noted by Catherine Kudlick, however, disability studies scholars and activists tend to already have some knowledge of women studies and feminism.<sup>158</sup> For some, this makes disability studies spaces more hospitable to feminist perspectives.<sup>159</sup>

The Society for Disability Studies (SDS) has been a critical location for emerging

theories between feminism and disability studies, and more than half of the eleven participants have participated in the organizing aspects of SDS at some point. Feminist disability studies scholars have played a critical role in the creation and development of SDS, and SDS has been a wonderful place for many of us who feel alone in our disciplines and theories. It can also be a haven for people with disabilities where norms (e.g. able-bodied privilege) are broken and disability pride is overflowing. Alison Kafer, in contemplating how she wishes that SDS was more welcoming of traditional activism, also reflects on how SDS has been a space of liberation for her personally, and how this alone, therefore, is a form of activism. I believe that this has been true for many, that SDS provided colleagues and friends, when most of us were feeling alone in our work against ableism.

Alison Kafer: ...SDS saved me in a lot of ways as a grad student, because I was working alone and nobody was doing disability where I was, and then there was this place where I could be with my people, and that feels like an activist project, because I think it saved me as an academic, but it also saved me as a person.<sup>160</sup>

Licia Carlson had a similar response to her experience of SDS, having felt in isolation with her work prior to SDS:

The first time I went to SDS was in ninety-five. And I was in graduate school, and actually that is another pivotal moment. I mean that was really...yeah, that was...that was huge. Because I felt like I had been working in total isolation on this topic. The University of Toronto's philosophy department is huge. It's like eighty-five faculty, two-hundred graduate students, and I knew of only one person working on anything remotely related to disability. And I went to this conference, and it was amazing.<sup>161</sup>

Many have had this experience with SDS, including myself. At the same time, SDS, as well as other disability studies conferences, are great locations to explore radical, emerging ideas. As Susan Burch notes, SDS is proactive and tries hard to keep working at being sensitive and responsible to issues that need to be addressed:

And in process...as much as I love the organization [SDS] I'm sure there is stuff that I am not even aware of, and then there are other things that I am aware of that I think we can do so much better. But I trust the people in it to work intentionally toward that, and to deal with the complicated issues in as sensitive and responsible ways as we are able at this point; and the understanding that we might not nail exactly right this time, but we're going to keep working at it, and that is...that mission is extremely important to us.<sup>162</sup>

Susan Burch, who was very involved with SDS at the time of the interview, noted both the room for improvement and the beauty of the SDS gatherings—and the need for both to



encourage coalition building:

...SDS I think is just an incredible organization and space for ideas to really grow and share. I love...just kind of witnessing people, after panels, seeking one another out and having these incredibly passionate conversations. It thrills me to just see a community that's being intentional about community building. I think we are all going to be drawing on each other a lot on the years to come.<sup>163</sup>

Another extremely pivotal conference experience was the Gender and Disability Studies Conference at Rutgers University in March 2001, which many of those who attended refer to simply as "Rutgers." This conference truly helped ignite an explosion of friendships, colleagues, mentors, publications, and collaborations, and was frequently spoken of fondly. I was a first-year graduate student at the time. The following participants were in attendance: Licia Carlson, Susan Burch, Catherine Kudlick, Alison Kafer, Brenda Brueggemann, Georgina Kleege, and Adrienne Asch. I distinctly remember feeling very naïve and somewhat on the margins at this conference, and yet extremely excited. This was also when I first met Rosemarie Garland-Thomson. She went out of her way to talk with me, and engaged me very kindly in feminist disability studies topics, although I was a true novice. Susan Burch and I reflected fondly upon Rutgers as well:

Kristina Knoll: Did you say you were at the gender...you were at Rutgers...?

Susan Burch: I was.

KK: Where were you at in your career, or...?

SB: I was on a panel with Brenda Jo Brueggemann and (Bobbi Buchanan)...terrific Deaf Studies folks, and...gosh...that was about seven years ago. So, that would have been about 2000. In 2000 I had been at Gallaudet University five years. I had taken my Ph.D. in ninety-nine. So, I was a newly minted Ph.D. I had a little bit of teaching experience, and was just really starting to move into gender stuff. Up until that point, I had been mostly...I like the image of dancing [laughter]...dancing around it with (general) deaf history, and was trying make my contribution mostly about focusing on the twentieth century, the early twentieth century, which most scholars (theretofore) have not really studied. But because of who I think I am, and the interest in feminism, I couldn't get past the kinds of rhetoric I was seeing and the sources I was reading, and the constant questions of, "Where are the women?...Where are the queer folk?...Where...where's everybody else?"...in this story...in the primary and secondary sources. I was deeply bothered by the (paucity) of that, which drew me to very basic questions at the outset, in very focused studies...just trying to point to areas where we as scholars need to go further. And that's kind of unraveled into a whirlwind of chaos and excitement in scholarly pursuits.

KK: That was an amazing conference. Another one needs to happen.

SB: Hear! Hear! (irony intended) I hope you will help organize that. Yeah, I think there has been a lot that's happened since that conference as well. Some good books are coming out. But also, for me, partly what is so exciting about this field is that there are new...almost generations of scholars every couple of years going to disability studies conferences...is endless excitement for me. The new ideas that are coming out, and the lack of restriction from traditional models, traditional even in disability studies or feminist rhetoric. And I think there is a real liberating experience of kind of just witnessing emerging scholars coming out with their own ideas that are fantastic and going right off the map...quickly, which bodes well, I think, for everyone.<sup>164</sup>

Susan Burch points out the excitement that can flow out of such conferences and encourage community, and Catherine Kudlick discussed how helping build community helps establish such spaces:

Catherine Kudlick: So, we were at that same conference.

Kristina Knoll: Yeah, phenomenal.

CK: I take some personal credit...not full, but I'm the one who started pounding away at Bonnie Smith initially, and she was so receptive. She is great. But she is one of the people in (French) women's history that I was studying and reading about, and I was looking through this stuff and I called her up on the phone, because there was something she had mentioned or more likely that she didn't mention in her textbook, and I said, "Bonnie"...I didn't know her very well, or, "Professor Smith, Why didn't you include disability here?" And you could hear this silence on the other end, and then what happened, ultimately, but before...or shortly after that, when I saw that she was receptive, I brought her into the Thérèse-Adèle Husson book that I was co-writing with Professor (Zina Weygand), my colleague and friend in France. We asked her to come and comment on our first ideas about the book at a French history conference. And Bonnie said, "Well, I don't know anything about disabilities." "Doesn't matter. That's exactly why you should (comment) on it." She did, and she was fabulous. So, that's what got her open to all this stuff.

KK: So, Rutgers happened after that? I mean...the conference?

CK: Yes.

KK: ...That is really interesting! That is good to know.

CK: It's good to know your genealogy...history. I think she and Rosemarie Garland-Thomson met, but I kind of talked to one, (after) the other one before too. I don't take credit for their actual meeting, but I think I kind of...helped put them on each

other's radar.

KK: Yeah...a part of the cycle of getting things going.<sup>165</sup>

I too have noticed the thrill and potential that comes from simply speaking up, risking putting out radical ideas, and introducing people who also have cutting edge feminist or disability studies ideas to one another. That was a big motivation in my doing this doctoral research project—to help document some ideas and people who have contributed to feminist disability studies. A goal of my research was to map part of the feminist disability studies coalition and to continue doing so, such that more community can be built through friendships, colleagues, and mentors working together toward similar and overlapping causes.

Many friendships and collegial and mentor relationships developed because of unique spaces like SDS and Rutgers, and it was fun to talk about how we have been and can be the best colleagues and mentors—to help build and sustain the feminist disability studies coalition.

Catherine Kudlick talks about all of the ways she tries her best to be a good mentor in this exciting and emerging field, and the hope to encourage it further:

Another way we can support each other is through reading and commenting on written work and sharing it back and forth. And if somebody asks you to do something, like chair a panel or do that...man...I'm so inclined to say yes, if I possibly can, because it's such a new field that we need to be there and helping each other out, and sharing our mistakes is another way to help....What else...complimenting when stuff is good, giving a critical commentary, but with respect, when it's not as good, and saying, "This is how you can do better." I think writing books that we believe in, and continue doing projects that we believe in. Right now I don't think that's so much of a problem because we all share a sense of urgency for doing the work and putting a new view of disability out there whenever we can. I'm thinking that in a few years that it might not be the case. That's my one worry. That as the field starts to grow, people become more strategic and instrumental, and base their choices purely on marketing strategies...that it will become more problematic to have points of view that might not be popular. I don't know...I'm just feeling this...I remember taking the train back after the Rutgers conference with a few people. And we were having the best time...there was this group, six or seven of us, and we were in the train car and we were so happy like we'd been at a birth. We were going back to New York City, and we were all thrilled to pieces that we had had this great conference. We knew that this being at the beginning of something transformative was what the early feminist scholars were all excited about, and we all knew this was a very rarified moment that in a few years orthodoxies would set in, and all that. I don't think necessarily those have set in yet, but it's always my fear. Or maybe they have, but I'm not aware of it...that really

scares me...We can also help by reading stuff in a timely manner if somebody asks you to read something...just little things like that...or going to people's panels, or seeking out people that are doing the work, and being contacted by them, and saying, "Look I believe in this. This is good." You know...all that stuff. There's just this sort of golden rule thing...Mentoring, informal or formal, is really important to younger scholars, or people not necessarily younger...generationally, but younger in terms of their approach to the material. You know...somebody that's been doing women's stuff just this way for twenty-five years, and suddenly, "Oh my god! It's disability!" And they are all excited, and you know you could slam somebody down pretty easily by saying, "Oh come on...that was done twenty years ago...Where have you been?" Rather than saying, "Wow, this is so great that you're here, and come on in. It's a big tent, and you know, and let's think about all of this, and talk together. And you might want to read such and such a book or article."<sup>166</sup>

I loved how Catherine Kudlick talked so excitedly and passionately about the Rutgers conference, and all of her ideas about how we can build coalitions through being excellent mentors and colleagues. She noted how we can give feedback on work, take requests to chair panels, share mistakes we have made (in hopes that others can avoid them), give critical feedback respectfully, and contact people after conferences to encourage them in their work. Particularly important is to be careful with someone new to disability studies so as to not douse their interest by making them feel ignorant for not being aware of particular disability studies topics. Rather, it helps to give a gentle nudge toward information that will help further their interests in feminist disability studies.

Susan Schweik iterates similar points about how little things, such as showing excitement and sitting next to someone, to big things, such as working on hiring someone who has a feminist disability studies focus, encourage the movement and coalition building:

How do scholars support each other? I think by...you know the simplest most every day, but really crucial things, from showing excitement about what someone is working on, to something as simple as scholars showing support to each other by who sits next to who in meetings, and who walks out the door. It's really, really basic everyday things, under the category as not marginalizing basically—something as minimal as that—really profound (laugh). When possible, working on hiring together. Again, women studies positions, departments may sometimes be in a position to help create jobs with a disability studies angle and emphasis. It is not happening too much, but we hope for it in the future.<sup>167</sup>

How we engage with one another can have an enormous impact, and a few participants noted other feminist disability studies scholars who have been pivotal mentors or colleagues. Licia Carlson talked about how Anita Silvers served as a critical mentor on her dissertation

committee, and I told Licia about how a simple lunch with Anita Silvers<sup>168</sup> had a significant impact on my studies as well, encouraging me to obtain a graduate certificate within philosophy to strengthen my disciplinary interests and post-graduate school marketability.

Licia Carlson: I think the other, actually, in terms of pivotal moments. I mean, I think, you know, for me, on my dissertation committee, I ended up getting Anita Silvers as my outside reader.

Kristina Knoll: Oh, really!

LC: Which was amazing, since she was the only person on my committee whom I would locate as a disability scholar. And, so, that was really valuable to me to have her as a part of that.

KK: She gave me some great advice. I just met her once for lunch, but she really gave me some great advice.<sup>169</sup>

Similarly, Amy Vidali talked about the critical mentoring she feels from knowing Brenda Brueggemann:

On a more personal level, I would probably say Brenda Brueggemann. Not because her work is particularly feminist in (orientation). I mean it can be, but just because I see her as kind of a strong person, who is extremely professional and prolific....and, then, our work is very close in terms of rhetoric, disability stuff.<sup>170</sup>

While feminist disability studies mentors impacted Amy Vidali, Licia Carlson, and I in a very positive way, it is important to remember that not all of us feel this way all of the time. Eunjung Kim discussed how she did not feel particularly energized by feminist disability studies. It is important for us to remember to question and work on the ways in which racism, xenophobia, homophobia, classism, Other-ableism (when one is bigoted toward another group of people with disabilities), and so forth can negatively impact our mentoring, and, therefore, also our coalition building. Susan Burch addressed how when we have certain privileges we should work all the harder to be asking, "Who is not here, and why?" and to support those who are not present in developing tools for liberation that might not be like our own. We have to fight for not only the intersectional perspective, but also the practice.

Susan Burch commented on how we need to support new people in the field in a manner that allows them to be different and to explore their ideas without feeling restricted by older models of feminism, disability studies, and feminist disability studies.<sup>171</sup> The same is true for faculty who are new to feminist disability studies (not just the students). We need

to work hard at welcoming and supporting as many people (at their different levels of intersectional awareness) into the identity-based politics of feminist disability studies. Both Susan Burch and Susan Wendell discussed how important it is to read other people's work and give them feedback, and how this provides a supportive network of colleagues.<sup>172</sup>

Wendell said,

Oh, I am not very good on the support issue, because I spend so much time alone in my study [laughter]. What support people get from me they get from reading my work, primarily. I mean, I know, there are people who can call me and email me, and say, you know, "I am having trouble with such and such again"—usually accommodation at a university (of some kind), and I do what I can to help mentor there. But most of the support people get from me is from reading my work, and most of the support I get from people is from reading their work; and some email exchanges, and so on.<sup>173</sup>

Working hard on creating pieces for people to read and comment on is also important in coalition building, and a part of the colleague exchange. Susan Wendell commented on how she best supports people through reading and writing, giving advice on fighting for accommodations, and being willing to speak up and risk ostracization. And sometimes we need mentors and networks outside of our departments and activist circles that can provide feedback and support in areas of privilege and oppression with which our disciplines and/or activist circles may be less familiar.

Licia Carlson suggested additional ways for networking and encouraging coalition building. We need alternative and accessible formats for obtaining support, such as mentoring and collaborating, in order to do identity-based politics and create coalitions. From the use of accessible technology, such as the Internet, to working on ways to keep feminist disability studies and disability studies open and welcoming, she warns against the "distancing discourses" so as to nurture coalition building. As Licia Carlson highlights, we need to work across disciplinary, scholarly-activist, and diversity issues—and this bridging is one of the best ways that we can be good mentors, colleagues, and perhaps friends to one another within feminist disability studies. Brenda Brueggemann talked affectionately about how both Rosemarie Garland-Thomson and Susan Burch have been excellent friends and colleagues, and how they encourage her to explore new areas:

Kristina Knoll: [pivotal moments that brought you to women studies and/or disability studies?]

Brenda Brueggemann: Well, ok, I guess I can't lie about this...meeting Rosemarie Garland-Thomson. I mean, who, you know, by now is by far one of my closest friends, not just colleagues, but closest friends in the world. (She's one) of those people who we'll go for months and months without any emailing or any exchange, and, then, when we have one it's all (hearts)...Yeah, so we'll count Rosemarie.

KK: When did you meet her?

BB: Let's see, I guess it was 1997, the forming of the MLA [Modern Language Association] committee on disability issues, and I actually got on that committee because of this colleague [Andrea Luxberg] was on the MLA executive committee, and this was when I was really coming out as Deaf and disabled, and (Andrea) had asked me that question about gender and identity. She's on the executive committee, forming the committee on disability issues, and she suggested my name. And I wasn't tenured at the time. So, I joined that committee, and the first time I went to New York City to meet with (them), Rosemarie was there and we were just sisters from (the...) that moment. We had connection both scholarly, but also kind of personally. Yeah, that was very strong, right from the start.

KK: I love hearing the connections of how people have met each other and overlapped.

BB: Yeah, almost like romance...

KK: And when did you meet Susan Burch?

