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ABSTRACT

A THEORY OF AN AESTHETIC OF DISABILITY

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The fields of disability studies and educational studies currently operate within four theories of disability: disability as personal deficit, disability as socially constructed, disability as membership in a minority group, and disability as a personal and political identity. While each theory has its strengths, each theory also poses problems for understanding and responding to disability, particularly when we attempt to understand disability from the perspective of disabled people. This dissertation offers a new theory of disability that interprets disability from inside experiences of disability while maintaining that both insiders and outsiders to disability can construct appreciations of experiences of disability. This is an inclusivity that other theories of disability do not accomplish.

In this inquiry, the appreciation of disability is conceptualized as an aesthetic of disability, wherein meaningful experience is artful and the appreciation of meaningful experiences is the aesthetic. This understanding of experience and aesthetics is borrowed from the philosopher John Dewey.

As an interpretive inquiry, this dissertation attempts to understand differently the phenomena of disability and to present alternative ways of viewing the human world in relation to disability. As a theoretical enterprise, the methods used are conceptual and analytical. Several conceptual tools, or concepts that have been submitted to critique and analysis, are explored and reconceptualized: disability, the body, identity, and community. These conceptual tools were selected for their relevance to disability and their frequency of use in current scholarly works within disability studies.

In the end, two basic premises emerge from this interpretive exploration: 1) "Disability" is a set of body-based experiences that can be appreciated for their meanings and contributions to the construction of the self and community; and 2) "Disabled" is an interpretation of the self constructed from one's own lived experiences. These premises are argued from multiple perspectives and using varied examples drawn from composites of personal experience with disability, observations of disability phenomena, and the work of other scholars.

In the last chapter of this dissertation an aesthetic of disability is examined for its applications to educational thought and practice. Four categories of applications are discussed: educational policy, teacher education, curriculum and pedagogy, and educational research.

For Tiffany

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Special thanks to my Dissertation Director, Susan Peters, and my Program Chair, Doug Campbell, who have seen me through this rite of passage. Thanks, also, to Cleo Cherryholmes and Lynn Paine, who served on my dissertation committee, and to Brian DeLany, who served as a program committee member for several years.

Looking back many, many years, I suppose I began the journey toward my dissertation during my childhood. My parents, Earl and Barbara Sharp, contribute much to this work.

I thank two very dear friends, whose conversations, debates, late night dinners, hugs, and tears made it possible for me to enjoy fellowship during these years. Special thanks, therefore, go to Sandi McClennen and Judith Sheldon. I look forward to more debates over future intellectual problems.

My family struggled and sacrificed along with me during my doctoral work and the completion of this dissertation. My husband, Peter, has been completely supportive and wonderfully sensitive, especially during my "affair with my dissertation." My children, Bob, April, and Benjamin are my joy. My husband and my children celebrate this accomplishment with me.

Finally, a posthumous acknowledgement goes to my oldest daughter, Tiffany, who died one year prior to the completion of this dissertation. She is the original inspiration for an aesthetic of disability.

TABLE OF CONTENTS

Chapter 1

Between Problem and Discovery

This dissertation is situated within an emerging field often identified as "disability scholarship" or "disability studies." Disability studies is a sociological, political, and intellectual trend in academic and public spheres that focuses inter-disciplinary attention on the problems and solutions related to disability in society. Following in the footsteps of women's studies, urban studies, and studies of race, ethnicity, gender, minority and other oppressed social groups (including gays and lesbians), disability studies are done by scholars from a wide range of academic and professional backgrounds: sociology, history, anthropology, public policy, psychology, medicine, education, mental health, public health. Disability studies values the contributions of people with disability just as women's studies values women's perspectives, and urban studies values the perspective of people who live or work in urban settings. In educational scholarship, disability studies should not be misunderstood as "special education studies" because that distinction is actually antithetical to the idea of disability studies. While the systematic study of disability might be housed in a particular college or department, it is applicable across disciplines because disability can be found in all arenas of human experience. Disability scholars, then, are interested in special education but they are also interested in education in general, as well as public policy, medicine, social problems, cultural studies, and the history and sociology of disability.

As a work that straddles two compatible fields of inquiry, disability and educational studies, my emphasis is on disability theory that can be applicable across institutional and social settings; however I pay closest attention to educational applications, primarily because that is the institution with which I am most familiar. My theoretical work, however, should be applicable to disability in other institutions and in society in general.

The goal of my dissertation is to develop a new theory of disability. I intend this theory to be compatible, or to at least co-exist, with other theories of disability. I review and critique four current theories of disability in chapter two. My theory of an aesthetic of disability is presented in chapter four.

Four concepts are central to my development of a theory of an aesthetic of disability: disability, the body, identity, and community. These concepts are the focus of much current inter-disciplinary scholarship analyzing race, gender, and sexual orientation. They are becoming the focus of research in the disability studies field as well. For example, most of the sessions at the 1997 meetings of The Society for Disability Studies, a small international community of disability scholars, addressed issues related to identity, community, or the disabled body.[1] Many of the presenters struggled with dilemmas of who can be called disabled or non-disabled, how such decisions are made, and the value of knowledge of disability from these two perspectives. In my study, I explore these concepts in inter-disciplinary ways that are connected to inquiries in other fields of study while attempting to expand upon our options for

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[1] The Society for Disability Studies, Tenth Annual Meeting, Minneapolis, MN, May 1997.

understanding them as general concepts and as connected specifically to disability. Later in this chapter I will elaborate on some fundamental ideas in my theory of disability and its importance as an interpretive work.

Problems and Questions Guiding Inquiry

I conceptualize "problems of inquiry" as questions that drive or focus inquiry, or as dilemmas for which someone searches for solutions. The problems guiding this inquiry are conceptual, yet they are also connected to real human experiences because they relate to the experience of living in one's body in relation to other people in this world. The questions I ask have emerged as I have attempted to clarify my place in disability studies and through my struggle to make sense of disability and disabled-ness as I have observed and experienced them. My questions are philosophical in nature and are as follows.

> 1. What is disability and how does a person come to know she is disabled or that she experiences disability?
> 2. What is a body and how do experiences of the body shape one's identity and community and one's construction of the self in relation to others?
> 3. What is an identity, how does a person know her identity, what meaning does knowing one's identity have for a person, and how do experiences of identity influence the construction of the self?
> 4. What is a community, what meaning is attached to community by its members and how do experiences of community influence the construction of the self?
> 5. How do aesthetics provide a meaningful interpretation of disability experiences and the disabled self?