BB: Oh wow...and Susan...that might have been the year before in 1996, because I was really fresh and green, my second or third (term) at (MLA), and she was there and gave a paper about AS...American Sign Language Poetry, and, you know, she had just finished her Masters. And she was so brilliant. It took...it's funny, because Rosemarie is ten years older than me, and Susan is ten years younger than me, and those two are by far my closest colleagues and companions, and sisters, and...in the field...So, it's truly almost like a romance, because I would almost feel like I was in love with Susan. She was so smart. How could she be so young, and so smart? [laughter] And her signing was beautiful. You know she is hearing, but they have always said that her signing is so masterful, and beautiful from the start. And then we just had that (geeky) thing where we loved poetry, we loved wine...we loved all these other things, you know, besides academia. We loved (obscenities) too and a sense of humor that we have always shared. We found that we collaborated really well. Rosemarie and I have only collaborated on a couple of things. Rosemarie, the first, probably, to say that she is of the generation of scholars and woman where collaboration (just) was not what they did. But I am kind of in the in between thing, but Susan and I would spend a lot of time chatting about personal things, but would always spend long hours (at night) about academics, and we would find all these interests that we had. That's the other thing about feminist studies, cause Susan put me on to things, because Susan said to me, "You need to...need to look into (Mabel

Hubbard Bell), who was Alexander (Graham) Bell's wife, who was Deaf." And I said, "Yeah...yeah...yeah...someday." And, then, finally I got into it, and it was so fascinating. But they send me into things, into projects that are even more feminist disability studies. And Susan only started out as a deaf studies scholar, and has only recently come into disability studies scholarship, probably because I encouraged her [laughter].

Catherine Kudlick noted as well that we need to work on opening doors to ideas and scholarship, not having taboo areas, challenging others, and being open to being challenged ourselves—and how this process can even be enjoyable at times.

...Every thinking person should be pausing to say, "What does this give me in this moment?" And to be able to be surprised, or to be...you know, mildly corrected, or ready to say, "Wait. You didn't think about that." Rather than trying to head off all the passes and put up the barricades. I'm always kind of excited, a little embarrassed of course, when I don't get it right, but I'm always a little bit excited that somebody has challenged me and how I think about something. I mean that is what it is all about.<sup>174</sup>

As part of this opening of doors, Kudlick also advocates "keeping a sense of humor," which is an additional technique for working through tension and creating encouraging spaces: using humor to counter oppression. I referenced this in the earlier section regarding barriers, when I mentioned Amy Vidali and I laughing, through a shared understanding, at how ridiculous emotional ableism can be. Catherine Kudlick also talks about humor being a central part of her character, and how she identifies herself within this field of study, claiming that we need to learn not to take ourselves so seriously all of the time. Susan Wendell also commented on humor, and shared a movie about disability comedy.<sup>175</sup> It is a powerful tool to connect through humor, and through the arts. Unfortunately, there was very little discussion with the participants about how powerful the arts are for the disability movement, even though disability studies often addresses it.

I appreciated how Kudlick summarized a few different critical ideas so succinctly in the quotes above: humor, maintaining an intersectional analysis, pursuing scholarship, and being open to challenges, new ideas, and corrections. Kudlick quickly synthesized multiple points that have been made in this section about how to create encouraging spaces for our feminist disability studies coalition, and, probably most importantly, discussed how important it is to her to be aware of what issues might not be present. This remains a constant theme within feminist disability studies—to keep trying to get it right, even when it



is hard and challenging (e.g. allowing tensions to emerge). This means always working to create space for new people, identities, and identity-based theories.

As discussed above, it is vital to identity-based politics to make sure that we are working to make our social justice work as inclusive and diverse as possible. We need the inter-minority group dialogues or identity-based politics, and we need to strengthen our skills in communicating with each other, versus always talking to the top (e.g. the privileged, dominant group). Eunjung Kim, in particular, raised this issue, and such dialogues help us begin to understand the complicated dimensions of privilege and oppression (e.g. perhaps the lived experience of disability, impairment, sexuality, and nationality). To understand these intersections we must be able to welcome and hear the perspectives. Therefore, Susan Burch's response to the question of activist components of her work gets at the heart of feminist disability studies. This is the activism that is essential to our theory and related to the heading of Part II about identity-based politics being inherently activist.

Alison Kafer shared how it is critical to juggle all of the different intersecting forms of privilege and oppression in our work, and that this is central to feminist disability studies. We must be asking who is not present, and why, and work toward creating spaces and invitations that bring more people into our conversations and activism. We want and need complex and diverse conversations.

Kristina Knoll: Do you have activist components to your teaching, activism, and/or research?

Susan Burch: Heck yeah. Yeah, I try to not to mask that, but be upfront with my students, because I think it is important to own when you are being manipulative. But I absolutely believe that with education comes responsibility and activism. That there is not a boundary. That is not to say that students must acquire my belief system and act the way I believe an activist should be, and so forth. But part of what I do as a scholar and educator, I hope, in its best sense, is work with others on obtaining or enhancing tools of empowerment so that they can seek their own path in a really effective way. And if that is a path antithetical to my own values, I would rather have that happen and have that person feel like they have tools and that they are aware of it, and that they got it from somebody from like me than to have students who agree with me but who don't do anything about it. I'm a true believer in democracy in that way. But, yeah, I think it's essential, again as a person with privilege, and having worked in the sanctuary of an academic setting to build programs like Women's Leadership Training Institutes and disability empowerment organizations, and to keep asking, "Who's not here, and why?" I think that's the question for both feminists and disability studies folks, to be asking, "Who's not here, and why?"—and to chase after

the answer.

Breaking down barriers that keep people out of conversations related to social justice, privilege, oppression, and identity politics is, or should be, at the heart of feminist disability studies. This has been reiterated throughout my research. That is why discussing how we can create encouraging spaces for coalition building is so essential to feminist disability studies, women studies, and disability studies. We are good at analyzing and being critical of social interactions, which are important tools to have, but we also need to work on, theorize about, and put into practice that which sustains such spaces for critical and emotional analyses of our personal, interpersonal, and often quite painful personal and generational experiences of oppression.

We need to balance working hard to include as many people and perspectives as possible, without tokenizing individuals by making them the only ones. We need to balance daring to speak out on an issue alone, and risking ostracization because of our ideas, while working to create spaces where people are not ostracized for their ideas, and to value and respect those present in our sometimes difficult dialogues. We have to balance not being continually oppressed by a colleague, with space for colleagues to make mistakes, not be ostracized, remain in conversation, and hopefully learn, grow, and change—as we are all entrenched in our cultures of privilege and oppression, and not always aware of the ways that we contribute to oppression.

Risking speaking out helps encourage coalition building, as it identifies one as working on something that another person might approach them on—to create a conference, write a journal article, or pursue some form of traditional activism together. Coupled with this, the first thing that Eunjung Kim expressed as key to supporting the feminist disability studies coalition was to openly critique one another. Speaking up, be it a new issues or a critique of an idea being presented, one on one, in a group, or in a written format can trigger new ideas and interactions. This can lead to priceless colleagues and friends. These friends and colleagues can also become excellent mentors for one another, their students, other colleagues, and each other's students. We support each other and participate in identity-based politics in our departments, universities, and even sometimes our personal lives when we face up to ableism, sexism, racism, homophobia, xenophobia, and so forth. From speaking

up at a lecture about an ableistic remark or the absence of a disability perspective to joking with a colleague about the ridiculous nature of pathology, we are creating and sustaining a coalition together to work toward social justice. These chain reactions between individuals often flow over into having impacts on groups of people, most notably the sustainment of the Society of Disability Studies (SDS).

We need to keep asking whom this chain reaction reaches, and who it does not reach and include, and figure out how to make our networks more expansive and inclusive. This has become more and more central to feminism, and, therefore, is also a major priority of feminist disability studies, as well as our role as feminist disability studies scholars and activists within disability studies. We have and want to encourage a continual awareness by asking, “Who is not present, how can we get them here, and will they feel comfortable enough to stay and talk and work with us?”<sup>176</sup>

## Chapter 7: Conclusion

To briefly recap, I argue that both my research and existing literature demonstrate that there is a feminist disability studies area of study. From the many insightful narratives by women with disabilities represented in literature to the intermingling of feminist and disability studies theories in literature and meetings, such as conferences, the need for feminist disability studies spaces is demonstrated through the liberation it creates for individuals. We need to continually cycle back to the question and concern over who is not present, and work to include and support those who are marginalized.

Participants discussed the ableistic and sexist barriers they have faced within women studies, disability studies, and other disciplines where, for the time being, the convergences and collisions between feminist and disability studies theories are not always understood and supported. On the other hand, feminist disability studies as an area of scholarship and a space for scholarly interaction provides support and a network for exploring intersecting forms of oppression and privilege with disability based oppression.

In addition, I argue that there is a process emerging within feminist disability studies for managing the tensions that accompany identity politics while doing identity-based politics. This is not to say that similar considerations are not occurring among other identity groups, but that feminist disability studies is deeply concerned with developing a process that not only manages but respects tensions and contradictions between identity-based concepts, because these tensions can serve as opportunities for knowledge production and political transformations. There are benefits to these tensions and contradictions, particularly as they provide opportunity for coalition building. Such tensions are the mortar for identity-based politics, so how we handle these moments and opportunities matters.<sup>177</sup>

For example, using social constructionism encourages necessary voices to emerge and reveals new issues and shared struggles with other people around certain systems and structures of power within a society. These points of contention reveal the need for a feminist disability studies definition of activism, in which activism is made accessible and accommodating.<sup>178</sup> Dismodernism, while in conflict with social constructionism, has the potential to reveal systems of privilege by working through the assumptions that everyone is dependent or interdependent. Impairment debates (in conflict with strong postmodernism)

challenge us to grapple with, and address, material realities of our bodies for which social constructionism alone cannot fully account.

In addition, understanding the power dimensions of traditional activism versus scholarly or non-traditional/grassroots activism helps reveal how both contribute to social justice. For example, exposing how traditional activism is revered by most, if not all, people fighting oppression because of its frequent need for and lack of support within academia does not prevent us from also exposing how traditional activism can have some sexist and ableistic components that keep some women with disabilities, and perhaps even feminists, from feeling like true activists. Looking at the importance of scholars and activists with disabilities versus non-disabled allies can also help reveal both the power systems that need to be addressed that keep people with disabilities from obtaining jobs, for example, while showing how non-disabled allies may need to take such jobs at times in order to help transform the systems.

Making the spaces where we have these ongoing identity-based debates feel manageable and hospitable is always in tension with recognizing that we may be ostracized for speaking up. When someone is being ostracized, we can glean information about systems of power from the tensions that create, and result from, such processes of ostracism. The speaking out that leads to tension has happened each time an oppressed group surfaces and exposes oppression; for example, participants speaking up about how their impairment experiences do not fit the social model of disability all of the time, or how their Deafness or ethnicity were not considered within a particular feminist or disability studies space. This “speaking up” and participating in the identity-based political process is activism, and it is essential that we support it.<sup>179</sup>

Feminist disability studies wants to be more attuned to how such tensions often signal learning moments that we want to support and encourage, and invite such experiences by continually asking, “Who is not here?” This, I argue, brings us continually back to the necessity of social constructionism, experience, and identity within our process. In order to work toward an identity-based politics, a concept and practice rooted in feminism, we must also employ disability studies theories that help make this process accessible and accommodating. Otherwise, identity-based politics is not truly doing what it strives to do, as large numbers of people with disabilities and impairments would be excluded without this

feminist disability studies take on identity-based politics.<sup>180</sup>

The arguments emerging from my research and from feminist disability studies remain as prevalent and critical now as they were when the first feminist disability studies writings began appearing in the early 1980s. As I pointed out in Chapter 3, Rosemarie Garland-Thomson and Ellen Samuels also appear to argue for a feminist disability studies process or method that permits or even encourages the use of sometimes contradictory or incomplete theories to come into conversation with one another. This dialectical process can help reveal various aspects of power, privilege, and oppression. While this process may be contentious at times, it exposes tensions that may provide insights into oppression, providing opportunities for transformation and liberation.<sup>181</sup>

The need for, and goal of, feminist disability studies is driven by the impact it has on individual lives, and the liberation it creates. As Garland-Thomson writes in the “postscript” of her reprinted article, “Integrating Disability, Transforming Feminist Theory” she intends, by naming this area of study, to help create a “quacking critter” (p. 42) that will develop into new forms of much needed and recognized social justice scholarship and activism (Garland-Thomson, 2011). She concludes with examples of how naming and creating this feminist disability studies space has created personal transformations of liberation.

It seems appropriate, therefore, to conclude with one of many examples I could use from current disability related debates, and to share how feminist disability studies is an entity that serves as a space and provides tools for me to subvert oppression within my personal life and beyond. In addition, to come full circle (since my first interview was with Adrienne Asch and one of the earliest feminist disability publications is by Asch on this subject matter), the issue of persons with disabilities having rights to life is just as relevant and pertinent now as it was when Fine and Asch wrote their 1982 article, “The Question of Disability: No Easy Answers for the Women’s Movement.”

The Feb 27, 2012 issue of *Time* magazine had an article by Bonnie Rochman, “Early Decision,” that reminds me of the importance of feminist disability studies for me as an individual and for fighting oppression in the daily, personal lives of people with disabilities. Selective abortion based on detected disability in the fetus remains largely unchallenged, and termination of pregnancies because of disabilities continues to be extremely common. As discussed by Rochman, earlier detection of various forms of disabilities and impairments in

utero is becoming possible through advances in genetic testing and represents current debates in popular culture that are quite personal for many of us, including me. Earlier and more detailed information about the genetic makeup of fetuses may permit a wide variety of selective abortions and the oppression of any group of people deemed less valuable. Rochman writes:

Of parents who learn of a prenatal Down-syndrome diagnosis, small studies have found that 9 of 10 end the pregnancy.

...

A single new genetic test can screen for nearly 600 mutations. (Rochman, pp. 37-40)

Rochman poses questions about how far we do and could take genetic testing and selective abortion, reminding us that even selective abortion of female fetuses in China and India are commonplace.

Although Fine and Asch published their article in 1982, and it is now three decades later, this article and feminist disability studies as a whole remains cutting-edge in exposing the oppressive and eugenic tendencies of selective abortion. Reading Rochman's article, while using Fine and Asch's article and analyses as a counterpoint, demonstrates how feminist disability studies brings out into the open internal inconsistencies within feminism that still need to be addressed thirty years later, and remain personal for many. It outlines how horrifying it is that feminism argues for reproductive freedom by using eugenic ideologies that seek to eliminate a group of "defective" people (e.g. people with disabilities and particularly people with certain disabilities). It is not only troubling, but frightening to me that popular culture and media, such as Rochman's article, expose the current stigmas and even genocidal tendencies toward people with disabilities within our culture.

The issues that Fine and Asch examined and that Rochman discusses touch me directly. It was shocking for me that one of my dearest childhood friends, when contemplating genetic testing while she was pregnant, expressed concerns to me that she "*might*" and "*probably*" would keep a baby like me (i.e. one with a learning disability and chronic ear problems). She was trying to figure out just how disabled or defective of a child she was willing to have, and she wanted confirmation from me that my life was not too terrible. She also wanted to discuss with me the heartache that my parents must have dealt with in seeing me struggle, and all of the extra help I must have needed and the costs they must have incurred in dealing with my disabilities and impairments.

I have heard similar stories from friends and colleagues with disabilities, where people seem to have no qualms over wanting to discuss the value of our lives. I also had to sit through a very similar conversation with genetics, disability, and feminist researchers at the University of Washington. Such questions imply a hierarchy of human value from which we are willing to create a genocidal culture. It was shocking and disturbing for me when my friend asked these questions. Instead of succumbing to the sadness and pain of such ideologies, feminist disability studies gives me a group of people and theoretical tools I can go to for comfort, shared anger over injustices, and collective action. I not only feel that I can keep my head held high now in the face of such insensitive and horrific questions, but I can also refute such ideologies on a personal and larger, academic and social level with publications, lectures, and so forth. I, and many others, including the participants, are drawn into this community of feminist and disability studies scholars and activists by daring public statements to counter such ableistic underpinnings of many fields. One of the reasons, if not the most important reason, that feminist disability studies exists and needs to exist is because it creates a network, theories, and processes to address oppression within many individuals' lives.



### **Part III: Research Methods & Positionality**

#### **Statement of Research Inquiry**

The purpose of this study is to discuss what scholars and activists would identify as “feminist disability studies.” I want to locate major themes and topics that may not be discussed often or that appear to be new and emerging key topics for feminist disability studies scholars and activists. The goal of my research was to dialogue with people whose work overlaps women studies/feminist activism with disability studies/disability rights activism, and to see if there are unique aspects of this overlapping and intersecting type of work.

#### **Purpose of Study**

The purpose of my research is to open up further conversation and inquiries among people whose work overlaps women studies/feminist activism with disability studies/disability rights activism. Although I argue that there should be some guiding principles for our process, I do not view my study as a concluding statement, but rather as a further “opening up” of questions, conversations, and, hopefully, interactions between these individuals. I want this research to be an activist tool. I hope that it will ignite more conversations and actions toward more liberating environments for all, through questioning and expanding upon my analyses and working together to create change.