It is clear that my questions and the conceptual tools with which I work are closely matched: disability, the body, identity, and community. Furthermore, I have asked a fifth question that demands that I construct an interpretive theory of disability, although I have made a methodological decision not to use "aesthetic" as a conceptual tool in the same way that I use disability, the body, identity, and community. The next section provides a preliminary discussion of the use of conceptual tools.

Conceptual Tools

To understand my methodological decisions discussed later in this chapter, it is first helpful to understand the conceptual tools with which I work. Therefore, I provide an explanation of those tools prior to a description of my methodology.

I have selected four conceptual tools to use in the development of my theory of an aesthetic of disability: disability, the body, identity, and community. I use these particular tools for three reasons. First, I believe that the concepts of the body, identity, and community are integral to an understanding of the experiences of disability. As integral concepts, they need further exploration by disability studies scholars. Second, to understand experiences of disability, we need to fill in the conceptual gaps related to disability. While there are several conceptualizations of disability (personal deficit, social construct, minority group, personal/political identity), to my knowledge there is no scholarly development of an aesthetic of disability, nor an explication of disability as the construction of meaning from one's lived experiences. Third, the theoretical connections between how we understand disability and how we conduct our social lives need to be developed in order to enrich our understandings of ourselves as humans. A brief discussion of the conceptual tools with which I work follows.

Disability

There are numerous ways of conceptualizing disability. Four of the most common conceptualizations are: personal deficit, minority group, social construction, and personal or political identity. In chapter two each conceptualization is summarized and critiqued. The purpose of my critique is to illuminate the ways in which each theory of disability poses problems from the perspective of disabled people and to reveal the likelihood that these theories are not significantly different from one another. I argue that their differences are not substantial enough to indicate that they provide sufficient alternatives for disability thought and scholarship.

The most common way of interpreting disability is to view it as a personal deficit, or as something wrong with a person. The tendency within this theory is to attempt to fix what is wrong. Medicine adheres to this view, as do education and psychology. Adherents to the deficit model of disability typically believe that disability is something within an individual, although they may disagree about the cause of disability. This view typically assumes that disability can be objectively identified. Special education operates within this model when it diagnoses students as "disabled" and prescribes a specialized treatment plan and the provision of special services from a separate educational system.

The "deficit model" has been critiqued by disability scholars and its problems and subjectivities have been revealed.[2] Criticism of the deficit model will be fully explored in chapter two; however a typical critical response to thinking about disability as a personal deficit is to construct it as membership in a minority group. This way of understanding disability

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[2] I cite three of the many works here: Harlan Hahn, "The Politics of Physical Differences: Disability and Discrimination," *Journal of Social Issues* 44 (1988): 39-47, which constructs an argument that focuses on physical disability; Michelle Fine and Adrienne Asch, "Disability Beyond Stigma: Social Interaction, Discrimination and Activism," *Journal of Social Issues* 44(1988): 3-21, uses the symbol of "stigma" to explain the consequences of the deficit model; and Mark Nagler's "The Disabled: The Acquisition of Power," *Perspectives on Disability*, ed. Mark Nagler (Palo Alto, CA: Health Markets Research, 1993): 33-36, in which Nagler calls for political action to gain power for disabled people. These scholars all respond to deficit thinking by arguing for a minority group approach to disability.

holds that people with disability are members of an oppressed group of people, as are members of minority racial, gender, or gay and lesbian groups. A scholar who has been instrumental in purporting this view of disability is the late Irving Zola, a sociologist of disability. Harlan Hahn has also been active in defining this view of disability, as have Robert Bogdan and Douglas Biklen.[3] As with the personal deficit model, there are problems with the minority group model and those problems will be explored in chapter two.

A third view of disability is the view that it is socially constructed. This view is related to the minority group model if one believes that societal structures create minority groups. Social constructivists have argued that there is no person who is essentially disabled, but that society creates physical, programmatic, or attitudinal barriers that subsequently shape perceptions of who is disabled and who is not. Scholars representing this view include Caroline Wang who examines the construction of physical difference through injury prevention campaigns; Hugh Mehan, et. al., who study special education referral processes in a West Coast educational system; Robert Bogdan and Stephen Taylor and their empirical study of families who care for loved ones with significant mental retardation; Harlan Lane in his exposition of the construction of disability in deaf people; Elaine Makas in her inquiry into the impact of "contact" with people who

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[3] One of Irving Zola's important pieces on this topic is "Self, Identity and the Naming Question: Reflections on the Language of Disability," *Social Science and Medicine* 36(1993): 15-24, in which he claims that naming, or labelling, has negative impact on individuals who are labelled. Zola argues for a vocabulary of disability that is active, that is person-centered, and that focuses on characteristics people "have" (as in "I have a disability") rather than features of being (as in "I am disabled"). In chapter four I disagree with Zola's application of person-centered language, although I agree with the philosophy from which he applies the language. Also see Hahn, "Politics of Physical Difference"; and Robert Bogdan and Douglas Biklen, "Handicapism," *Social Policy* March/April(1977): 14-19.

have disability; and James Trent who has developed a fascinating argument about the construction of mental retardation.[4]

More recent work in disability studies has begun to interpret disability as a personal and political identity.[5] This view of disability is related to the minority group model because both views agree that disability has social origins with political consequences. It differs from the minority group model in its ability to accept that disability might not be experienced as membership in a minority group for all individuals with disability, and that the general experiences of oppression by minority group members does not necessarily require all group members to share exactly the same identities. The personal and political identity model also agrees with constructivism because both models adhere to the idea that disability is a phenomenon, or a variety of phenomena, constructed by social processes. While the constructivist model provides an explanation for the existence of phenomena of disability, the personal and political identity model places stronger emphasis on taking action as a response to the social problems that create disability and its negative consequences.