#### **Overview of Interview Questions**

The interview questions were broken down into three categories: (1) “Locating Feminist Disability Studies;” (2) “Resistance, Innovation, and Social Justice;” and (3) “The Future of Feminist Disability Studies.” There were thirteen questions, and four had a couple of follow up questions.<sup>182</sup>

The first section of questions encouraged the exploration of “feminist disability studies”: does it actually exist and, if yes, what does or should it look like? I probed further with such

questions as “3a. Has disability studies informed your feminist thinking?” and “4. Have you taught any classes or workshops that you think would fall under ‘feminist disability studies?’” I also asked, “2. Would you call yourself a feminist disability studies scholar and/or activist?” The final chapter in Part I expands upon participants’ definitions of or resistance to the idea of “feminist disability studies.”

The second section of questions gets at the heart of where there has been, or how participants have experienced, resistance and liberation in terms of sexism, ableism, and additional forms of oppression. This included resistance within women studies/women’s rights activism and disability studies/disability rights activism. This section also grapples with how participants self-identify in a world that seems always to identify us in particular ways. The questions in this section are meant to highlight participants’ self-conceptions and motivations to do work that overlaps women studies/feminism/women’s rights and disability studies/disability rights. I also asked, because I want to consider how we can work together to resist oppressions and work toward liberating environments, “9. How do we, and/or can we support each other, as Feminist Disability Studies scholars and/or activists?”

The responses to both the first and second set of questions often focused on how one is or is not an activist, and trying to flesh out identity on many levels (e.g. including if/how one identifies as an activist and/or academic; disabled, impaired, and/or chronically ill, and intersections with additional identities across various forms of oppression and privilege). Due to many of the questions having the terminology “scholar and/or activist” this ended up becoming a fairly central topic of discussion with the academically-centered activist participants. Part II of my dissertation explores this prevalent interview discussion in-depth. The latter section of Part II celebrates the creativity and tenacity of the participants in their ideas and actions in doing identity-based politics.<sup>183</sup>

The third section of interview questions had to do with what participants thought we (those who are working in these overlapping areas of feminism and disability studies) ought to explore further or start exploring. We talked about our individual and collective goals, and the emergent scholars and activists we have encountered, which discussions I do not include here. Since these were the last four questions during my discussions with the participants, the responses tended to be shorter. Interviews lasted from a little over an hour to over five hours. In terms of responses across all of the participants, it does, unfortunately, feel a bit

unbalanced. Although responses were exciting and informative, due to the imbalance and their somewhat tangential nature, the section was laid aside for future research and publishing.

### **Parameters, Barriers, and Limitations of Research**

A social justice perspective heavily informed my methods and methodology, using critical hermeneutics and feminist standpoint theory. There were many limitations to my research process that caused me to consider and adopt these particular research methods. For example, due to chronic health issues with my ears, which make it hard to fly without pain and sometimes cause me to rely on lip-reading, I had to come up with creative ways to “cast my net” as wide as I could. I needed to limit my flight travel, and I needed to see people face to face. Over the phone would not work. My primary goal was to find people who are public figures in the areas of women studies/feminist activism and disability studies/disability rights.

During the time when I was recruiting participants in 2007 and 2008, the Society for Disability Studies (SDS) conference was held in Seattle, and the University of Washington Disability Studies Program brought in a couple of speakers, making it possible for me to interview five of the participants. This advantage in and of itself was limiting, however, as most of the people who attend SDS are from the United States and are predominantly white. I also feel that SDS has become less activist-centered, which I believe has deterred more traditional activists from attending. I did request interviews with people who are more centrally located within community or grassroots activism.

A couple of activists declined, one had personal family issues come up (but she contacted me much later wanting to do the interview), and one was on the East Coast and we could not find a time to meet within my time and health constraints. That was disappointing, as she is well known for her feminist and disability rights activism and scholarly publications.

The complete lack of voice from community activists is a very disappointing limitation in my research. I bring this up in Part II, discussing how people who are more centered in community and traditional activism surely have some different and insightful points about all areas that were brought up in relation to the interview questions, but in

particular to the “bridging” between academia and activism. This is an area that I want to address when I find further means to continue this research.

It is interesting, however, that how I shaped the research to be inclusive of people who are more centrally located in community or traditional activism spurred quite a fascinating discussion around social justice. Had I not used inclusive language in my questions, I wonder if identity and activism would have emerged as such a paramount element of feminist disability studies, although it is clearly there. Nonetheless, the more traditional activist element is a piece that is missing from my dissertation.

There were only two participants who identified as being of a nationality other than that of the United States. This, and the fact that the high majority have white privileges, also limits the perspectives needed to round out these discussions regarding feminist disability studies. I did try contacting a few additional people of non-U.S. nationalities and people who do not identify as white, but with no success.

There are often certain elements of privilege that can influence one’s ability to attend conferences, including SDS, such as economic and current and generational oppression. Departments often provide full or partial funding to conferences, and a well-paying professorship of course makes it more feasible to attend a conference. This combined with my needing face-to-face interviews (without or with minimal flying) limited the pool of participants from which to select. It is critical to note and reflect upon this barrier and (although mostly unintentional and unaware) racism and xenophobia.

My not feeling comfortable on the phone, due to my chronic health issues with my ears and the need to see the person’s lips, again, limited recruiting. If I were to find myself in a similar situation again, I would fight harder for accommodations, and have IRB/Human Subjects Boards and Disability Services work together to make the research process accessible and ethical for all involved (researcher and participants). For example, I would request that Disability Services work with IRB to create some sort of protocol for accommodation needs in research (e.g. an assistant to call potential participants). I discuss more of these issues at the end of Part III.

Taking into consideration that disability studies is still a rather young field, there is quite a bit of material that addresses the intersections of women and disability and women and queerness. However, modern analyses that address the lived, daily intersections of

disability with race, ethnicity, and nationality are much more limited. Involvement and materials written by people of color and of non-U.S. and European nationalities are extremely limited within both disability studies and feminist disability studies. This is a pertinent issue that remains central to the criticisms of disability studies and feminist disability studies. In “Introducing White Disability Studies,” Chris Bell speaks directly to this issue:

If Disability Studies as a field had taken a reflexive look at itself at some point, particularly with regard to its failings in examining issues of race and ethnicity, there might not be such a glaring dearth of disability-related scholarship by and about disabled people of color. As it stands, Disability Studies has a tenuous relationship with race and ethnicity: while the field readily acknowledges its debt to and inspiration by inquiries such as Black Studies, its efforts at addressing intersections between disability, race, and ethnicity are, at best, wanting. Disability Studies claims to examine the experiences of a vast number of disabled people, yet the form that representation takes is, far too often, a white one. This is by no means a sporadic occurrence. Quite the contrary, the slights occur habitually and, as the preceding examples prove, in various contexts, from published works to conferences. I think it is essential to illuminate the fragile relationship between disability, race, and ethnicity in extant Disability Studies, arguing not so much for a sea-change in this formulation, rather for a more definitive and accurate identification of the happening. (Bell, 2006, p. 278)

Chris Bell’s criticism of disability studies is glaringly true. Although disability studies has reflected upon the ways in which disability, race, ethnicity, nationality, religious status, gender, and status have historically been linked through ableistic ideologies, such as the eugenics movements, there is little current literature by and about people with disabilities who are people of color or of non-U.S. or European descent. Bell walks the reader through a few of the white privileged slants of various disability studies films, scholarship, conferences, and so forth, pointing out critical missing analyses that could and should include people of color. He also rightfully “slams” disability studies in a somewhat sarcastic manner for not addressing readily available intersections of analyses between disability studies and American ethnic studies, for example by only addressing “race” and erroneously linking race and ethnicity as one and the same or at least closely related, thereby collapsing the two. He also provides a few great examples of how various, non-disability studies texts can be used to interrogate the intersections of race, ethnicity, and disability.

Those who participate in disability studies and feminist disability studies must always

contend with the issue of there being a "white disability studies," not only in the content of the scholarship but also in the absence of people of color and of various nationalities in our disability studies work. Perhaps the sheer cost of bringing people together from around the world for conferences has been another barrier. Whatever the reasons may be, it is discouraging, especially when one takes into account the international disability rights conversations that have taken place since the 1970s or earlier, and the conversations that have taken place internationally among women with disabilities. In 1995 at the "World Conference on Women" in Beijing, and at the follow-up gatherings in 2000, there were substantial discussions and organization by women with disabilities.<sup>184</sup>

An estimated 10,000 women representing their governments or non-governmental organizations (NGOs) descended on New York City in early June to make their voices heard in the United Nations "Beijing+5" meetings. Among them was a small dedicated group of 65 women with disabilities from 31 countries around the world...participating in both the overall activities and in a unique training program. (Duncan, para. 1)

International and transnational feminist disability studies does seem to be bubbling just below the surface, and is emerging.

In the introduction to the 2008 special issue of the journal *Wagadu* on "Intersecting Gender and Disability Perspectives in Rethinking Postcolonial Identities," editor Pushpa Naidu Parekh also discusses, as mentioned in Part I, that an in-depth study on intersections between gender, disability, and post-coloniality has not yet been made (p. 12). In summarizing the theories behind her work, she writes:

The analysis in this study is framed by Postcolonial feminist disability theory and praxis that includes an examination of lived experiences, collective knowledge, political engagement, and ethics of responsibility. I also point to the need for specific historical analysis of the (neo)colonialist/imperialist systems and operations of power at the intersection of gender and disability. This study takes into account the expressed, silenced, deferred as well as negotiated subjectivities across the spaces and dynamics of power relations, and examines notions and politics of care, mutual dependency, intersubjectivity, and diverse valences of "marginal and resistance modes and experiences" (Mohanty, 73). (Parekh, 2008, p. 175)

Parekh also identifies some key areas that need further inquiry within disability studies and postcolonial theories, while holding intersectional analyses as central to the queries:

How did the colonized native body become the site of anarchy and in what ways did

gendering/disabling/colonizing processes differ in settler versus exploitative colonies? What connections can be made between the disciplining, categorizing and managing of colonized bodies in the colonies and the colonizer's home grown practices of classism, ableism, racism and sexism in the exclusion and dehumanization of the poor, women and disabled and immigrants in the metropolis? In what ways do interdisciplinary investigations and collaborations inclusive of intersectional analysis of identity categories complicate the construction of postcolonial identities as another version of the colonial centered in the metropolis of global circuits? (Ibid, p. 18)

Parekh suggests multiple issues to which we need to attend, including looking at how various international disability organizations could and do work together, without the more imperialist cultures at the center and in control of such interactions and gatherings. We also need to remain attentive to the increasing issues of war, terror, trauma, and disability, while taking into account imperialist and colonialist histories that influence understandings, terminologies, and treatments of pain, disability, emotional or psychological trauma. While this issue of *Wagadu* is a great inaugural text to postcolonial feminist disability studies, it just scratches the surface of a wide range of intersectional issues that have gender, disability, and postcolonial theory at the core of their inquiries.

The emergent works on race, ethnicity, nationality, and disability direct us to a future of much needed expansion of disability studies and feminist disability studies. We have started unraveling the ableistic connections with racism, sexism, homophobia, xenophobia, and so forth. We have learned that there are deeply interconnected roots between ableism, racism, and xenophobia. The socially constructed pathologies of bodily difference have segregated people deemed dominant from those deemed less-than-human, primitive, more animal-like, defective, and so forth. Discrimination among the "less-thans" has also contributed to the strengthening of imperialist cultures that have bound us with ableistic ideologies, and is something we need to explore further. I hope to find more accessibility and innovative means to further my research by interviewing people who can provide more insights on these critical limitations within my research.

Another limitation that I did not realize until I had set up and was partially through the interviews was that I had been focused on feminist intersectionality (beyond the women studies and disability studies focus). I was focused on trying to get a broad span of perspectives in terms of race, class, gender, nationality, and sexuality. This oversight is due to my research methods and methodologies coming from women studies, and the fact that

disability was hardly ever mentioned (and was never a topic of diversity, let alone diversity perspectives within disability). I was not focused on trying to get perspectives from people with varying and overlapping disability and chronic health issues (e.g. diversity within disability). Although I did get a fairly diverse sample of people with varying disabilities, chronic health issues, and non-disabled allies, I came to realize that the intersections and ways that disabilities and impairments can overlap are very rarely addressed. It seems like an obvious and critical oversight by most in disability studies and feminist disability studies, and is an issue I touch upon in the last chapter (my personal narrative).

In the future, I want to include more people who identify with psychic and cognitive disability rights and pride in my research. A couple of non-disabled participants and I raised concerns and insights related to these diversity issues within disability and chronic health.

Although the participant pool I collected limited some potential critical perspectives, each participant provided phenomenal insights. I hold each in very high regard, and cherish the time and discussions I had with them. Finally, accommodation issues for myself (and for my participants, to a degree) became rather large problems for my study, analyses, and written production of my work, which I discuss in more depth in the final section of this paper.

### **Significance of Study**

This study helps us map out the topics that are being covered in this emerging school of thought. My research is meant to recognize critical thinkers and activists, and to create discussions about the issues that we believe do and do not encapsulate feminist disability studies.

It was incredibly insightful to talk with the participant-scholars about if they would identify with “feminist disability studies,” and, if yes, how they would define it. Although most identified with “feminist disability studies,” not all did, and this provided fruitful information. Among the explanations given for not identifying with feminist disability studies, the most poignant is the concern over breaking people or groups down into smaller and smaller identity categories instead of everyone working together against all forms of oppression.

On the other hand, however, participants felt that “feminist disability studies” is an



important label for acknowledging a certain type of work or perspective, and for being able to identify who is and who is not meeting certain expectations that come with identification as a feminist and disability studies scholar or activist. This makes experience and identity a critical principle for part of the feminist disability studies process. As an activist tool, the label or identity can be implemented as a means of identifying people who are receptive and knowledgeable about topics that need the multiple theoretical frameworks in each discipline.

Not having a feminist disability studies label to identify people could be detrimental to a student who is autistic, for example, and wants to do a research project on autism and pride and is directed to a mentor who only has a women studies perspective. At this point in time, most women studies faculty have little to no disability studies background, and may have a “medical-model” framework that views autism as bad and in need of a cure. Many disability studies scholars do not have a feminist framework that makes intersectionality and non-essentialistic practices central. This can be extremely oppressive for a student who works toward psych-pride initiatives, and is perhaps directed toward mentors who do not have the necessary liberatory tools to explore their topic. Therefore, participants discussed various reasons why it is pertinent for us to have identifiers such as “feminist disability studies,” and I agree.

I was also able to include small portions of my research that help frame feminist disability studies culture and history. Such portions tell a brief story about when and how certain key people within feminist disability studies met in the United States and Canada. In fact, I created a feminist disability studies time line, with which I hope to create a collaborative online space in which feminist disability studies scholars can add and correct information about our area of study and movement. Finally, participants gave feedback on what they deemed as positive and negative toward coalition building and supporting one another in such work. We also looked to the future and discussed what topics we need to address further within feminist disability studies, such as transnationalism, religion, relationships with partners and family members, and so forth.<sup>185</sup>

This study captured additional critical issues that are being grappled with in women's studies and disability studies, such as the dynamics around identity politics and one's role as an activist when an academic. What emerged was a heavy link between being involved in identity politics and one's struggle and/or pride over identifying as an activist. This included

one's social justice actions within teaching, research, writing, and community and/or government interactions.

### **Critical Hermeneutics & Feminist Standpoint Theory**

I began with a particular thesis question that I wanted to explore with participants whose work overlaps feminism and disability studies: "Are there people who do or would think of themselves as feminist disability studies scholars, and, if yes, how would they attempt to define such a school of thought?" No single methodology or method seemed to fit my work perfectly, which propelled me to fuse multiple methods and methodologies, using both critical hermeneutics and feminist standpoint epistemologies. Also, at the same time, I kept disability studies frameworks at the forefront of my mind.

There was a sense of discomfort with some research methods. I, and many other feminist scholars, believe it is a false notion that one can truly distance or disconnect oneself from one's research. Feminist methodologies counter this presupposition, and involve the researcher and work to make the data responsible to the community in its endeavors and its analyses. I was amused when Elliot G. Mishler in his book *Research Interviewing: Context and Narrative* (1986) discussed such research modeling of objectivity as "hygienic," as it implies a medical model of research.

Further, the criterion as to what is legitimate or illegitimate to include in a research report reflects a masculine model of research and "has led to an unreal theoretical characterization of the interview as a means of gathering sociological data which cannot and does not work in practice" (p. 31).

In a wide-ranging critique of the "hygienic" "textbook paradigm" of research interviewing, Oakley observes that "what is good for interviewers is not necessarily good for interviewees" (p. 40).<sup>186</sup> She argues that the emphasis in standard practice on objectivity, detachment, and the hierarchical relationship between interviewer and interviewee is "morally indefensible" and has "general and irreconcilable contradictions" at its heart (p. 41). (p. 31)

Additionally, as stated above, "the criterion as to what is legitimate or illegitimate to include in research" not only reflects a masculine model, but also a medical and able-bodied model. There is no clean and perfect research model that will get at objective truth, but rather more meaningful data will be collected through methods that will be less oppressive and more

liberating. Feminist methods work toward multiple and ever-evolving narratives in order to be true to the many varying perspectives that continually help us “fill in the gaps” (and/or open up new ones). When normalcy of our bodies and minds is a fallacy, so too are our research outcomes, as they are implicitly and explicitly entangled with ableism. Research methods are effective if they work to counter oppression and seek empowerment and liberation, rather than trying to claim some sort of objective, static truth.

Therefore, I have selected methods and methodologies that draw out the perspectives of the participants through narratives, or story-telling. My goal has been to highlight participant voices, as well as my voice, and to be attentive to how my positionality impacts my methods and methodologies. Both privilege and oppression have informed this research project (e.g. in the ways my experiences inform my interpretations), and I have worked hard to articulate these analyses.

Hermeneutics focuses on the process of the author’s interpretation of research data. However, there is a wide variety of hermeneutic approaches, and beliefs around the role of the researcher in the interpretative approach. Objectivist hermeneutics holds that one can obtain neutrality with interpretation of research data:

These positions are objectivist in the sense that they carry an injunction against the bias of the researcher or scholar. On this account, interpretive methods are adequate if they “bracket,” or suspend, the bias of the scholar and disclose the original meaning of the object of inquiry. In this sense, the objectivist perspective bears a clear resemblance to both positivist and phenomenological notions of value neutrality and presuppositionless approaches in research. It resembles positivism in its search for ahistorical principles of objectivity and its emphasis on value neutrality. (Thompson, 1990, p. 252)

Contrary to traditional phenomenological methods and methodologies and objectivist hermeneutics, critical hermeneutics helps break down the idea that one should and could “bracket” oneself and have objective interpretations of one’s research. Instead, Gadamerian and critical hermeneutics highlights how it is important to address one’s social and cultural positions within one’s interpretations of the texts. Janice Thompson clarifies this point in her text *Hermeneutic Inquiry*:

In this sense, Gadamerian—unlike a Schutzian—interpretive work is not concerned with “bracketing” the perspective of the researcher. Rather, the point is to *explicate* how and why the interpretations (horizon) of the researcher have informed the choice of the research question and the research process.

One outcome of this theoretical and methodological position is that there is not a single, accurate privileged perspective in hermeneutic scholarship (Leonard, 1989). Rather, interpretations necessarily change with interpreters and with the questions, historical standpoints, and theoretical schemes or conceptual leanings that inform their research. (Ibid, p. 257)

Acknowledging that my social and cultural standpoints within this space and time impact my interpretations, it is essential to identify and demystify my cultural background to the best of my ability, and to try to realize how these experiences may inform my interpretations in both negative and positive ways. It is also true and quite likely that I could have a completely different interpretation of the interviews over time, and that this is important to recognize as part of the interpretative process of creating meaning (and be responsible for the power this can wield). As Thompson explains, these tenets are central to critical or radical hermeneutics:

Like other postmodern acts of interpretation, critical hermeneutics maintains that texts or messages have a history of the development of meaning and that, with each successive interpretation, meanings are constituted. Critical hermeneutics further operates explicitly on the assumption that not all social actors are heard; that tradition contains many socially accepted meanings that are hegemonic, that represent the interests of a few; and that it is important to demystify socially oppressive meanings that may be unnoticed by participants themselves. (Ibid, p. 258)

My doctoral work in women studies and disability studies has provided a substantial background in various critical standpoints and an understanding of intersecting forms of privilege and oppression. This theoretical background, plus lived experiences through everyday interactions to working within activist organizations, such as the “Disability Pride Project” with Communities Against Rape and Abuse, has developed a keen sense of awareness within me of just how rampant unaware and unintentional forms of privilege can be in our lives.<sup>187</sup> Instead of letting this awareness freeze us, like a deer caught in headlights, we should work to develop understandings of privilege and oppression and to apply these analyses as best we can.

Our interpretations will likely reveal our positionalities, as well as our unaware forms of privilege and oppression. These prejudices reveal critical information in the interpretative and meaning development process. We must be aware of our power within the research and meaning development process, and humbled by our inevitable student position of always learning more and more of the ways we are privileged and/or oppressed. Therefore, within

critical hermeneutics it is important to own up to our location within our socio-political context, and for both the researcher and participants in one's research to be both students and teachers simultaneously.

The purpose of this phase of inquiry is to provide accounts that are a basis for further analysis and a corrective to the "investigators preconceptions regarding the subjects' life-world and experiences." Second, critical inquiry inspires and guides the dispossessed in the process of cultural transformation. At the core of the transformation is a "reciprocal relationship in which every teacher is always a student and every pupil a teacher." ... (Lather, 1986, p. 268). (Ibid, p. 266)

As Thompson outlines Lather's argument above, it is central to critical hermeneutics to make one's position transparent and subject to inquiry within one's interpretations, working toward creating a reciprocal process of deciphering meaning through chains of interpretation with one another and working to understand not only how oppression influences us, but also how privilege may influence us. Critical hermeneutics calls attention, again, to the importance of intersectionality in feminism and feminist disability studies.

I am going to do my best to explain my cultural locations within privilege and oppression, and will provide more detail and analysis later in Part III. I am a white woman, who is unemployed and poor as an individual. However, I have the (relative) privileges of my United States culture in that I can go into debt in order to go to school and to survive day to day. I also have parents from a middle-class background to protect and support me when I am in a crisis. I have the privilege that comes with being seen as a heterosexual woman in a committed relationship with a man. I was born and raised in the United States, and do not have to worry about my national status to maintain my access to work, food, housing, and relationships. I am also a feminist Christian, which has come with some forms of privilege, as well as some forms of stigma and resistance.<sup>188</sup> I face ableistic oppression on a daily basis.

Critical hermeneutics and feminist standpoint epistemologies strive to attend to the power dynamics between people, which is critical to consider when thinking about how and why we employ certain research strategies. Understanding and working to reveal our positionality with research participants and readers allows for more honest engagement and illuminations. Such moments of potential insight can happen when, for example, ~~when~~ identities perhaps come into conflict with one another and expose the social and political

aspects they represent. Those working toward an identity-based politics respect each other by honoring our commitment to this identity-based politics process. Our theories and allegiances to power systems, perhaps implicit and unaware at times, are more likely to be addressed and transformed into liberation when we make ourselves mutually vulnerable in this process.

I too have feared making my forms of privilege and oppression known and have also struggled over critiquing colleagues' positions and theories. Due to both deep respect and not wanting to make anyone feel silenced, I continue to work at trying to do so in ways that hopefully keep people engaged and excited to be fleshing out this complex and very personal process together. Aída Hurtado reflects upon how Gloria Anzaldúa also struggled and dealt with analyzing participant reflections:

So I, too, take Anzaldúa's challenge to disclose at the risk of sounding biased, unsophisticated, unscholarly, and lacking in objectivity. I have chosen a style of writing that communicates to the reader that I admire my respondents, that I do not take their struggles for granted, and that I do not feel I have the authority to judge them. I let them speak for themselves rather than only analyzing their words to make theoretical points. I have chosen to follow Gloria's advice to "put myself into it more," not to glorify myself or to decenter my respondents. I do so in spite of the fact that this may lead some readers to exactly those conclusions, when, in fact, I am trying to enhance my respondents' life stories by not denying my own. (Hurtado, 2011, p. 54)

I hope to respect our process in doing identity-based politics by revealing myself through both my personal narratives and my analyses. It is important how we do this work, however, as I reflect in the chapter on coalition building. I hope that together we can continually refine this process so that we continue to bring marginalized voices to the surface, resist being isolated or ostracized (and discourage such politics), and celebrate these contested spaces in which we make ourselves mutually vulnerable.

### **Ableistic Barriers, Vulnerable Researcher**

Writing Part III on Research Methods and my role as researcher was difficult for several reasons; the first and foremost being that most methods and methodologies do not seem to adequately (if at all) address the function of ableism within research. There are particular methodologies that provide more opportunities for disability perspectives and disability methods and methodologies to emerge and develop. Two of these perspectives

include feminist standpoint epistemologies and critical hermeneutics, as these theories have been applied to research seek out or encourage the possibility for missing perspectives and voices around privilege and oppression to emerge. Disability oppression and able-bodied privilege are sorely missing in research considerations.

In *Qualitative Inquiry and Research Design: Choosing Among Five Traditions* (1998), John Creswell also recognizes that there are many different approaches to research, and traditions from which to select (p. 9). He explains that there are many critical theoretical questions and issues tied to each research method, and that he chooses to focus on the structure of research methods and not on the philosophical issues of each. There is not “a right way” of doing research, but rather there are guides that have been thought through, tested, and proven to be fruitful and possibly (hopefully) more ethical. Therefore, much necessary attention is paid to how and why we do research.

There are many aspects of methodologies and methods that have ableistic components, and the way that research is structured is often oppressive to both the participants and the person doing the research. Such methodological shortcomings have caused me to use a mixed methods approach and a mosaic of theories. There are aspects of particular research methods that are useful, creating some structure for me to inquire about gaps and oppression within research methods and methodologies, and to leave the door open for participants to share in the directions the conversations go.

A critical hermeneutic approach provides a very open question-and-response narrative or dialogue to emerge between the participant and the researcher—more than the traditional, objective phenomenological approach. This style also helped me to ask questions, and to let go of control over the interview process and permit the development of other, unexpected foci with the participants. This process of using more open-ended questions brought more nuanced perspectives on identity and activism into my research, because the responses morphed from my questions and overlapped with issues that the participants felt were critical to address. This method acknowledges the collaborative process of interviewing.

In addition, I am using feminist standpoint epistemologies and critical hermeneutics to counter the ableism embedded in most methodological styles. Central to my research methods is this need to address how research often has ableistic underpinnings. Research is

structured for the able-bodied. Therefore, I am using critical hermeneutics, feminist standpoint theory, and disability studies to help uncover the oppressive elements of conducting research. We must do this for researchers and participants in research who live with disabilities and chronic health issues. Similarly to the importance of understanding white privilege and its impact on research methods, it is pertinent that able-bodied privilege be explored and understood.

Aida Hurtado and Abigail J. Stewart reflect on why white privilege has been, and often still is, overlooked in social justice research in their article, “Through the Looking Glass: Implications of Studying Whiteness for Feminist Methods” (1997):

It also seems like useless “work,” like pressing the already ironed dress or putting clean dishes in the dishwasher—since it isn’t a problem and everybody knows what it is, why indulge in introspective angst that leads nowhere? There is the rub; privilege has the semblance of naturalness that in itself defends it from scrutiny. Much of the struggle in the twentieth century has been to problematize “the natural,” and progressive scholarship has accomplished an admirable body of research problematizing many forms of oppression. But the challenge of the twenty-first century will be to continue the work of the enlightenment—when royalty was problematized and the privilege of lineage was dismantled to provide avenues for democracy to flourish. Race privilege has substituted for lineage of royalty in our time. It countervails class, at times, just like “royal blood” did in the past. We believe in its goodness as former subjects believed in the direct connection to God through their kings. (p. 300)

Similarly, able-bodied privilege cloaks academia and research methods with this unquestionable position of authority and goodness. Most are unaware of it, as there are assumptions about bodily, mental, and emotional normalcy, which are also heavily value-laden. Hence, people of non-white ethnicities, women, and other oppressed groups have worked hard to counter beliefs that have contributed to their oppression, such as a belief that they are less intelligent or too emotional, all of which were pathologized into psychological or medical problems.

Take for example this quote from one of my favorite feminist methodologies books, *Decolonizing Methodologies: Research and Indigenous Peoples* by Linda Tuhiwai Smith (1999):

The ways in which scientific research is implicated in the worst excesses of colonialism remains a powerful remembered history for many of the world’s colonized peoples. It is a history that still offends the deepest sense of our humanity. Just knowing that someone measured our ‘faculties’ by filling the skulls of our



ancestors with millet seeds and compared the amount of millet seed to the capacity for mental thought offends our sense of who and what we are. It galls us that Western researchers and intellectuals can assume to know all that it is possible to know of us, on the basis of their brief encounters with some of us. (p. 1)

I found many texts that have to do with deconstructing racist and xenophobic research methods the most relevant to my concerns and tensions with qualitative research methods and methodologies. They are ripe with techniques for stripping the cloaks of privilege that shroud research methods. However, no matter how much I connect with these feminist research methodologies, the majority of texts are also overwhelmingly riddled with ableistic interpretations and values, although likely completely unwittingly.

The last quote demonstrates one of many oppressive research methods used by Westerners. However, such analyses typically never go further than addressing the oppressive racist and xenophobic aspects of such methods and methodologies. It is the rare case that a researcher incorporates analyses of how a practice was ableistic, and how ableism has fueled racism, xenophobia, sexism, homophobia, and so forth. I used this quote as an example as it grapples directly with a double or triple layer of oppression (in relation to racism, xenophobia, and intellectual ableism). The racism and xenophobia of this method depends upon the assumption that not only is it possible to judge intellect, but also that a possible intellectual difference is bad (and, therefore, becomes a means to subjugate a group of people).

This is often how privilege functions, and can foster intersections with other forms of privilege and oppression. Oppression often begets oppression, and oppression can also be used to liberate a group of people into a more privileged class (in this case, claiming intelligence as one humanizing marker to obtain more respect and status). I am not arguing that one should not claim who they are, but to be careful so as to not further objectify, Other, and oppress another group of people through resisting oppressive forces in the process.

Such belief systems, methodologies, and methods foster beliefs and systems that deem and treat individuals or groups of people as less valuable and less human. I doubt that externalized and internalized ableism having to do with cognitive and psychological disabilities is more rampant in any other area than in the higher echelons of academia, where it is fueled and refueled by ableism that is projected by our colleagues and the systems within the institution. It can be frightening to approach, enter, proceed, and finish academic paths

when constantly aware of how people like you are not considered even to be present or, worse, not welcomed and even possibly loathed by some. These ableistic marks bear traces in all areas, especially in research methods and methodologies.

Where else is what determines intelligence and rationality more sharply defined than in academia? How many of us scholars with disabilities have felt nervous or fearful of sharing our own methodologies and methods to account for not only the participants, but also ourselves as researchers with disabilities and chronic health issues? How many fear articulating research methodologies that protect those of us who are discriminated against in general in academia? For example, awareness of access and accommodations for researcher and participants is null to limited.

Expectations and norms within academia and our general culture are making researchers with disabilities and participants with disabilities vulnerable subjects within our own research. Our dreams, our goals, our livelihood, and our desire to create social justice depend upon accessibility, which many of us do not have. There has been little exploration and discussion of how researchers with disabilities can have new and more accessible ways of doing and interpreting research. Coalition work needs to happen to figure out new and alternative disability studies research methodologies and methods.

Therefore, my primary goal has been to fuse together disability studies theories with the feminist methods and methodologies that will provide the most space and support for dialogues between the participants and me to emerge, as well as my social and political positionality on these insightful yet limited and ever-evolving perspectives to intermingle toward some hopefully more liberating methodological practices. I have sought out methodologies that will, as Smith writes, help me “talk back” or “research back” against ableistic techniques and ideologies.

Part of the project of this book is ‘researching back’, in the same tradition of ‘writing back’ or ‘talking back’, that characterizes much of the post-colonial or anti-colonial literature. It has involved a ‘knowingness of the colonizer’ and a recovery of ourselves, an analysis of colonialism, and a struggle for self-determination. Research is one of the ways in which the underlying code of imperialism and colonialism is both regulated and realized. It is regulated through the formal rules of individual scholarly disciplines and scientific paradigms, and the institutions that support them (including the state). (Smith, 1999, pp. 7-8)

Similarly, one of the key ways in which ableism has been regulated and actualized has been

through research. To get to the point of conducting research, however, one needs access to a good education from primary on up to secondary education in order to get accepted into a university. If oppression has limited one's access, the ability to create counter-ideologies through research, publication, teaching, and creating new laws and policies is significantly reduced.