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[4] Carolyn Wang, "Culture, Meaning and Disability: Injury Prevention Campaigns and the Production of Stigma," *Social Science and Medicine* 35(1992): 1093-1102; Hugh Mehan, Alma Hertweck,and J. Lee Meihls, *Handicapping the Handicapped: Decision making in Students' Educational Careers* (Stanford, CA: Stanford University Press, 1996); Robert Bogdan and Stephen Taylor, "Relationships with Severely Disabled People: The Social Construction of Humanness," *Social Problems* 36(1989): 135-148; Harlan Lane, *The Mask of Benevolence: Disabling the Deaf Community* (New York: Vintage Books, 1992); Elaine Makas, "Getting in Touch: The Relationship Between Contact with and Attitudes Toward People with Disabilities," *Perspectives on Disability*, ed. Mark Nagler (Palo Alto, CA: Health Markets Research, 1993): 121-136; James Trent, *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley, CA: University of California Press, 1994).

[5] Susan Peters, "The Politics of Disability Identity," *Disability and Society: Emerging Issues and Insights*, ed. Len Barton (New York: Longman, 1996): 215-234; and Simi Linton, "Disability Studies: Who Are We and Where do We Want To Go?" a Plenary Panel at The Society for Disability Studies Annual Meeting, held in Minneapolis, MN, May 1997.

The personal and political identity model is closest to the way in which I understand disability but it, too, has problems. One major problem is that it politicizes disability to its very core and although it includes notions about how individuals understand their selves, it has not been fully fleshed out in this regard. More will be argued in chapter two related to this theory of disability. While the entire second chapter is devoted to analyses of the concept "disability," my next three conceptual tools share space in the third chapter.

The Body

In my framework, experience and identity formation are whole body cultural processes. This notion of the body's involvement in cultural processes comes from the influence of a wide range of scholars who study the body. Bryan Turner is a sociologist of the body who has worked to understand society and social beliefs in light of body experiences and institutional responses to the body. His work is reminiscent of Michel Foucault's theory of body power that holds that individuals' bodies are controlled by the power wielded by social institutions. Mary Douglas views the body as a symbol of society upon which we "write" our cultural beliefs.[6] By this she means that the body is a symbol system that mirrors cultural beliefs in the ways in which we talk about and interact with the body. She and others view the body as a form of discourse or communication. In one way they understand the body as a metaphor for culture or society while in another way they view culture or society as emanating from the experiences of the body. I use their work along with Turner's and

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[6] Bryan Turner, *Regulating Bodies: Essays in Medical Sociology* (New York: Routledge, 1992); Michel Foucault, *The Order of Things: An Archaeology of the Human Sciences*, trans. Editions Galliard (New York: Vintage Books, 1970; Mary Douglas, *Implicit Meanings: Essays in Anthropology* (New York: Routledge, 1975/1991).

Foucault's more loosely. I cannot claim that there are objective truths inherent in the scholarship of the body but I find it helpful to understand the disabled self by utilizing the body, experiences of the body, or beliefs about the body as a metaphor for understanding ourselves. Understanding the body as a symbol of the self or culture has its limitations, one of which is to prioritize groups of people, or societies, over individuals. While I do not make an argument for individualism, I argue for an understanding of the body from the perspective of the one living in that body, even though "living in a body" is itself a construct. To put this another way, I argue that in addition to understanding the body as a site of cultural discourse, the body must also be interpreted by the body of the individual herself. It must be understood as a thing that experiences living.

The body and experiences of the body, then, become more tools with which I work to construct understandings about disability. Three scholars are particularly helpful to me in conceptualizing the body. First, Elizabeth Grosz, a feminist theorist, notes that the body is a kind of "sexed corporeality," by which she means that the body's knowledge and experience are essentially gendered.[7] While she agrees that the body can be conceptualized socio-culturally, as purported by Douglas and Turner, she maintains that the body's gender is the basic interpretive force for the experiences of the body and the knowledge generated by those experiences. I find at least one problem with this view of the body. It ignores disability and the fact that while most humans will never experience both maleness and femaleness (most of us experience one of

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[7] Elizabeth Grosz, "Bodies and Knowledges: Feminism and the Crisis of Reason," *Feminist Epistemologies*, eds. Linda Acoff and Elizabeth Potter (New York: Routledge, 1993): 187-215.

those gendered corporealities in our lifetime), we all have the potential for experiencing disability. Grosz and other scholars of gender do not appear to recognize that it is disability that we all have the potential for experiencing; therefore I view disability as a more potent experience for shaping individuals' interpretations. Put another way, disability is a category of experiences that is more likely to be shared by all humans, whereas male or female gendered experiences are only shared by some humans. This recognition is important to studies of the disabled body.

Another feminist scholar, Paula Cooey, deals openly with the question "what is the body?"[8] Her own conceptualization of the body is that it is the embodiment of the imagining and agency of a "human subject." She writes that "the body lived in relation to the body imagined (is) a testing ground ... for mapping human values, as they are informed by relations of and struggles for power" (p. 9). Her notion of the influence of power over the identification of the body is reminiscent of Foucault's work.

Jonathon Rutherford has made a fascinating suggestion that "in this post-modern, 'wide-open' world, our bodies are bereft of those spatial and temporal co-ordinates essential for historicity, for a consciousness of our own collective and personal past" (p. 24).[9] Furthermore, he indicates that existence is "personal" and "nomadic." Rutherford's concept of the body as not being bound by time, space, history, or collectivity is a unique perspective explored in chapter three.

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[8] Paula Cooey, *Religious Imagination and the Body: A Feminist Analysis* (New York: Oxford University Press, 1994).

[9] Jonathon Rutherford, "A Place Called Home: Identity and the Cultural Politics of Difference," *Identity, Community, Culture, and Difference*, ed. Jonathon Rutherford (London: Lawrence and Wishart, 1990): 24-25.

A final way of conceptualizing the body is explored through the work of Michel Foucault, who conceives of the body as acted upon by institutional power. While Foucault does not explicitly conceptualize about the body itself, he theorizes about the ways in which social institutions interact with the body. Two of his metaphors are analyzed in chapter three: the gaze, or the institutional examination of the body and institutional construction of notions about bodies; and discipline, or the monitoring and managing of bodies to conform to social norms of practice. Extending Foucault to conceptualizing about the body allows a view from the inside of the power relations between bodies and institutions.

A brief digression is required here. In this inquiry I compare disability to other identities (race, gender, sexual orientation). I do not compare it to social class for a specific reason. I view race, gender, sexual orientation, and disability as identities or experiences that are typically believed to be located in the human body. Whether or not these experiences are social constructions and whether or not we agree on definitions of race, gender, or disability, our descriptions of them and our beliefs about them are directly related to the bodies of those who share the identities. Once we have defined a race,[10] that definition is based in perceptions derived from the bodies of individuals. Gender, too, is dependent upon some type of body experience or beliefs about a body experience.