Sandra Harding also emphasized this point in *The Feminist Standpoint Theory Reader: Intellectual & Political Controversies* (2004):

It cannot be overemphasized that the epistemic privilege oppressed groups possess is by no means automatic. The "moment of critical insight" is one that comes only through political struggle, for it is blocked and its understandings obscured by the dominant, hegemonous ideologies and the practices that they make appear normal and even natural. That oppressed groups are indeed capable of precisely the forms of rationality so highly valued by logicians, scientists, and in law courts cannot become visible so long as those groups are denied access to the educations and practices it takes to make logicians, scientists, and lawyers. That women are physically inferior to men appears obvious as long as ideals of womanliness require women to appear weak and frail, to be discouraged from athletic training, to be encouraged to wear clothing that restricts their movement, and as long as athletic performances such as ballet and modern dance are treated as mere entertainment. (p. 9)

The normalization of what qualifies as success in academia, and who even has access to trying to demonstrate those abilities, limits knowledge production. Also, we need to address why certain abilities are valued, and why we value some people and their perspectives more than others based on these values around perceived abilities. Disability studies will help us to challenge those norms "by seeing the stairs as the barrier" and not the bodily, emotional, and/or mental difference.

Oppressive ideologies that deem certain people to be inferior and incapable of contributing in a positive manner block those people from contributing their unique backgrounds and perspectives. For example, even the last quote by Harding reifies some oppressive norms (although most likely unintentionally) by implicitly stating values around norms of rationality, physical inferiority, and weakness. What I agree with is that we do need to challenge ideologies, norms, and stereotypes about groups of people. However, again, we must be careful not to oppress another group of people in doing so.

One way of privileging certain types of people is by almost always demanding visual or written expression in research opportunities, research funding opportunities, publications,

and dissertations. These visual expectations are often accompanied by highly inaccessible formats (such as online applications that screen-readers are unable to track and read aloud). I also find that when I call to try and get help with filling out online forms, I often face resistance such as not calling me back, even if I call again multiple times.

To some this resistance may seem unintentional and implicit, but for me it feels intentional and explicit, since I am the one facing the roadblocks. For example, a couple of years ago I attempted to track down the dissertations of the participants in my research, but was told that I could not obtain them from the central holding of dissertations in any alternative format. I contacted librarians at the University of Washington and was apologetically assured that it was not possible for me to take out a dissertation for it to be recorded or for us to borrow one from another university to record it into an auditory format. I told them that they should look at the Americans with Disabilities Act and that they probably should start working on changing it pretty quickly.

I recently noticed, however, that on the University of Washington library website there is now a way to get full-text dissertations online, which can make dissertations much more accessible with the right computers and/or software. Unfortunately, it appears that at this point it will take some time to make the system accessible. Nonetheless, it is a positive step that we are heading down a more accessible and universally designed pathway for accessing theses.

There has been a multitude of barriers for me in my university experience. Key barriers have been the time it takes to organize accommodations and then the delay in receiving them for multiple reasons (e.g. professors usually not having their syllabi ready until the first week of class). I have always had to work hard to “keep up” (while materials were being put into an accessible form), and, then, to make up work once I finally did obtain materials in an accessible format. My classes were a blur of overlapping demands, but fortunately most of my professors were willing to work with me over extended periods of time. I also nearly always prescreened professors for ableism, however, and avoided those who I determined might be ableistic. This only works as long as there are not required courses being taught by one person within a year or two. This process has been particularly grueling, and definitely wore on me over the years (especially with a quarter system). It prolonged my studies, my research and my dissertation, and increased costs for me

significantly. For example, the lull in ironing out an accommodation issue during writing my dissertation forced me to pay for at least one additional quarter.

One might wonder why all of this matters, especially in this portion of the dissertation that is focused on methods and methodologies. Addressing ableism in academia, including in feminist disciplines, is important because people of oppressed groups, and in this case I am addressing people with disabilities, are frequently barred from not only entering academia, but also from surviving and finishing. We have to get here and make it through if we want to have the necessary access in order to impact social justice on a larger epistemological and institutional level.

Consider, for example, my role as a researcher. Human Subjects Review Boards and supervisors are rightfully concerned about protecting vulnerable subjects. However, this can be problematic for a few different reasons. First, how a participant is deemed “vulnerable” can greatly limit or squelch the emergence of counter-ideologies.<sup>189</sup> In one instance, I was discouraged from doing qualitative research with people with disabilities who are not well established (and definitely not anyone younger than 18). This was due to the anticipated limitless barriers that IRB/Human Subjects would impose, because of the perceived vulnerability of people with disabilities, which is very true in some circumstances. This was largely the case historically (e.g. regarding eugenics, psychiatric, and many other forms of research), and we must remain attentive to potential oppressive implications of our research methods and methodologies.

Ironically, however, for people who are so concerned with vulnerability, there was little to no consideration by official channels within the university as to how I could and should make things accessible for my participants. I bent over backwards on my own to have various versions of consent forms and interview questions in various formats, including Braille. Unofficially, there have been multiple times when colleagues with disabilities and allies on campus helped make things more accessible for me as a student and as a researcher through “back door” means. My gratitude and pride for these radical acts is overflowing.

Secondly, it was never considered that I might be a “vulnerable participant” in my own research. There was little to no thought about the potential vulnerability of me as the researcher in regards to accommodations, access to IRB materials in an accessible format, and potential issues to arise within research due to physical and social barriers.

Thirdly, there was no consideration by the human subjects review board of the potential ripple effect that my being a “vulnerable researcher” might have on both me or the participants. It scares me to think of the ableism that could propel this issue toward grounds for making it even harder for a person with disabilities to do research. However, I know that those working toward identity-based politics and disability rights will not back down from these issues. Therefore, it is time to “out” the barriers we are facing at these higher levels.

There are many ways that I felt vulnerable as a researcher. Disability services only offered me editing accommodations by someone who is physically at the University of Washington, although most of the time I write in California and need someone to double check quotes from my books, and sometimes things as simple, yet critical, as making sure quotation marks are still in place after I cut and paste material during the revision process. Therefore, I am assuming that even larger scale accommodations would probably be considered unthinkable, but it is time not only to think about it, but to say it, theorize about it, and work toward it. A multitude of barriers impacted my research, and it is important to address at least a few of the various barriers I faced at different stages of the research, so as to reveal and explore ways to create more accessible, non-oppressive, and liberating research environments.

One issue that I should have anticipated, but did not until already underway with the interviews, was that I would have issues tracking and reading the interview questions. This is often a problem. I am often pushing so hard to keep up and make up work, due to lack of, or slow-in-coming accommodations, that I do not feel like I have the time to think through the steps of accommodation needs that could arise during any particular academic project.

Out of respect for the participants, I was under particular stress to try and do everything perfectly, and high stress can impact my visual processing disorder. This is an additional way that I felt vulnerable, even though I do hold power and privilege in many ways as the researcher. Everyone I interviewed holds a much higher status than I and could have and still can greatly impact my success or failure as an academic. The high stress made tracking, reading, and comprehending more difficult. One strategy I eventually used was to share the interview questions with the participants in advance, or to have the participants read the questions aloud themselves. This made the interview process much more accessible for a few of the participants, as well as for me.

If visual formats are inaccessible for both the researcher and the participant, one could use a cassette player or a computer to read the questions one by one (although this would require visual tracking as well). A great accommodation would also be an assistant, who could read and track visual material. However, I would also like to propose a much more free-flowing interview format, probably along the lines of an oral history dialogue. I believe that this creates a more barrier-free interview process for both the researcher-participant and the interviewee-participant.

Another area that made me feel vulnerable as a researcher was the need to create and use my own form of coding methods according to my accommodation needs. Visual material, especially high-contrast material, is hard or impossible for me to read and comprehend. Therefore, I had to shape my coding methods around my visual processing disorder. I contacted companies that make data organizing software, and was told that they did not believe that their software was accessible. Boxes, lines, and so forth, around words, phrases, and names of people created problems for my auditory computer software to recognize all aspects on the computer screen. Such software was too risky for me to use, for fear of missing information or misinterpreting information because of how the auditory software read the material.

This meant that I needed to get visual research materials into colored formats, and, preferably, auditory formats. This was a long and trying process for me. To make things accessible meant that I had to do things in an unconventional manner, and I have felt questioned and scrutinized by a couple of graduate student colleagues, due to my lack of recognized methods of data organizing (e.g. software and data processing). This has been quite stressful for me, as the focus has been on my inability to follow expected research norms, versus the inaccessibility of being a researcher. Research methods are structured for a certain type of body, mind, and emotions.

To color code the interview transcripts, I listened to them on my computer and followed along with visual print transcripts on light purple paper. I had color-coded key themes that emerged between my questions and prevalent topics raised by the participants. Then, I copied and pasted the colored themes together, fusing together the participants by themes and raw transcript data. I also listened to all of them straight through and multiple times. After this stage, I often ended up doing a second layer of color-coding themes within

the larger, original color-coded themes. The layering of colors also helped me identify areas of overlap and important emergent topics, such as the inextricable connection between identity politics and activism across most of the interviews.

Although this is only a glimpse into the barriers I faced, and the innovative tools I developed, it is pertinent to bring issues like these to the surface. Revealing how academia privileges one type of body by creating access for certain bodies, minds and emotions, while socially and physically creating barriers for those who do not fit those norms, will help deconstruct an oppressive environment and construct a more accessible one.

Finally, I believe that most of these issues have not been considered, because typically in order for one to obtain the status of a researcher in academia, one must fit the norms of ability to climb the academic ladder. One must especially fit the intellectual and emotional norms of quality rationality. Most people with cognitive, mental, and/or emotional disabilities have been barred from entering higher education (especially graduate school), flunked out, or have been so squashed by exhaustion and oppression that they simply drop out. However, I am also well aware that privilege in my life has permitted me to continue and to finish, such as my white privilege. This has probably fed into my parents' class privilege, which has helped pay for accommodations when the university refused or was too slow in accommodating, and so forth.<sup>190</sup> I also proudly note that the Gender, Women, and Sexuality Studies (GWSS) Department gave me accommodations that the university refused to give me.

My hope through my research is to bring empowerment and action through the participants' and my narratives, that we may bring new, alternative perspectives to motivate us and others to action against oppressions. As Mishler explains, some of the goals of feminist research methodologies and methods are often to motivate activism. I believe and argue that good feminist research always motivates activism, in its various forms and on many levels.

Through their narratives people may be moved beyond the text to the possibilities of action. That is, to be empowered is not only to speak in one's own voice and to tell one's own story, but to apply the understanding arrived at to action in accord with one's own interests. (Mishler, 1986, p. 119)

Feminist disabilities studies methodologies and methods have and will 'research back' against oppressive ideologies. "Researching back," I believe, is a statement of activism



always at the core of feminist methodologies, including feminist disability studies methodologies. The goal is to name and/or reclaim identity and subjectivity in order to counter oppression and create liberation. Disability studies perspectives remind us of how rampant ableism has been and still is within research methods and methodologies, and feminist methodologies and methods provide excellent theories for creating less oppressive and more liberating methodological tools.

I hope that this research project encourages an ongoing development and refinement of feminist and feminist disability studies research methods, to counter ableism and the intertwining forms of oppression that depend upon ableism. To create such an analysis I have drawn from disability studies, critical hermeneutics, feminist standpoint epistemologies, and my limited experiences as a researcher with particular accommodation needs. At the heart of this project is a desire to collaborate with feminists and disability studies scholars and activists to create social justice, while acknowledging both the barriers that have limited this project and also created new activist endeavors.<sup>191</sup>

## Endnotes

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<sup>1</sup> In fact, I ended up cutting over one hundred pages of material that looks more at the topical intersections of identities from a feminist and disability studies perspective, including topics that we believe need to be addressed or further explored. However, my committee and I agreed that it became too tangential to the primary research focus that developed around how identity debates influence and shape feminist disability studies, and vice versa.

<sup>2</sup> Since it would be somewhat redundant or tangential to include the wealth of critical literature by the participants, I have concentrated on feminist and disability studies scholarship that is critical for all of the identity-based discussions and critiques here.

<sup>3</sup> The tensions that occur in exploring identities and working across identity-based theories and groups can potentially provide insights into an array of liberatory ideas, such as how and why concepts and access to feminist activism need disability studies perspectives (Chapter 5). I intend on returning to this concept of “tension” regularly within this dissertation and demonstrating how it has the potential to inform our identity-based politics throughout my research.

This is not to say that the negative feelings that occur frequently with these tensions are good (nor necessarily bad). I anticipate that future contributions from feminist/disability studies will also inform our stigmas around what are typically considered negative emotions and their relationship with the disability-impairment debates. I look forward to future feminist disability studies discussions around the physical and emotional, and impairment and disability elements of oppression.

Most are aware that identity politics is frequently quite personal and emotional, and it is one of the reasons for the negative connotation associated with the term “identity politics.” The emotional components are extremely critical. While I address ideas by the participants about ways we might manage such contentious spaces, I acknowledge that much more attention and theorization than I do here needs to be done on the emotional elements of identity politics and identity-based politics. My research focuses on the opportunity that occurs to see oppressive power structures, which also provides an opportunity to transform them.

<sup>4</sup> Gwyn Kirk and Margo Okazawa-Rey describe the difference between identity politics and identity-based politics thus:

Identity politics is a politics that puts identity at the center... It usually involves the assumption that this particular characteristic is the most important in the lives of group members and that the group is not differentiated according to other characteristics in any significant way...

At the same time, identity politics has serious limitations... Groups tend to remain separate, focused on their own issues and concerns, often competing with each other for recognition and resources. The language of identity politics gives voice to people’s discrimination and oppression. It does not encourage us to think about identity in a more complex way, as a mix of privilege and disadvantage....identity-

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based politics...has a strong identity component and also a broader view that allows people to make connections to other groups and issues. (2004, p. 526)

<sup>5</sup> This process of using multiple theories in order to address issues that require cooperation between people in order to meet some sort of social, moral goal is not new. It is different from intersectional analyses in that it extends its focus to also include multiple and even sometimes contradictory identity-based theories.

In her 1985 article, "What Do Women Want In a Moral Theory?" Annette Baier argues that men's moral theories tend to concentrate on obligation and contracts between people, which requires some cooperation and trust, but also relies heavily upon someone holding potential power and punishment over another, and, hence, also the potential for abuse of trust. Men's moral theories also tend to have one core idea or theory that is a cornerstone to support and guide all other ideas, and typically broadly brushes over them in doing so.

On the other hand, Baier argues that women are often absent from moral theory discussions because of the hesitance to accept a theory that is meant to be so comprehensive or universal. Women philosophers are more concerned with multiple moral concepts that usually have to do with an ethics of love, according to Baier. They are also primarily concerned with what function as guiding moral principles in relationships that women have perhaps had more theoretical access to than men historically, such as parent-child relationships and care-taker relationships in general. While not neglecting men's obligation and contractarian moral theories altogether, Baier argues that women's moral concepts provide more critical dimensions for a mosaic of theories.

Baier shows that a mosaic of theories gets us closer to a more comprehensive and less problematic moral theory by being attentive to the underlying concern of cooperation and trust in relationships in both women's and men's moral theories and principles (but built less off of the threat of someone holding potentially abusive power over another and the threat of inappropriate punishment and abuse of trust and power).—She demonstrates that our trust in moral judgments becomes more secure when we get more specific about multiple and particular issues, relationships, and histories. This is in contrast to typical male approaches to moral theory, which tend to rely upon particular abstract rules and principles to govern an overriding grand moral theory. Instead, Baier outlines a possible, alternative and feminist approach to moral theory. In discussing men's moral theories of obligation, she writes:

Morality on this model becomes a nasty, if intellectually intriguing, game of mutual mutually corrective threats. The central question of who should deprive whom of what freedom soon becomes the question of whose anger should be dreaded by whom (the theory of obligation) supplemented perhaps by an afterthought on whose favor should be courted by whom (the theory of the virtues). (p. 60)

Baier argues instead for what many types of relationships demonstrate: a complex variety of different kinds of trust. There is a lot to learn and employ from the concepts that emerge from these extensions and practices of trust-distrust between people. The theories and practices that come into play to create feminist disability studies, and likely identity-based politics as a whole, consist of complicated dances of trust and distrust in order to cooperate together in working toward a less oppressive society. It is the collection of our

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theories, although they are perhaps sometimes in conflict, that has the potential to move us toward a more comprehensive moral account (and reveal potential methods and illuminations toward social justice paths). Identity politics work, such as my research data also explores, grapples directly and constantly with a large family of theories that deal with underlying concerns of “who should trust whom with what, who should accept and who should meet various sorts of trust, and why” (Baier, 1985, p. 62). Further, “these questions might enable us better to morally reason together than we can when the central moral questions are reduced to those of whose favor one must court and whose anger one must dread” (Ibid).