I argue that even identities that are believed to be located in the mind are body-based identities. Schizophrenia, for example, is believed to

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[10] Here I understand ethnicity to be subsumed under race. Although I recognize that an argument could be made against such an assumption, for simplicity I have made this choice.

be a mental illness but there is disagreement about the extent to which schizophrenia is emotional or physiological in origin. Regardless of its origins, schizophrenia is a whole body experience. The person with schizophrenia may perceive sights or sounds that others do not see or hear. She may move her body in certain ways when anxious or angry. She may scratch herself or pull at her hair in her fear. She may scream or cry in utter terror. She may sit passively, over-medicated to prevent her from injuring herself. These are all whole body experiences. It does not matter from where they come in order to understand them as body based. It only matters that they are experienced, that someone feels them, that someone knows them, that others believe they observe them in the body. When attempting to differentiate between identities, male or female for example, we might disagree on what that experience is and how it presents itself to us, but the experience is nevertheless located first within the body: in the sexual organs or in the mind of the person experiencing the gender, or in the mind of the person perceiving the gender in another. The body interacts with the social or physical environment and with other bodies but the identity itself starts with the body: what the body does, how the body looks, what the body says, how the body feels, and how others experience that body.

Class, on the other hand, has economic and political origins that shape subsequent body experiences but that do not arise from the body. Although class does not appear to us to originate from the body, I would agree that class-related experiences have the potential for altering the body in a variety of ways, for example: by the clothes that are worn, the hygiene that is used, the places one sleeps, or the health care one can afford. I would also agree that class or perceptions of class alter the ways in which others interpret the body. I would further agree that these body alterations cause social interactions that might feel similar to those experienced by members of racial, gendered, or disabled groups of people. I am not claiming that class has no impact on the body or on the experiences of the body that contribute to identity formation. Nor am I claiming that class is a less important concept for understanding disability, the body, identity, and community. I am claiming, however, that class is not in the same conceptual category as identities that begin with the body or that are believed to begin with the body.

I am making this claim for reasons of simplicity as well as for intellectual reasons. Some post-structuralist scholars would disagree with me here, if only because I am making a distinction between class and other "structures".[11] I recognize this potential discomfort but I find it intellectually necessary to set some boundaries. I also recognize that there are problems of logic with my claim. For example, one might ask why I use non-essentialist scholars' works to make claims about disability while I behave structurally by refusing to include class as a category dependent on body experiences. If I am implicitly assuming that boundaries are subjective in nature and that I can pragmatically select the outcomes I wish as I study subjectivities, then I could also accept class within my identity categories. I have explicitly chosen not to do this. Due to my very subjectively determined distinction between identities that begin with the body and experiences that affect the body but do not originate within the

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[11] By post-structuralist, I refer to scholars who adhere to the view that there are no objective categories of truth. This is in opposition to structuralist views, that there are objective categories of truth.

body, I have chosen to avoid the use of class in my examples of identity and community.

The body, then, seems to have some type of corporeality, some physicality we think we can see and touch. We seem to experience ourselves as body-based beings. There are philosophical arguments to suggest that the body is not essentially a corporeal experience, but that it is a social construct necessarily without spatial and temporal boundaries. It seems possible that we appear to ourselves as thinking, feeling bodies but that we are actually beings that cannot know our real selves, that we are limited in recognizing our selves when presented with our selves. What, then, does this have to do with disability? I argue that it has everything to do with disability and that our ideas about our bodies are at the root of our construction of our identities and communities. In chapter three I further explore the body literature and I construct an interpretation of the body. In chapter four, I utilize my interpretation of the body, along with interpretations of identity and community, to construct a theory of disability.

Identity

Identity studies are trendy at the moment and I suppose I contribute to this trend in doing this work. However, there is precedent for the importance of the study of identity earlier in this century. Martin Heidegger noted in his seminal philosophical work, *Identity and Difference*,[12] that the "principal of identity is considered the highest principal of thought." For this inquiry I conceive of identity as implying both how a person views herself and how others view her. I view identity to be

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[12] Martin Heidegger, *Identity and Difference*, trans. Joan Stambaugh (NewYork: Harper and Row Publishers, 1957/69).

expressed through understandings of how an individual or individuals are simultaneously the same and different from others. Identity is clearly a relational way of knowing the self. This view of one's self or another is a whole body understanding that is influenced by one's cultural context and that involves the following: the physical senses (seeing, hearing, etc.), thoughts and emotions about the self or other (or the absence of thoughts and emotions), kinesthetic knowledge of oneself or another (moving or not moving in a certain way, holding one's body in a certain position, having one's body probed or moved in certain ways), and in the case of some disabilities unique perceptions that are not perceived by others (as in schizophrenia, with which many individuals hallucinate).

In chapter three I explore some of the work in identity that stems from feminist and race theory scholars. Feminist theorists are helpful in their work on the body and identity. Critical race theory is a field of inquiry and from this field I utilize one emerging scholar. Anna Stubblefield has examined race from a non-essentialist perspective and claims that there is no "race" except where groups of individuals are bound together through common experience.[13] She argues that most often the common experience is oppression and that through oppression, racial identity and community are formed. Her arguments about race can be applied to disability and at least one disability scholar has made such claims.[14] I pursue this line of thought in my explorations of identity.

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[13] Anna Stubblefield, "Racial Identity and Non-Essentialism about Race," *Journal of Social Theory and Practice* 21(1995): 341-368.

[14] David Pfeiffer made the same claim in "Similar and Different: Core Concepts and the Coming of Disability Studies," The Society for Disability Studies Annual Meeting in Minneapolis, MN, May 1997.

Perhaps the richest body of scholarship I have discovered comes from gay and lesbian studies, where I have found empirical descriptions of identity and community formation and from which disability studies can gain much insight. I carefully explore this literature in chapter three. Here I provide two examples. Judith Schuyf conducted a study of lesbians in the Netherlands.[15] She observes that there appears to be infinite possibilities for lesbian identities and that there is no one way in which all or most lesbians come to know themselves as lesbian. She identifies a variety of identity formation processes that emerge from her work and she categorizes them into a continuum that is somewhat misleading because it suggests a move toward objective reality that she seems to denounce elsewhere. Nevertheless, Schuyf describes multiple lesbian identities that reminds one of the "multiple identities" concept in general. She notes that there are many ways of "being" a lesbian. This seems to be a similar claim to the notion that there are many identities one experiences throughout one's life and that claiming an identity does not necessarily indicate that a person shares a set of experiences with others who claim that identity.

Peter Davies has studied coming out among gay men. He notes that "coming out is a central feature of the experience of lesbians and gay men in the western world" (p. 75).[16] He claims that coming out is the cumulation of many processes that result in becoming a different person within the gay community. He argues that "we need a post-modern

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[15] Judith Schuyf, "The Company of Friends and Lovers: Lesbian Communities in the Netherlands," *Modern Homosexualities: Fragments of Lesbian and Gay Experience*, ed. Ken Plummer (New York: Routledge, 1992): 53-64.

[16] Peter Davies, "The Role of Disclosure in Coming Out Among Gay Men," also in *Modern Homosexualities*: 75-83.

account of identity which recognizes multiple identities and life as a process of achieving a more or less satisfactory *modus vivendi* with them" (ibid.). He echoes many scholars' beliefs of the centrality of the social world in identity formation when he writes, "...identity is a process of accommodation to a social world, rather than a dominating and pre-disposing psychic force" (ibid.). Davies' work, and the work of other gay scholars, suggests that a social process of "coming out" is beneficial even though it might be the result of a climate of oppression. In chapter three I analyze the potential meaning the process of coming out could hold for people with disabilities.

In conclusion, chapter three of this dissertation utilizes the work of a variety of identity scholars who hold a range of views on identity. I examine feminist scholars for their notions of a gendered identity. I examine race scholars for their claims about racial categories. I also examine gay and lesbian scholars for their work on the development of a gay identity. In each case, I critique the applicability of these literatures to studies of the disabled identity.

Community

If identity is a body experience that is forged through thought and action, and if the body is either an objective corporeality or merely the subjective experience of being-ness we cannot fully understand, what, then, is community and how is it important to understanding disability? First, like the tides and tensions of experiences of identity and like the body and the ways in which our bodies appear to us, the communities to which we belong also have fluidity, movement, and motion. We belong to many communities at once. Some of our communities are more prominently featured at certain times in life while at other times or in other contexts, they fade and different community affiliations feel strong. Is community a body experience, though, and whether or not it belongs to the body, how can it be understood?

In chapter three I argue that community is a body experience with some experiential features that are both different from and connected to individual identity. Our perceptions of identity are dependent on the sensations we feel in our bodies as we experience ourselves and others as disabled, or gendered, or raced, or sexual. Identity is formed through interacting with others but it is, to a great degree, one's own, as is one's perception of the identity of an other one's own. Even though one might share identity features or beliefs with others, one's identity is uniquely one's own in that no other can ever experience an identity in the exact same way as any other individual who shares that identity experiences the identity.

In contrast, community is dependent on the joint experiences of many individuals or many bodies, or at least the perception of shared experiences. Community, it would seem, is entirely dependent on some type of real experiences or perception of shared experiences in combination with either a choice to belong to those shared experiences or being assigned to belong to those experiences. By its very definition, community is something that a group of people do or share whether by choice or not, although experiences of community certainly influence experiences of identity and affect the body or the perceptions of the body.

A community of people with disability, or of women or lesbians might be composed of individuals who believe they share an identity and body experiences or who have been assigned by others to a community based on social values and processes. Perhaps even more so than individual identity, community is dependent on certain social processes that designate the community and its members and that establish its values and customs.

In chapter three I explore the social processes that contribute to the formation of community through ritual. Victor Turner, Bruce Lincoln, and David Kertzer develop models of ritual that indicate that rituals are one form of "social glue," one way of binding groups of people together into community.[17] When the function of ritual is applied to a common ritual connected to disability, for example intelligence testing, I believe it will be clear that rituals of disability facilitate the shaping of community in several ways. First, it identifies members of the disabled community in society. Then, it segregates those members physically. To continue the example of schools, students with certain intellectual abilities are segregated in a legally mandated separate educational system. Finally, ritual's powerful symbolism perpetuates the meanings inherent to ritual acts. To expand my school-based example, intelligence test results symbolically mark students so that every adult connected to that student's education becomes familiar with his status as disabled, has access to his test results, and is influenced by the implications of test results and the disabled status for that child's education. Furthermore, the non-disabled community is identified through intelligence testing by omission. Students who are not tested are believed to be non-disabled. Students who are tested and do not qualify for special education can either be viewed again as non-disabled or their teachers

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[17] See Victor Turner, *The Ritual Process: Structure and Anti-Structure* (Ithaca, NY: Cornell University Press, 1969); Bruce Lincoln, *Discourse and the Construction of Society: Comparative Studies of Myth, Ritual, and Classification* (New York: Oxford University Press, 1989); and David Kertzer, *Ritual, Politics, and Power* (New Haven: Yale University Press, 1988).

could continue to believe them to be disabled while discounting the test results. Intelligence testing clearly marks the disabled and non-disabled individual in schools and contributes to the development of certain types of school communities in which individuals marked by test results are assigned to certain roles or functions in the whole school community. Likewise, students who are not marked by intelligence test results are also assigned to certain roles or functions. Ritual, then, plays an important role in community and disability in schools and in society as a whole.

The theory of reciprocity is an example of another intra-community social process that focuses on interactions among members of a community. Marcel Mauss' theory of reciprocity states that a community maintains social stability when all members have reciprocal relations.[18] Reciprocity is a form of social relations in which all social members or institutions comprised of social members contribute to the good of society, each playing his or her role in good faith. In a nation such as the United States, according to Mauss, this means that the government promises to protect its citizens, who in turn promise to cooperate with government officials and rules, including rules of giving and receiving. In a tribal society, it could mean that the chief provides protection to tribe members who pledge their support and who present the chief with goods and services that he wants or needs. In a school community, my argument is that reciprocity is also at work. Just as nations grant rights and responsibilities to those who follow the rules of reciprocity (even if the rights or responsibilities are differently conceived and understood between

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[18] In Marcel Mauss, *The Gift: The Form and Reason for Exchange in Archaic Societies* (London: Routledge, 1950/1990).

different nations), school communities do too. And as in tribes and nations, individuals in schools who are shut out or who opt out of reciprocal relations are marginalized and do not participate in the social interactions that occupy the rest of society. My claim, then, is that students with disability are often shut out of reciprocal relations in schools by the legalization of a separate educational system and the identity and community building consequences of such legalized policies. Their inability, for whatever reason, to participate in the "social economy" (the exchange of social "goods and services" for the return of the same) of school communities marginalizes them.