<sup>6</sup> The Society for Disability Studies was established in 1982.

<sup>7</sup> A few of the key disability rights dates mentioned can also be found in this text.

<sup>8</sup> “The Combahee River Collective was an important black feminist group that began in 1974 as the Boston chapter of the National Black Feminist Organization (NBFO), founded in 1973” (The Combahee River Collective, 1995, p. 231).

<sup>9</sup> Wallace also notes how she was one of the founders of The National Black Feminist Organization in 1974 (Wallace, 1995, p. 219).

<sup>10</sup> This term was coined by McRuer (1999).

<sup>11</sup> I use this phrase with Sandra Harding’s concepts in mind. In “Comment on Hekman’s ‘Truth and Method: Feminist Standpoint Theory Revisited’: Whose Standpoint Needs the Regimes of Truth and Reality?” she writes: “...scientific claims are supposed to be held not as true but, only provisionally, as “least false” until counterevidence or a new conceptual framework no longer provides them with the status of “less false” than those against which they have been tested. Thus, my discussions of “strong objectivity” and of “less false” claims were intended to distance standpoint thinking from remnants of popular modernist ideology that did not even match modernist science theory” (2004, p. 260).

<sup>12</sup> For one example of a table on intersecting forms of privilege and oppression look at “Figure 2.1: Intersecting Axes of Privilege, Domination, and Oppression” in *Women’s Voices, Feminist Visions* (Shaw, 2001), p. 47.

<sup>13</sup> Standpoint epistemologies are similar to critical hermeneutics, which I address in my research methods section. Such theories are critical to consider when thinking about how we employ our research strategies and how we understand our positions of privilege and/or oppression within the relationships with participants.

<sup>14</sup> Both theories also believe in a coalition’s involvement in and reflection on the ways in which research methods have been employed, or how the researcher has interpreted the material. See Naples (2003) and Weeks (1998).

<sup>15</sup> See Aptheker (1989).

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<sup>16</sup> Some of these examples I extrapolated, though not directly quoted, from examples given by undergraduate and graduate students at the University of Washington. I also published this in part in my article “Feminist Disability Studies Pedagogy” (Knoll, 2009).

<sup>17</sup> Using a few feminist theories and tools can help feminist disability studies continually address not only how we have been subject to discrimination and oppression, but also how and why we need to weed out oppression within our own movements.

<sup>18</sup> Also, participants discussed how women’s studies offers disability studies some templates for working in a field that is highly interdisciplinary, and using multi-methods approaches, but I do not fully address it in this work.

<sup>19</sup> Although I could make the argument that Adrienne Asch is also doing this feminist intersectional work, she is not included in those nine.

<sup>20</sup> Within interview quotes, the formatting is as follows:

- Brackets and the letters ‘KK’ indicate short interjections from the interviewer.
  - o Ex. [KK: Yeah.]
- Parentheses around a word or letter indicate that it is the interviewer’s interpretation of something that is partially inaudible on the interview tapes.
  - o Ex. “I put sexuality (stuff in) feminism.”
- Three ellipsis points indicate a pause in speech.
- Four ellipsis points indicate that the quote has been edited for use in the paper and some material omitted.
- Three ellipsis points within parentheses, such as (...), indicates a completely inaudible word or phrase on the interview tape.
  - o Ex. “a feminist philosopher (...) a disabled woman”
- Brackets can indicate:
  - o Insertions after the fact from either the interviewer (e.g. “one[s]”) or interviewee (e.g. “Deaf plus” [meaning deafness in addition to other disabilities])
  - o Unspoken noises, e.g. [laughter]
  - o Clarifiers, e.g. [in agreement]
  - o When surrounding a question posed by the interviewer, brackets indicate that the question was paraphrased during transcription of the interview.
- When there is a line break and three ellipsis points in brackets (e.g. [...]) within a quotation, it indicates a large amount of omitted material between the

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two quoted sections, for example when two quotes from different interview tapes are used in the same block quote.

<sup>21</sup> This response was to interview question 1.

<sup>22</sup> See interview question 1a.

<sup>23</sup> See interview question 3b.

<sup>24</sup> See interview question 3.

<sup>25</sup> See interview question 2.

<sup>26</sup> See pp. 128 -129 of Gareth William's 2001 article "Theorizing Disability" for an excellent summary of a disability studies perspective on the developments of impairment and disability definitions in relation to the World Health Organization.

<sup>27</sup> To give just one example, doctors have told me that I am not or should not be feeling pain in my ears when I am, as well as vice versa.

<sup>28</sup> It is telling that Davis did not include "queer" identities, and that we do not say "queer American."

<sup>29</sup> After all, Othering has happened, and still does happen between Other identity groups. Religions can stigmatize people of color, people with disabilities, queer people, and so forth by saying they are demon-possessed or reincarnated god/esses, and such beliefs are not necessarily going to change by proving one's abilities (as a stigmatized class). In addition, to counter Davis, not all universities, diversity programs, or diversity books discount disability. Disability is newer to the scene but is becoming much more widely incorporated into the diversity fabric of universities.

Humans are creative and can, and most likely will, come up with new ways to have power over other people, and new ways to resist oppressions as well. While it is true that oppressed groups have used people with disabilities quite a bit as their "Other," this is not, nor ever will be the entire story. Therefore, dismodernism is not the only answer or way out of identity politics or oppression. Universalizing theories, as this one is, are dangerous as they commonly silence or muffle the cries of those who are marginalized (when the theory is not true for them, or does not speak the whole truth).

Finally and thankfully, it is also absurd to think that this would or could lock disability out from diversity. That idea alone is very disempowering and does not recognize the human and political potential we do have to socially construct new meanings, and the ability to claim our identities, identity politics, and our diversity

Somewhat similar to Davis' theory, yet more complex, is Jerome E. Bickenbach's likening of non-talents to impairments (2009). His theory also fights to defuse the notion that impairment and disability are limited to a particular class and instead claims that we are all susceptible to non-talents and impairments. His focus on policy and the need to draw

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boundaries around accommodation needs makes some, including me, uncomfortable. Bickenbach identifies that those working in social-cultural (including medical), public policy, and economic arenas tend to draw the lines between these categories. He argues that people with disabilities should be central in determining these definitions and policies regarding these definitions. A significant difference for Bickenbach, however, is the need to create boundaries around these terminologies in order to address the practical needs of accommodations.

<sup>30</sup> See interview question 5b. Rosemarie Garland-Thomson noted in her article “Integrating Disability, Transforming Feminist Theory” (2002) that Robert McRuer coined the term “compulsory able-bodiedness” (1999).

<sup>31</sup> See interview question 1.

<sup>32</sup> In reviewing how I incorporated her reflections into my dissertation, Amy Vidali commented that she has been involved in a “female-oriented disability community, and interdependence has become central to who [she is] as a woman” (email communication, February 27, 2011).

<sup>33</sup> Chapter 6 discusses the issue of “safe” and “comfortable” coalition work, referencing Bernice Johnson Reagon. People with disabilities may not feel “safe” if a space is inaccessible, because it is a physical sign to many people with disabilities that the group may likely be ableistic, which can extend so far as having eugenic beliefs (e.g. selective abortion of babies with disabilities, euthanasia, etc.).

<sup>34</sup> See Siebers’ use of Paula Moya on page 18 of “Disability Studies and the Future of Identity Politics” (2006) for reflections on the interconnectedness of “physical realities that contribute to political knowledge and consciousness.”

<sup>35</sup> See my bibliography for the many feminist disability studies texts that have informed my research and writing, yet have been cut, for the time being, for brevity.

<sup>36</sup> See page 15 of “Integrating Disability, Transforming Feminist Theory” (2011).

<sup>37</sup> Part I and Chapter 1 outline these systems of power and oppression, with reflections on Hill-Collins (2001) and McIntosh (2001).

<sup>38</sup> For example, disability studies theories have developed tools that challenge the belief that people want special provisions, and instead reveal how special provisions are already allocated, but to certain classes of people (e.g. privileges). Again, these social and political facts can be mutually seen and addressed. For example, Siebers discusses how disability studies theories that have emerged from identity-based theories can transform identity politics, and possibly our aversion to it:

Here is where disability studies might effect a sea change by asking that the

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inclusion-exclusion binary be reconceived in terms of accessibility and inaccessibility, thereby taking power and momentum from those on the inside and stressing that societies should be open to everyone. In short, all worlds should be accessible to everyone, but it is up to individuals to decide whether they will enter these worlds. We live in a built environment that is inaccessible, so it is a stretch to think about a moral and political world that would be wholly accessible, but this is the challenge issued by disability studies. How will the language of universal access transform politics in the future? (Siebers, 2006, p. 26)

Equally powerful, feminist identity-based theories remind us that disability studies theories such as “universal design,” which Siebers discusses above, while still providing some excellent liberating tools, can be essentializing and silence and neglect the person with, for example, overlapping identities who may remain on the outside of the universal ideas of universal design. This makes it imperative that feminist practices that encourage and support marginalized voices to emerge remain a cornerstone to feminist disability studies. Feminism, at this point in time, is probably the most diverse arena for identity politics, thereby providing possibly the ripest arena for tensions between identities and identity-based theories to teach us new liberatory practices. However, feminism and women studies too often neglect critical disability studies theories, such as the few mentioned above.

<sup>39</sup> See Burgstahler & Cory (2008) for information regarding universal design.

<sup>40</sup> This article was originally printed in the 2002 special issue of the *NWSA Journal* devoted to *Feminist Disability Studies*.

<sup>41</sup> See Appendix A for all of the interview questions.

<sup>42</sup> There are at least seven participant responses that comment on these intersections to some degree within their response to the first interview question.

<sup>43</sup> See interview question 1.

<sup>44</sup> See interview question 1.

<sup>45</sup> While all of the participant responses to this point directly followed the first interview question regarding defining disability studies, we will continue with reflections, or themes that are specific to the ways in which women studies and disability studies inform each other.

<sup>46</sup> All four comments were in response to question 1a: “Of the topics just mentioned, which topics do you think fall under the heading of ‘Feminist Disability Studies?’”

<sup>47</sup> Although there are some theoretical concerns with the term “intersectional” as limiting to the number of layered identities involved, I use it because it is the most recognized term for analyzing how multiple identities can overlap.



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<sup>48</sup> See endnote 5 for more on using a “mosaic” of theories.

<sup>49</sup> A few of the participants pointed out the ways in which some disability studies work is unwittingly feminist in nature (i.e. lack of awareness of its feminist roots). However, other critical feminist components are missing in disability studies despite its feminist roots.

<sup>50</sup> See interview question 1.

<sup>51</sup> See interview question 1a.

<sup>52</sup> The preceding interview questions were 3a and 3b. See Appendix A for the full questions.

<sup>53</sup> See page 15 for Asch’s initial comments on fragmentation.

<sup>54</sup> See Chapter 6 for discussions related to the concern over “safe spaces.”

<sup>55</sup> Note also that Wendell mentions that medical practitioners, whose medical perspectives are often abhorred, are not barred from disability studies or feminist disability studies, but that making the voice of the person with disabilities, impairment, and/or chronic illness is the central task at hand. This provides space for the debates and wisdom that emerge by encouraging both social-constructionist and social justice pursuits of people who are ill and disabled.

<sup>56</sup> See Wendell (2001) for more on this argument.

<sup>57</sup> See interview question 1.

<sup>58</sup> In Part II, however, the scholars do reflect upon the complicated politics of identity and power, such as being able-bodied and teaching disability studies. Although everyone is invited to participate in disability studies, participants make arguments for why it is imperative that we attend to the histories that provide privilege and power to one group over another—and to counter such systems.

<sup>59</sup> See Asch’s full quote in the last section of Chapter 5, “Activist Components of Identity Politics and Identity-Based Politics.”

<sup>60</sup> These tensions between activist and academic pursuits and between identity studies/identity politics are discussed in depth in Part II, “Crippling Feminist Activism & Identity-Based Politics.”

<sup>61</sup> See Asch and Kafer’s full quotes in the last section of Chapter 3, “Participant Reflections: Feminist Disability Studies.”

<sup>62</sup> Catherine Kudlick’s response was to interview question six: “How do you identify yourself (socially, culturally, etc.) and how does this influence your work?”

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<sup>63</sup> Regarding the title of this section, in *Claiming Disability*, Simi Linton discusses how people with disabilities have reclaimed the term “cripple” as a word of pride (17). She also references one of the foundational disability studies scholars, Joseph P. Shapiro, and how in his book, *No Pity*, he noted that many people use the term cripple as a form of “militant self-pride” (Shapiro, 1993, p. 34).

<sup>64</sup> It was interesting for me when I searched for definitions of activism in some of the books used, and anticipated feminist definitions of activism and social justice, but only found loose to no definitions. In Naples and Bojar’s *Teaching Feminist Activism: Strategies from the Field* (2002), they note, in regards to defining activism, “...it is clear that authors have different understandings of what counts as activism as well as very different priorities” (p. 3). Baumgardner and Richards also discuss this issue in *Manifesta: Young Women, Feminism, and the Future* (2000): “Webster’s defines activism as ‘the doctrine or policy of taking positive, direct action to achieve an end.’ Regardless of how you define it, activism, like feminism, can be something organic to our lives, a natural reflex in the face of injustice and inequality. Also like feminism, activism is one of the most confused concepts we know” (p. 282). Webster’s definition leaves open, however, what “positive” and “the end” mean, which could be used by oppressive people and groups toward negative and even genocidal means. That is why I, despite acknowledging the loose and confused use of the term “activism,” provide a definition for feminist disability studies activism.

<sup>65</sup> Please see Asch & Fine (1997), Clare (2003), McRuer (2003), McRuer & Wilkerson (2003), Wilkerson (2002) and Kafer (2003) for information on disability and sexuality. Some of those references came from a 2003 special issue of *GLQ: A Journal of Lesbian and Gay Studies* on *Desiring Disability: Queer Theory Meets Disability Studies*, and the issue as a whole is very informative as well. See also page 74 of this paper for a prior discussion regarding sexual harassment.

<sup>66</sup> See the full quote on page 121 of this paper.

<sup>67</sup> See interview question 3.

<sup>68</sup> See page 66 for a longer excerpt of this discussion.

<sup>69</sup> See interview question 1.

<sup>70</sup> As feminist epistemologies have taught us, we obtain “stronger objectivity” in our work when we bring in perspectives that are shaped by different social experiences. As Sandra Harding noted in *Rethinking Standpoint Epistemology: What is “Strong Objectivity”?*,

The notion of objectivity has valuable political and intellectual histories; as it is transformed into “strong objectivity” by the logic of standpoint epistemologies, it retains central features of the older conceptions. In particular, might should not make right in the realm of knowledge production any more than in matters of ethics.

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Understanding ourselves and the world around us requires understanding what others think of us and our beliefs and actions, not just what we think of ourselves and them. Finally, the appeal to objectivity is an issue not only between feminist and prefeminist science and knowledge projects but also within each feminist and other emancipatory research agenda. (2004, 138)

<sup>71</sup> See Siebers (2006) for his reflections on universal design.

<sup>72</sup> See interview question 5a.

<sup>73</sup> See page 8 and Chapter 3 for more on Davis' dismodernism.

<sup>74</sup> See interview question 13.

<sup>75</sup> See interview question 6.

<sup>76</sup> See interview question 6.

<sup>77</sup> Kim conveyed this critical point to me in an email, reflecting upon my use of her interview transcripts, on March 14, 2011. She also wrote, while reflecting on my use of the term "ally," "I don't identify as ally because to me it assumes I am fighting for a cause for someone else." I believe what Kim is arguing is that oppression is bad for everyone, and, therefore, concerns her and is important for her to address.

<sup>78</sup> See interview question 6.

<sup>79</sup> Critical race studies concepts, such as those presented in *This Bridge Called My Back* (Moraga and Anzaldúa, 1983), provide critical insights for this as well.

<sup>80</sup> This is an issue that I really became attuned to from cross-cultural experiences between the United States, Germany, and Austria. I have found the atmosphere in most university courses in the United States is often a general fear of disagreeing with the professor and/or colleagues. My experience in Austria, however, particularly at the University of Innsbruck, was that the process and ability to openly and passionately disagree with professors and colleagues was valued nearly above all else. It creates a powerful and liberating learning space, where I frequently saw people celebrate their heated debate with smiles, handshakes, a hug, and perhaps drinks afterwards. An ally places herself in criticism's way—open to being challenged and changed. Punitive measures, such as shaming and the risk of being ostracized, tend to shut down ally-work, and, I believe, slow down liberation movements.