Michel Foucault has a large body of work that examines the interactions between individuals and social institutions and that is relevant to my analysis of the concept of community.[19] Foucault's theory of body power, or power relations, shifts the emphasis to ideology and power. His theory is often synonymously called "body power" or "power relations;" however I prefer the use of "body power" because of its consistency of focus with my purpose. Foucault's theory holds that power flows through society and social institutions, controlling the lives or bodies of individuals. On one level, Foucault's theory is highly personalized, focusing on individual bodies and lives and the ways in which social institutions and the powerful ones who "run" institutions affect the lives of those without power. Foucault's accounts of the institutions of medicine, psychology, psychiatry, and prisons give agency to institutions and construct bodies as

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[19] See the following works by Michel Foucault: *Mental Illness and Psychology*, trans. Alan Sheridan (Berkeley, CA: University of California Press, 1954); *Madness and Civilization: A History of Insanity in the Age of Reason*, trans.Richard Howard (New York: Vintage Books, 1965); *The Birth of the Clinic: An Archaeology of Medical Perception*, trans. A. M. Sheridan Smith (New York: Vintage Books, 1973); and *Discipline and Punish: The Birth of the Prison*, trans. Alan Sheridan (New York: Vintage Books, 1979).

receptors of and actors with institutional agency. He describes them as though they are real characters in a surrealistic play. Foucault's power almost takes on human traits. It is active in the human drama. It interacts with other characters in the human story and colludes with institutions as characters to control bodies. Power simultaneously reflects humanity and is instrumentally used by humans. Understanding community in light of Foucault's theory of body power is another way of interpreting community and disability.

Positive and intimate human relationships are missing in Foucault's work but the work of another scholar, a philosopher, is useful for this purpose. Nel Noddings' theory of caring is an ethical framework within which to interpret interactions between people.[20] Using her definition of caring as a reciprocal relationship between the carer and the one cared-for, where the cared-for must recognize that caring has taken place and must be able to reciprocate with caring, we can further understand school communities and the relationship of students with disability to the school community. Noddings' theory of caring enhances Mauss' theory of reciprocity. Through Noddings, community can be understood as a place where caring does or does not occur, or where caring interactions occur with some community members but not others. To remain entirely consistent with Noddings, school could be understood as a place where some individuals are members of the community and where others are shut out of membership because they are not full participants in reciprocal caring with other members of the community. Carried to its fullest extent,

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[20] Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (Berkeley, CA: University of California Press, 1984).

then, Noddings' work suggests that evidences of caring relationships are marks of community membership.

An Aesthetic of Disability

My four conceptual tools have constructive uses in addition to critical ones. In chapters two and three I interpret these concepts to lead to a construction of a theory of disability contingent on experiences of living, or as John Dewey would claim, as multiple aesthetic pursuits.[21] Briefly, aesthetics can be understood as a way of constructing and appreciating artful meaning from experience. John Dewey's theory of experience and the aesthetic informs my development of a theory of an aesthetic of disability. Dewey writes about the tensions inherent to the process of giving meaning to and appreciating one's experiences:

> Since the artist cares in a peculiar way for the phases of experience in which union is achieved, he does not shun moments of resistance and tension. He rather cultivates them, not for their own sake but because of their potentialities, bringing to living consciousness an experience that is unified and total (p. 536-537).

In the chapter, "Experience as Aesthetic," Dewey continues by claiming that in a perfect world, where problems and tensions are resolved, there can be no aesthetic, no appreciation of art or experience because it is the tension, the struggle toward resolution, that creates an eventual aesthetic awareness and appreciation. To Dewey, the struggle toward resolution is the attempt to achieve some type of aesthetic and the achievement of resolution is the aesthetic experience (or resolution) itself. In this line of thought, aesthetic experiences in our "unfinished world" are fleeting. We daily struggle for small pleasing experiences or we work hard to find

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[21] John Dewey, *Experience and Nature* (Chicago: Open Court Publishing Company, 1926).

meaning in sorrow. Sometimes we are rewarded. We are, to Dewey, fully alive when "the future is not ominous but a promise" (p. 539), something to which we look forward, regardless of the problems getting there.

In disability studies, the future includes attempts at figuring out how to think about disability that brings consequences that are not only pleasant and from the perspective of people with disability, but that also get as close as possible to an understanding the experience of disability from within the experience. An aesthetic of disability would affect individuals and our understanding of the disabled identity. It would also affect communities, groups of people who can appreciate the struggle to unify their lives and their thoughts, whether or not these communities are comprised of disabled people or of people with mixed abilities.

If experience and art are inextricable, as Dewey claims, then the disabled identity has the potential for an aesthetic expression and experience as do other identities. It could be understood as the pursuit of pleasant outcomes: a self concept with which one is comfortable and happy, self esteem, confidence in the face of struggle, courage when confronted with fear, fulfilling sexual expression, or whatever the individual defines as "pleasant outcomes," although in chapter four I argue that to be consistent with Dewey an aesthetic of disability also includes the appreciation of meaning in unpleasant experience. Outcomes, then, are self-defined although I accept the probability that choices made by the self are, themselves, socially constructed. Understood from a community perspective, the aesthetic pursuit could include the attempt to understand our similarities and differences, the struggle to get along with one another, the tensions between the rights of various individuals and the needs of the community, solidarity in pursuit of civil liberties, or the ability to belong to an inclusive community in which one might be a minority member. Again, Dewey's claim is that the resolution of tensions are the materials of the aesthetic experience. Without struggle, he argues, aesthetic appreciation is not possible. In chapter four, I fully develop an aesthetic of disability, integrate it with the body, identity, and community, and propose possible implications of this theory. In order thoroughly to develop a theory of an aesthetic of disability, other works from the literature on aesthetics are utilized that examine aesthetics from traditional and feminist perspectives.

Methodology

Since this inquiry deals primarily in the realm of ideas, concepts, and imagination,[22] methods that can analyze and interpret ideas and concepts must be used. To find such methodological strategies and apply them to my inquiry requires an inter-disciplinary search and a blending of various strategies identified in that search. The analytic tools that I use in this inquiry are submitted to creative strategies that constitute a "thought experiment" common in philosophical inquiry.[23] Alternatively, Patty Lather suggests that this type of work is best done with "rigorous confusion."[24] When combining Noddings' and Lather's ideas, it might be accurate to describe my inquiry as a thought experiment that allows for rigorous confusion.

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[22] Here I use imagination to refer to ideas conceived by me and then put into writing for the purpose of this inquiry.

[23] A common phrase used in philosophical inquiry, I borrow it from Nel Noddings, *The Challenge to Care in Schools: An Alternative Approach to Education* (New York: Teachers College Press, 1992).

[24] Lather uses this phrase in her paper, "Writing as a Method of Inquiry: The Fields of Feminist Qualitative Research," at the American Educational Research Association conference, in Chicago, IL, March, 1997.

Following is a discussion of my use of the interpretive method, which is the primary methodological basis for my dissertation. For clarity, I have intentionally categorized my methodological theory (interpretivisim) as distinct from my methodological strategies or tools for analysis (conceptual analysis, pragmatic analysis, and heuristic analysis). All are discussed in the remaining pages of this chapter.

Interpretation: Providing Alternative Understandings

The interpretive tradition prioritizes ideas and the ways in which we understand how things are. Interpretivists critically explain events or ideas in alternative ways, as does Jacques Derrida in his critique of empiricism[25] and Michel Foucault in his analyses of the institutions of medicine and prisons. One can also interpret events or experiences in light of other events or experiences. Or, interpretation can take the form of examining ideas in comparison to other ideas. Interpretation, then, allows the scholar to provide alternative meanings or different ways of understanding what is perceived or experienced by humans. For the interpretivist, these alternative meanings are not claims about the way things really are. Rather, they are constructed as another way of thinking about or conceptualizing the way things are so that, in the end, an account is given of the way things seem to be. Brian Fay explains interpretive methods well:

> The interpretive social scientist uses concepts to understand beings who define themselves by means of their use of concepts, so that to construct a theory in which one employs new concepts to grasp the sense of

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[25] Jacques Derrida, "Structure, Sign, and Play in the Discourse of the Human Sciences," in *The Structuralist Controversy: The Languages of Criticism and the Sciences of Man*, eds. Richard Macksey and Eugenio Donato (1972).

> one's own or another's social behaviour is to afford people a new means of self-comprehension and thereby to interject new possibilities into their lives. New ways of living become real alternatives when one is able to see the sense of alternative life styles and different ways of looking at the world (p. 81).[26]

Fay's claim, then, is that interpretation offers new ways of thinking and, subsequently, new ways of living or new alternatives for living. Interpretation aims to figure out the values underlying thought or action. This gets at the central purpose of my work, which is to analyze disability and some related concepts and to provide alternative ways of thinking about those concepts with the hope that the alternatives will be realized, enacted, or pursued by some readers and some readers' readers.

One criticism of interpretive work has been that it does little to tell people what to do. Others have argued that interpretative scholars critique without proposing practical alternatives. Fay has an answer to this:

> ...the interpretive model would lead people to seek to change the way they think about what they or others are doing, rather than provide them with a theory by means of which they could change what they or others are doing, and in this way it supports the status quo (p. 91).

This provides an explanation for why interpretive work feels so critical or biting but often does not give many concrete solutions. I attempt to respond to this criticism by responding to the problems of current conceptualizations of disability through careful construction of a theory of an aesthetic of disability and then by providing some ideas for applying an aesthetic of disability to educational thought and practice.

The questions I ask are conceptual and abstract as are their current applications. I claim, however, that there are future practical

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[26] Brian Fay, *Social Theory and Political Practice* (London: Unwin Hyman, 1975).

applications and I discuss those connections at a conceptual level in chapter five. Consistent with the problems I have posed and the methodological traditions I have selected, I am, indeed, intending to change the way people think about disability, the body, identity, and community. I am not at this time intending to influence specific practices nor to propose an empirical model that could be immediately implemented.

It may be helpful to give examples of interpretive strategies that I use in this inquiry. A concrete example of interpretation is my use of vignettes, or composite descriptions, of experiences of disability that I have known or observed or can imagine. These descriptions of experiences can be understood in many different ways. I attempt to understand them from the perspective of a disabled person. Another example of interpretation is my use of reflection, imagination, and construction activities which build toward application to practical matters of life. In each example I attempt to provide different ways of understanding phenomena that are perceived as disability but for which alternative explanations give new meaning.

My inquiry is interpretive in nature because it attempts to assign alternative meanings to phenomena that appear to us as "disabilities." The primary materials for my interpretive criticism will be my ideas, the concepts of my "thought experiment," where the thought experiment consists of imagining other explanations for the ways things appear to be while focusing specifically on some central concepts. I attempt to interpret experiences of disability by imagining alternative meanings for disability and I use Dewey's theory of aesthetics as the point from which I take my imaginative leap.

The data in this form of interpretive research are primarily the experiences, imagination, and thoughts of the analyst; and texts or written ideas from relevant scholars or authors. While ethnographic research can be interpretive by attempting to explain possible alternative meanings of the qualitative data typically gathered through interview transcripts, participant observation notes, and cultural artifacts, the brand of interpretivism I am describing uses data that emerge from the processes involved with thoughtful analysis of other's ideas and experiences and one's own ideas and experiences. My data, then, are as follows: conceptual tools as I have imagined and described them, my ideas and others' ideas related to disability, my ideas and others' ideas related to the body, my ideas and others' ideas related to community, my ideas and others' ideas related to aesthetics, and my real or imagined experiences with disability.

A key strategy for analysis that I use is conceptual analysis. Conceptual analysis is a form of rhetoric that depends upon the analyst's ability to persuasively undermine the claims or foundations of a text through logical argument and counter-argument. This form of analysis has been used by Jacques Derrida in his argument against empiricism, by Cleo Cherryholmes in his analysis of several theoretical concepts in educational thought,[27] and by Michel Foucault in his examination of power relations in social institutions. Conceptual analysis is similar to deconstruction, a strategy used in philosophy and literary criticism. The literary theorist Terry Eagleton provides insight into deconstructive

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[27] Cleo Cherryholmes, *Power and Criticism: Poststructural Investigations in Education* (New York: Teachers College Press, 1988).

strategies.[28] His emphasis on text mirrors my emphasis on concepts and constructs. Eagleton's description of the rationale behind deconstruction is useful at this point:

> The tacit of deconstructive criticism...is to show how texts come to embarrass their own ruling systems of logic; and deconstruction shows this by fastening on the 'symptomatic' points, the...impasses of meaning, where texts get into trouble, come unstuck, offer to contradict themselves (p. 133-34).