<sup>81</sup> See interview question 9.

<sup>82</sup> This was in a personal email correspondence during March 2010.

<sup>83</sup> This article can also be found in the 2001 edition of this book.

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<sup>84</sup> A couple of the participants also noted negative experiences with NWSA, but only after I shared this story with them.

<sup>85</sup> See interview question 6.

<sup>86</sup> This touches upon the topic of critical hermeneutics, which is covered in Part III.

<sup>87</sup> See interview question 1 and 1b, and page 66 for more of the quote.

<sup>88</sup> One topic raised by a couple of participants that I do not address, yet is critical, is the identity and role of passing as able-bodied or performing disability (what Licia Carlson referred to as the “keep them guessing strategy”). Blurring the lines between disability and able-bodied in performativity of identity is a complex subject, but not one that I felt that the interviews addressed enough to discuss in depth here.

<sup>89</sup> A few simple words, for example, can change a person’s life by liberating their self-perception from internalized sexism, ableism, and the like using feminist disability studies ideas.

<sup>90</sup> Although I do not know Alison Kafer’s reasoning behind using the term “traditional activism,” she did use it in our interview. This is how she differentiated some of the various forms of activism: “... Depending on the class... it varies as to what that looks like. So, sometimes that means they actually have to do some quote, un-quote activism. At others times they don’t necessarily have to do any, but they need to research activists. And, then in those moments, I usually mean activist in the more traditional sense... not the academic-activist sense. Because I want them to get exposure to people who are talking about similar ideas, but doing it in very different way than the theorists or historians or social scientists that they are encountering in the classroom. So that looking... I don’t know... looking at some activist organization, at the way in which they are actually theorizing about gender, or about race, or about disability, and being able to look at the ways it gets talked about differently in that context... versus quote, un-quote in an academic context.”

<sup>91</sup> See interview question 7.

<sup>92</sup> See interview question 2.

<sup>93</sup> One of my favorite historical, yet highly autobiographical texts, which really outlines the roots of U.S. disability rights activism, is Longmore’s book. He gives background and sensation to historical disability rights moments such as a couple of which Asch speaks. See Longmore (2003).

<sup>94</sup> See interview question 2.

<sup>95</sup> See page 260 in Sandra Harding’s “Comment on Hekman’s “Truth and Method: Feminist Standpoint Theory Revisited”: Whose Standpoint Needs the Regimes of Truth and Reality?”

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(2004)

<sup>96</sup> See interview question 1 (although I am not fully clear which lead question she is responding to in the interview transcripts).

<sup>97</sup> It was interesting writing this section, because part way through I realized that I was starting to write from a somewhat defensive position—protecting non-traditional-activism. It caught me off guard, because I have always been a strong supporter and “squeaky wheel” in my department about the need for undergraduate internships, graduate level practicums, and so forth to provide opportunities for traditional activism. This led me to be one of the few in my department to do a long-term master’s practicum with an organization called “Communities Against Rape and Abuse,” and to develop and teach our internship seminar for undergraduates.

<sup>98</sup> See interview question 3a.

<sup>99</sup> See interview question 5.

<sup>100</sup> See interview questions 1, 2, and 7 (unclear as to which lead question/s she is responding).

<sup>101</sup> See interview question 10.

<sup>102</sup> However, as a quick side note, we also need to attend to making traditional activism accessible for those who are kept from participating due to disability barriers. I think most if not all of the participants would agree. We need to have ramps ready, and assistants available. We need to think of new and creative traditional forms of activism as well that are universally designed. One of my closest friends is a very active traditional feminist disability studies activist, and these traditional activist allies have many tools to offer us. Had I been able to acquire interviews with traditional activists, I am sure that points such as this one and many more would have been critical insights for this dissertation.

<sup>103</sup> See interview question 7.

<sup>104</sup> Rosemarie Garland-Thomson uses and discusses the term “academic activism” in her article “Integrating Disability, Transforming Feminist Theory” (2002).

<sup>105</sup> See interview question 1.

<sup>106</sup> See interview question 4.

<sup>107</sup> See interview question 7.

<sup>108</sup> See interview question 7.

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<sup>109</sup> See interview question 7.

<sup>110</sup> From “504 Memories” by protestor Raymond Uzeta in Stein 1997, p. 43.

<sup>111</sup> From “An Army Marches on its Stomach” by protestor Hale Zukas in Stein 1997, p. 43.

<sup>112</sup> See interview question 2.

<sup>113</sup> See interview question 2.

<sup>114</sup> See interview question 1.

<sup>115</sup> See interview question 2. Also, I am fairly certain that she is referring to Tanis Doe, who was a Canadian feminist and disability studies scholar, who also taught at the University of Washington. I took a class from her, and she mentored me some—up until she passed away.

<sup>116</sup> See interview question 7.

<sup>117</sup> See interview question 10 and 11.

<sup>118</sup> See interview question 12.

<sup>119</sup> See interview question 1 and 1a.

<sup>120</sup> While a person may be a part of an identity-based political process, they may act oppressively. However, although they may not address the oppression and may possibly even leave the coalition, the tensions that occur still have the potential to reveal key issues that can be addressed and provide additional mortar to the identity-based politics and coalitions we are building.

<sup>121</sup> A significant amount of these stories are not shared here, and I look forward to sharing these incredible stories of activism in the future.

<sup>122</sup> See Reagon (2001) for more on coalitions versus community.

<sup>123</sup> This research will also help with future oral history projects about the movement and coalition that is emerging across feminism and disability studies scholars and activists. This part of my dissertation highlights how a portion of the feminist disabilities movement has come into fruition, how it has been impeded and how it continues to grow and flourish. A very exciting and critical topic that emerged from the interviews was the warm reflections of when people met each other for the first time—creating for my research a mapping-out of part of the beginning of the feminist disability studies genealogy. I have started a feminist disability studies timeline, which I anticipate contributing to the fields in the future, perhaps in an online format to which other people can add information.

That genealogy is mostly limited to the participant’s reflections, however, and

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therefore is missing a lot of the feminist disability studies lineage—such as many of the writings by and reflections from such luminaries as Rosemarie Garland-Thomson, Nirmala Erevelles, Anne Finger, Simi Linton, Corbett O’Toole, and many others. I also did not design my research questions to draw out dates and places of significant feminist disability studies events. Rather, these things emerged naturally in our discussions, and surely there are a lot of gaps. It has also become abundantly clear to me that there are a lot more international feminist disability studies activists, scholars, and examples of literature that I need to read and include in a feminist disability studies timeline in the future. The timeline also includes a few critical disability rights dates, as well as the emergence of some of the first pivotal feminist disability studies literature that has informed this research.

<sup>124</sup> Again, terms such as “discipline,” “field,” and so forth were rarely used in the interviews. Participants would often simply refer to “feminist disability studies,” as did I.

<sup>125</sup> See interview question 2.

<sup>126</sup> See interview question 2.

<sup>127</sup> See interview question 6.

<sup>128</sup> See Appendix A for interview questions.

<sup>129</sup> This is an internalization of, and version of what I call the “Goddess Syndrome.” See endnote 155 for more on this.

<sup>130</sup> See “The Sexist Inheritance of the Disability Movement” (2004) by Corbett O’Toole for more on this.

<sup>131</sup> See interview question 9.

<sup>132</sup> I have used the term “compulsory able-bodied sexism” when talking with people about the ways in which sexism has masked some compulsory able-bodied issues within academia, feminism, and so forth.

<sup>133</sup> See interview question 9.

<sup>134</sup> See Catherine Kudlick’s transcript response about how our work is not taken seriously.

<sup>135</sup> As noted in Chapter 5, academia does not usually support traditional activism.

<sup>136</sup> See interview question 9.

<sup>137</sup> See interview question 9.

<sup>138</sup> See interview question 5b.

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<sup>139</sup> I am distinguishing inter-minority group politics from identity-based politics. Identity-based politics highlights a choice and desire to work across minority groups, whereas inter-minority group politics may be occurring and yet be resisted—potentially causing coalescing to halt. However, both participate in conversations between minority groups, versus toward the center (or in the language and systems of those in a position of privilege).

<sup>140</sup> See interview question 6.

<sup>141</sup> This is a phrase that I created, and have been using since 2001.

<sup>142</sup> See interview question 2.

<sup>143</sup> See interview question 9.

<sup>144</sup> Thanks to my advisor, Angela Ginorio, for pointing out a critical concept and possible issue, which I hope to explore further in the future, regarding when and why to address tension and how it relates to violence. In “What is Peace Psychology the Psychology of?” Daniel J. Christie discusses how addressing violence at the episodic level “produces intergroup tension reduction,” and addressing violence at the structural level “produces intergroup tension enhancement” (2006, p.1-17).

<sup>145</sup> See page 159 for Kim’s full quote on this subject.

<sup>146</sup> For a brief history of the independent living movement, see page 48 of Braddock and Parish’s 2001 article “An Institutional History of Disability.”

<sup>147</sup> Braddock and Parish provide some information about the Deaf culture and pride in “An Institutional History of Disability”:

In 1864, President Lincoln signed legislation authorizing Columbia to confer college degrees. Columbia later became Gallaudet University (Gallaudet 1983; Lane 1989).

Suppression of sign language was championed by Alexander Graham Bell in the United States at the end of the nineteenth century....Also in 1880, the National Association of the Deaf was organized by deaf people. This organization would become the leading association fighting the oralists for manual instruction of deaf people in the United States (Baynton 1996).

One of the first self-advocacy organizations by people with disabilities was the British Deaf and Dumb Association (BDDA), now the British Association of the Deaf. The BDDA initially organized in 1890 in direct response to the International Congress’s sign language ban and the view that deaf persons did not need to be involved in matters that concerned them. The 1880 International Congress on the Deaf had only two deaf teachers in attendance (British Association of the Deaf 1999). (Braddock, 2001, p. 35)



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<sup>148</sup> See page 260 in Sandra Harding's "Comment on Hekman's "Truth and Method: Feminist Standpoint Theory Revisited": Whose Standpoint Needs the Regimes of Truth and Reality?" (2004)

<sup>149</sup> For the film *Murderball*, see Rubin (2005).

<sup>150</sup> This is an example of how often one can be put in the situation of feeling trapped by speaking to the center rather than to other oppressed groups.

<sup>151</sup> I look forward to, again, future feminist disability discussions regarding *how* to do identity-based politics, while considering stress, impairment, chronic health issues, self-care, and inter-dependency.

<sup>152</sup> If you would like to know more about the participants' professional endeavors, please see Appendix B for some appropriate web references.

<sup>153</sup> This subject reminds me of a theory I developed as a fledgling feminist and undergraduate student (and pre-disability studies inception) that I call "goddess syndrome," which I describe below. I witnessed my friends in women studies classes being overcome with realizations of sexism, racism, homophobia, xenophobia, and so forth. It was almost like seeing a "religious experience" of having their eyes opened to amazing and hidden truths. It makes sense, because the information obtained often applies to one's own experiences. Public education hides a lot of facts. It often is not until one takes a women studies course that one realizes how pervasive oppression is across many groups of people. It is startling to realize the potential power of this knowledge: that activism has caused radical changes, and that we have our own potential to create social justice.

Students often esteem the instructors of such courses so highly that there is no room for error. I saw several friends practically enamored of their women studies professors, talking about how amazing they were. As soon as these students realized that their feminist professor was flawed (such as perhaps struggling with internalized sexism or deeply encapsulated in oppressive white privilege), they not only felt disenchanting with the individual person, but also frequently with the entire movement. It was also often a highly emotional process of anger and sadness. I had a friend who completely gave up on feminism because of such an experience, and a couple of friends who fluctuate in and out of the movement due to a feeling that the movement is flawed because even the leaders have a lot to continually learn about how they are being oppressive to themselves and others. I believe this is one of the key reasons why we lose people from anti-oppression movements—disillusionment from, understandably, wanting everyone not to act oppressively, yet seeing that they sometimes do. I think that we can want it, fight for it, and maybe even aggressively push each other toward it, but we need to recognize that it is actually a process, and a continuum rather than a static state of being for feminists, disability rights activists, and so forth.

We should not confuse an expectation of a common goal and process of anti-oppression work from our colleagues with counter-productive expectations of all-knowing

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and always-perfect goddesses. Rather, we need to theorize more about how we are all so entrenched in our cultures that there is a lot of continual unlearning that we have to practice and encourage from one another, and we do that better together than apart. Also, as my participants point out, we need to learn ways in which we can critique and challenge one another respectfully, which can be harder to do when it is personally painful. If I were to not accept anyone into my feminist disability studies coalition who exhibited sexism or ableism, I would be alone. I would likely not even be there myself, because I recognize that I too struggle with internalized sexism and ableism from time to time.

<sup>154</sup> It is striking how participants did not make similar references about the National Women's Studies Association conference.

<sup>155</sup> See interview question 5b.

<sup>156</sup> See Hall (2002) & Kittay (2001).

<sup>157</sup> I believe that the National Association of Women's Studies (NWSA) conference used to conflict with the Society for Disability Studies (SDS) conferences.

<sup>158</sup> See page 138 for Catherine Kudlick's full quote on this subject.

<sup>159</sup> See page 97 for the story of a negative experience I had with NWSA regarding their inaccessibility.

<sup>160</sup> See interview question 7.

<sup>161</sup> See interview question 3.

<sup>162</sup> See interview question 8.

<sup>163</sup> See interview question 3b.

<sup>164</sup> See interview question 3b.

<sup>165</sup> See interview question 3.

<sup>166</sup> See interview question 9.

<sup>167</sup> See interview question 9.

<sup>168</sup> This lunch took place in Seattle in Summer 2004.

<sup>169</sup> See interview question 3.

<sup>170</sup> See interview question 9.

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<sup>171</sup> The full quote is in the second section of Chapter 6, “Encouraging Coalition Building.”

<sup>172</sup> For more from Susan Wendell on this, see page 156.

<sup>173</sup> See interview question 9.

<sup>174</sup> More from this quote can be found on page 77.

<sup>175</sup> The movie was from 1995 and I believe it is called “Comics with Disabilities.” I have been unable to find additional information on it.

<sup>176</sup> See Chapter 4 for the varying perspectives on the tensions that emerge from focusing on difference versus focusing on commonality, for example, and how that plays a critical role in propelling a social justice movement forward.

<sup>177</sup> This is one of the four central points to my dissertation that address the connection between activism, identity-based politics, and feminist disability studies influences.

<sup>178</sup> This is the second of four claims that I developed throughout this dissertation.

<sup>179</sup> This paragraph gives an overview of the third of the four key points to my dissertation, which addresses the connection between activism and identity-based politics.

<sup>180</sup> This is the fourth and final point I make regarding the interconnectedness between activism, identity-based politics, and how feminist disability studies provides new insights and practices toward a more accommodating and less oppressive identity-based politics.

<sup>181</sup> See Garland-Thomson’s 2002 article “Integrating Disability, Transforming Feminist Theory” and its 2011 reprint in the book *Feminist Disability Studies* (Hall) for perspective on the continuing importance of these arguments and theories. Samuels’ article “Critical Divides: Judith Butler’s Body Theory and the Question of Disability” was also originally published in 2002 and reprinted in the same book in 2011.

<sup>182</sup> See Appendix A for all of the interview questions.

<sup>183</sup> See also Rosemarie Garland-Thomson’s ideas on “academic activism” from her 2002 article “Integrating Disability, Transforming Feminist Theory,” discussed in Chapter 3.

<sup>184</sup> For more information regarding the Beijing conference, and subsequent conferences that stemmed from the Beijing “World Conference on Women” visit the “United Nations Entity for Gender Equity and the Empowerment of Women” website: <http://www.un.org/womenwatch/daw/beijing/index.html>

<sup>185</sup> The points referred to here have been removed from the final dissertation and will

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hopefully be used in further research and publishing.

<sup>186</sup> See Oakley (1981).

<sup>187</sup> I worked and volunteered as an intern at Communities Against Rape and Abuse for a couple of years, and this served as my practicum site for my Master of Arts project.

<sup>188</sup> I also understand a lot of the resistance, however, because there have been/are many Christian organizations that have been/are extremely oppressive to certain people. There are also many Christians who work hard against oppression and believe that their faith calls them to counter oppression.

<sup>189</sup> I remember Angela Ginorio discussing the issue of people being deemed as "vulnerable subjects" as possibly limiting voices of a minority group (although it is important to protect people who have been or are subject to unjust research) at a departmental discussion group at the University of Washington, Seattle Women Studies Department. Please see Ginorio (2004) for more on this.

<sup>190</sup> See my article on feminist disability studies pedagogy to read more about how disability oppression can intersect with additional forms of privilege and oppression (Knoll, 2009).

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## **Appendix A: Interview Questions**

### LOCATING FEMINIST DISABILITY STUDIES

1. If someone were to ask you what "Feminist Disability Studies" is, how would you define it?
  - a. Of the topics just mentioned, which topics do you think would fall under the heading of "Feminist Disability Studies?"
  - b. Of these topics, what are you interested in particularly?
2. Would you call yourself a feminist disability studies scholar and/or activist?
3. What are a couple of pivotal moments that have brought you to the work you are doing, as related to women studies and/or disability studies?
  - a. Has disability studies informed your feminist thinking?
  - b. Has women studies/feminism informed your disability studies thinking?
4. Have you taught any classes or workshops that you think would fall under "Feminist Disability Studies?"

### RESISTANCE, INNOVATION, AND SOCIAL JUSTICE

5. What are some of the challenges of being a feminist and/or disability studies scholar and/or activist?
  - a. Have you experienced resistance to women studies or feminist perspectives in disability studies circles?
  - b. Have you experienced resistance to disability studies in feminist or women studies circles?
6. How do you identify yourself (socially, culturally etc.), and how does this influence your work?
7. Do you have activist components to your teaching, research, and/or work outside of academia?
8. Do you have any stories about creative ways that you have participated in or encouraged resistance to ableistic and/or sexist forces?
9. How do we and/or can we support each other as Feminist Disability Studies scholars and activists?

### THE FUTURE OF FEMINIST DISABILITY STUDIES

10. What is your current research, activism, and/or work?
11. Where do you see your research, activism, and/or work leading you?
12. What are some topics or issues that you think need to be explored or further developed by feminist disability studies scholars?
13. Are there any scholars and/or activists who you would recommend I interview who are perhaps not as widely known, but doing critical and cutting-edge work? Are there any persons of color, men, international, and/or LBGTQ scholars or activists that you think I should potentially interview in future research?

## Appendix B: Participant Information

**Adrienne Asch**

<http://www.socialdifference.org/fellows/adrienne-asch>

**Brenda Brueggemann**

<http://people.cohums.ohio-state.edu/brueggemann1/>

**Susan Burch**

<http://www.middlebury.edu/academics/amst/faculty/sburch>

**Licia Carlson**

<http://www.providence.edu/philosophy/Pages/carlson.aspx>

**Alison Kafer**

<http://www.southwestern.edu/departments/faculty/faculty.php?id=kafera&style=feminist>

**Eunjung Kim**

<http://womenstudies.wisc.edu/professional-pages/eunjung.htm>

**Georgina Kleege**

<http://english.berkeley.edu/profiles/45>

**Catherine Kudlick**

[http://history.ucdavis.edu/professor/catherine\\_kudlick](http://history.ucdavis.edu/professor/catherine_kudlick)

**Susan Schweik**

<http://english.berkeley.edu/profiles/68>

**Amy Vidali**

<http://clasfaculty.ucdenver.edu/avidali/index.html>

**Susan Wendell**

<http://www.sfu.ca/gsws/FacultyStaff.html#Emerita>

<http://litmed.med.nyu.edu/Annotation?action=view&annid=1651>



**Curriculum Vita**  
**Kristina R. Knoll**

**EDUCATION**

**Ph.D., Feminist Studies**

University of Washington, Gender, Women, and Sexuality Studies Department,  
Completed June 2012

Dissertation Title:

Feminist Disability Studies:

Theoretical Debates, Activism, Identity Politics, & Coalition Building

Abstract:

I interviewed eleven prominent scholars and activists in the field to map out some of the major themes in feminist disability studies, and discussed topics from identity politics to community building and creative methods for countering oppression.

**Fields of Concentration:**

Disability Studies

Curriculum Design, Learning Goals, and Pedagogy

Bridging Feminist & Disability Theory with Community Engagement and Social Justice

**Certification, Program on Values in Society, (Ethics and Justice)**

University of Washington, Philosophy Department, Completed June 2010

**Certification, Master Adviser Program**

University of Washington, Advisor Education Program, Completed April 2007

**M.A., Women Studies**

University of Washington, Completed June 2003

Master Practicum Title: "Supporting Survivors with Disabilities:  
Building Understanding to Strengthen Advocacy"

**Fulbright, Women Studies**

Universität Innsbruck, Austria, August 1998 - July 1999

**B.A., Philosophy and Germanics (Double-Major)**

Pacific Lutheran University, Completed May 1998

Including Study Abroad: University of Freiburg, Germany;  
Goethe Language Institute, Staufen and Freiburg, Germany

## TEACHING

Instructor, Women 497: Fieldwork in Women Studies

The duties of this position expanded from supervising our interns to being a more formal instructor (see page 4, “Internship Supervisor”). I selected readings, held group discussions about bridging theory and activism, created a venue to display final projects, and reviewed and graded students’ work. During the spring one internship group was focused on feminist disability studies and creating a more accessible environment. We organized a panel for Disability Awareness Week on Multiple Chemical Sensitivity—among additional activities.

- Autumn 2009, Spring 2009, Winter 2009, and Fall 2008

Co/Facilitator, Women 299: Women Studies Community in Colloquium Course

Co-created and co-facilitated course with faculty & undergraduates.

- Autumn 2009, Winter 2005 and Winter 2004

Instructor, Women 290: Feminism and Disability Studies

Developed and taught first course on feminism and disability at our university.

- Summer 2004

Instructor, Women 200: Introduction to Women Studies

Developed, revised, and taught own syllabus--and incorporated service learning options.

- Spring 2003 and Summer 2002

Teacher's Assistant, Women 345: Women and International Economic Development

- Winter 2003

Teaching Assistant, Women 200: Introduction to Women Studies

Lead weekly discussion sessions, met individually with students, and graded.

- Winter, Spring, and Fall 2002 and Winter 2001

Service Learning Instructor, Women 322: Race, Class and Gender

Guest lectured once, helped facilitate in-class work, met with students, and graded.

- Fall 2001

Service Learning Instructor, Women 200: Introduction to Women Studies

Supervised, met individually with, and graded students working on community projects in the Seattle area—in hand with the content of the course.

- Fall 2000

Co-Supervisor, Women Studies Undergraduate Senior Thesis

Topic: Women, Visible Disabilities, Sexuality, and Beauty Constructs

- Winter and Spring 2003  
Topic: Women, Physical Disabilities, and Care-Giving
- Winter and Spring 2002

## **RESEARCH EXPERIENCE**

### Research Associate, Disability Studies Curriculum Transformation Project

Helped select readings to teach faculty about Disability Studies, and organized the travel and schedule of prominent guest speakers.

- Winter and Spring 2006

### Research Assistant, Women Studies Learning Goals

Reviewed, discussed and synthesized course and departmental goals and assessment strategies with most departmental members, the prior research assistant, and Catherine Beyer, Research Scientist, of the Office of Educational Assessment.

Women 200: Introduction to Women Studies Focus

Women 322: Race, Class, & Gender; Course Focus

- Fall 2005, Winter 2006, and Spring 2007

### Research Assistant, Disability Studies Resources for the Curriculum Transformation Project

Researched and compiled all materials, websites and articles, etc., for the Director, Betty Schmitz.

- Fall 2003

### Research Assistant, Grant Writing

With the support of Angela Ginorio, Ph.D., and Communities Against Rape and Abuse, I assessed grant opportunities for non-profits that are working to address issues related to women and girls with disabilities. I applied for the grant on behalf of CARA, and we were offered the funding.

- Spring 2001

## **ACADEMIC ADMINISTRATION & STAFF RELATED EXPERIENCE**

### Member, Disability Studies Steering Committee

Helped develop the Disability Studies Program by actively promoting disability studies perspectives to students, faculty, and administration through guest lectures and individual and group meetings; co-developed program curriculum objectives; and committee discussions and review of obtaining and sustaining program funding. Fundraised/Co-Organized, "The Dennis Lang Student Award in Disability Studies."

- Fall 2001 to Fall 2009

### Undergraduate Academic Advisor, Women Studies

Remained informed of university-wide changes for undergraduate curriculum.

Worked with community college transfer students--nearly half of our majors.

Created a documentation process for courses transferred as women studies credit.  
 Assessed student transcripts, in terms of university and departmental requirements.  
 Assessed qualification of study abroad courses for departmental credit.  
 Registered students for classes related to our minor and major.  
 Administered graduation approval forms for students in our major.  
 Recruited at community college transfer fairs.  
 Helped facilitate constructive feedback between students and faculty.  
 Advocated for students facing financial and/or disability related barriers.  
 Worked with students striving for university or departmental honors.  
 Worked with students to consider academic and career options.  
 Rewrote the Women Studies Handbook.  
 Fostered departmental community.  
 Acted as spokesperson for decisions made regarding undergraduate program.

- Fall 2009, Fall 2008 through Spring 2009, Fall 2006 through Summer 2007, Summer 2003 through Spring 2005, and Summer 2001

#### Member, Women Studies Curriculum Committee

Reviewed, assessed and worked together to make curricular changes.  
 Discussed and finalized course time schedule allocations.  
 Addressed student needs, with student committee members.  
 Advocated for undergraduate and graduate student concerns.

- Fall 2009, Fall 2008 to Spring 2009, Fall 2006 to Summer 2007, Summer 2003 to Spring 2005, and Summer 2001

#### Internship Supervisor, Women Studies

Help undergraduate students determine and negotiate internship opportunities with local feminist communities. In some cases, I worked with students to read correlating feminist material.

- Fall 2006 through Summer 2007, Summer 2003 through Spring 2005, and Summer 2001

### **ADDITIONAL RELATED WORK EXPERIENCE**

Intern, The Disability Pride Project with Communities Against Rape and Abuse, Seattle

- Winter 2001 through Spring 2003

Certified Completion of 10 hours of training of, "Managing to Be Different"  
 Domestic Violence and Non-profit Management  
 The Washington Coalition Against Domestic Violence 10th Annual Conference

- September 2001

Guest Teacher, San Juan Unified School District, Carmichael/Sacramento, CA

- Fall 1999 through Spring 2000

English as a Second Language Instructor, Austria

- Fall 1998 through Spring 1999

Program Assistant, Women's Center, Pacific Lutheran University

- Fall 1996 through Spring 1998

### UNIVERSITY OF WASHINGTON SERVICES

Member, Disability Studies Steering Committee

- Fall 2001 to Fall 2009

Member, Committee Charged to Review Disability Resources for Students

- Spring 2008 through Winter 2009

Member, Organizing Committee, Feminisms and Religions: Countering Mutual Silence Conference, Seattle, Seattle Pacific University

- April 5, 2008

Member, Local Organizing Committee, Society for Disability Studies Conference, Seattle

- June 2007

Member, Advisory Committee on Disability Issues

Sub-committee of the President's Diversity Committee

- Fall 2003 through Spring 2004

Lead Organizer, Social Justice Forum: Building Bridges Between Activism and Academia

- March 5, 2004

### PUBLICATIONS & WORKS IN PROGRESS

Knoll, Kristina (Forthcoming: DSQ Editors Requested My Review). Book Review of "Feminist Disability Studies." Kim Hall, Ed. For *Disability Studies Quarterly* (Spring 2012).

Knoll, Kristina and Joanne Woiak, Dennis Lang, Sara Goering, and Rebecca Cory (accepted, final revisions). Disability Studies Curriculum Transformation: Building a Program and Cultivating a Community. *Disability Pedagogy In and Outside of the Classroom*.

Knoll, Kristina (2009). Advising Students with Invisible Disabilities: "The Dual Spotlight Effect." *Voices from the Field: National Academic Advising Association Journal*.

Knoll, Kristina R., (2009). Feminist Disability Studies Pedagogy. *Feminist Teacher*. Maralee Mayberry, Sara Crawley, and Jennifer Lewis, Guest Eds., (Vol. 19.2; Winter 2009).

Knoll, Kristina R. Book Review of "The Story of My Life: An Afghan Girl on the Other Side

of the Sky" (By Farah Ahmedi, with Tamin Ansary). For *Disability Studies Quarterly* (Spring 2006).

Castagnetto, Susan, Barbara DiBernard, Pat Fontaine, Parrilla de Kokal, Kristina Knoll, and Pearlie Peters. "Disability Issues: An Open Letter to the President and Governing Council of NWSA." In *NWSAction* (Vol. 15 No.1; Fall 2003).

### **PROFESSIONAL PRESENTATIONS**

Paper Presentation, Feminist Disability Studies Insights Into Doing Identity-Based Politics  
NWSA national conference, Oakland, CA, November 8-11, 2012

Paper Presentation, Exploring Feminist Disability Studies  
Society for Disability Studies, San Jose, CA, June 17, 2011

Co-discussant Leader with Dennis Lang, Erica Sekins, Marisa Hackett, and Monica Olson,  
Students as Activists: Pursuing Universal Design and Disability Justice in Academia  
Society for Disability Studies, San Jose, CA, June 17, 2011

Paper Presentation (in absentia, presented by Amy Vidali), Exploring Feminist Disability  
Studies  
NWSA national conference, Denver, CO, November 2010

Guest Speaker, Understanding Able Bodied Privilege  
Edmonds AAUW Branch, November 15, 2008

Guest Speaker, Disability as Diversity in the Classroom  
University of Washington's Annual T.A. Conference, September 17, 2008

Keynote Speaker, Feminist and Disability Methods for Creating Social Change: Challenges  
and Celebrations  
Walla Walla AAUW Branch's Annual Dinner, May 14, 2008

Guest Workshop Presenter, Able-Bodied Privilege and Disability Oppression: Looking at  
the Intersections  
AAUW WA State Convention, April 25–26, 2008

Guest Speaker, Introducing Feminist Disability Studies  
AAUW Highline Branch, March 1, 2008

Presenter/Departmental Representative, Overview of the Women Studies Programs at the  
University of Washington  
Northwest Women Studies Association Conference, November 2 – 3, 2007

Panelist, Students as Educators and Activists  
Society for Disability Studies Conference, Seattle, June 1-3 2007

Workshop Presenter, Inclusive Teaching: Bodies, Minds, and Emotions in the Classroom  
University of Washington T.A. Conference, September 19, 2006

Panel Organizer and Moderator, Graduate Student Professional Development Panel  
Society for Disability Studies Conference, Washington D.C., June 8-11, 2006

Guest Presenter, Exploring T.A. Diversity  
University of Washington T.A. Conference, September 19-21, 2005

Paper Presentation, Gender Violence, Able-Emotioned Privilege, and Stigma  
Society for Disability Studies Conference, St. Louis, June 3-7, 2004

Guest Lecturer, Able-Nationed Privilege: International Economic Development, Disability  
Studies, and Interdependency  
Women and International Economic Development Course, Winter 2003

Organizer/Facilitator, Incorporating Disability Perspectives into Women Studies  
Classrooms  
National Women Studies Association Conference, New Orleans, June 19-22, 2003

Guest Speaker, Able-Bodied Privilege and Incorporating Disability Studies Perspectives into  
University of Washington Courses  
Faculty Workshop, Invited/Sponsored by Betty Schmitz, Curriculum Transformation  
Project, August 2003

Co-Presenter with Joelle Brouner, Communities Against Rape and Abuse,  
Supporting Survivors with Disabilities: Building Understanding to Strengthen  
Advocacy  
Washington Coalition of Sexual Assault Programs, November 7, 2002

Paper Presentation with Joelle Brouner, Communities Against Rape and Abuse)  
Art as a Catalyst for Social Change  
Society for Disability Studies Conference, Oakland, June 6, 2002

Paper Presentation, Cross Culture Coalition Building  
Society for Disability Studies Conference, Oakland, June 8, 2002

Presenter with Tanis Doe, as organizer, Disability Studies in the Northwest  
Society for Disability Studies Conference, Oakland, June 9, 2002

Paper Presentation, Able-Bodied Privilegism in Feminist Theory and Practice  
Women Studies Graduate Student Conference, Kentucky, March 1-2, 2002

Guest Speaker & Lecturer, Breaking the Silence about Sexual Violence  
Sacramento & Seattle, 1992 to 2002

### **HONORS & AWARDS**

American Association of University Women (AAUW), American Fellowship (Dissertation Fellowship), July 2007- June 2008

Women Studies Doman Teaching Award, 2005

Fulbright Scholar, Women Studies, Austria, August 1998 - July 1999

Honorary Section Chair, Washington Undergraduate Philosophy Conference, 1998

Scholarship, Women as Leaders Seminar, Washington D.C., 1998

### **PROFESSIONAL AFFILIATIONS**

National Academic Advising Association (NACADA)  
American Association of University Women (AAUW)  
National Women Studies Association (NWSA)  
Society for Disability Studies (SDS)  
Fulbright Association