Constructs (or texts), then, can be examined by the scholar in an attempt to unstick them, to find their problems of consistency or logic where logic is understood from the perspective of inside experiences of disability and to expose those, knowing full well that all texts, constructs, or theories could be exposed through deconstruction or conceptual analysis. In my dissertation, conceptual analysis is used for the purpose of illuminating possible problems with the concepts and constructs I propose or for the purpose of revealing the problems with the constructs developed by others. This is necessary to assure that I have considered as many consequences of my constructs as possible and that those consequences are preferable to the consequences of others' constructs.

But "logic" itself is a sticky concept. In contrast to the traditional rational, linear brand of logic to which the reader might think Eagleton is referring, I will use logic to mean anything that makes consistent sense from a particular point of view (e.g., an individual with a certain kind of disability, a female, a student). In this work, that point of view is often my own or my imagined point of view of an individual with a disability. My

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[28] Terry Eagleton, *Literary Theory: An Introduction* (Minneapolis, MN: University of Minnesota Press, 1983).

imagined point of view has clear ideological roots that have been nourished by the work of others and that rely upon my experiences with disability and with people with disability.

For my purposes I see a clear distinction between literary deconstruction and philosophical conceptual analysis. In literary deconstruction, the focus is on a text of some kind. Literary deconstruction proceeds through textual evidence and using textual problems of logic or consistency. My use of philosophical conceptual analysis places the strategy within the realm of ideas or concepts. Although one could argue that ideas and concepts are texts (and Eagleton would agree, since he believes that ideas or experiences are themselves "text"), I have made a rhetorical decision to avoid the use of the vocabulary of literary criticism in my dissertation, so that the focus of my work is clearly upon my ideas and their merits or problems rather than arguments about whether or not those ideas constitute texts and the problems of texts.

I also use a form of conceptual analysis that I have not found cited by other scholars but that I must assume is not new to interpretive scholarship. I call this strategy conceptual blending. In it, I select several concepts that I believe to be related to my central concept. In this work, my central concept is disability and my related concepts are the body, identity, and community. Aesthetics, too, could be considered a related concept. Then, I examine the concepts as others have constructed them and as I, too, construct them in order to find their connections, or their relationships. I do this with a particular purpose in mind. It is the purpose of discovering connections or relationships that have not, to my knowledge, been explicated by the scholars whose work I utilize. Finally, I blend these new ways of conceptualizing or connecting terms to create a new theoretical perspective. In my dissertation, this process culminates in chapter four, in which I outline my theory of an aesthetic of disability.

Pragmatic analysis is another methodological strategy I use. Pragmatism is both a methodological tool and a philosophical perspective. In my use of pragmatism as a methodological strategy, I borrow from Cleo Cherryholmes' scholarship, as well as from Thomas Skrtic, John Dewey, and Richard Rorty.[29] Cherryholmes notes that pragmatism is a "post-modern collection of methods of analysis" that trace "conceivable practical consequences" (p. 155). Description without purpose, or without thinking about intended outcomes, is useless according to Cherryholmes. It is this assumption, that there must be a practical purpose for one's scholarship, that drives my work. This is why I do not stop with my descriptions and analyses of experiences of disability and its related concepts, nor do I end with my chapter on an aesthetic of disability. I carry ideas through to examining or imagining their practical consequences. The examination or imagination of practical consequences of ideas or concepts is what I call "pragmatic analysis." Chapter five is devoted to a pragmatic analysis of the aesthetic of disability.

There is some tension, however, between Cherryholme's pragmatism and Fay's interpretivism. For Cherryholmes, practical consequences are necessary in the pragmatic method. For Fay,

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[29] Cherryholmes, "Pragmatism, Modernity, and Educational Change," in *Discourse and Power in Educational Organizations*, ed. David Corson (Cresskill, NJ: Hampton Press, Inc., 1995): p.149-165; and Cherryholmes, "Postmodernism Challenges for Educational Administration," unpublished manuscript in author's possession, 1996; Thomas Skrtic, *Behind Special Education: A Critical Analysis of Professional Culture and School Organization* (Denver, CO: Love Publishing Company, 1991); John Dewey, "The Need for Recovery in Philosophy," *The Philosophy of John Dewey*, ed. John McDermott (Chicago: University of Chicago Press, 1917/1981); Richard Rorty, *Consequences of Pragmatism* (Minneapolis, MN: University of Minnesota Press, 1983).

intellectual or thought consequences are expected of interpretation. I believe "thought consequences" are practical consequences, if practical means something connected to real people or real life that has the possibilities of being useful to practice. I take practical to mean something concerned with the useful ends of knowledge; therefore my work can be classified as practical because it is connected to the experiences of real people and their relationships to others and their world.

Dewey's contribution to my use of pragmatism comes from his proposal that our thoughts must focus first on the outcomes we wish to see. What, asks Dewey, do you want to be the result of your thought? Although early in this report it is likely to be unclear to the reader, I follow Dewey's suggestion in my inquiry by asking about outcomes before I begin my analyses and while I conduct them. The outcomes, or desired results of my work, are implicit throughout the entire work. This is in contrast to traditional qualitative educational inquiry in which the scholar collects data and attempts to describe the way things are and, perhaps, makes recommendations for the way things might be. In this process, I am holding everything to the standard of what I want it to be although my standards are in the realm of ideas. It is an inherently subjective inquiry, an examination of concepts and a construction of theory entirely from my own perspective. I do not claim any objectivity in this pursuit whatsoever.

Rorty claims that concepts are methodological tools that can be used for specific philosophical purposes. He denies the possibility that concepts can tell us how the world really is, but he accepts that concepts contribute to the conversations we have with ourselves about our world and our experiences within the world. The concepts with which I struggle are my tools. In a sense, they, too, are my materials. I take Rorty seriously when he admonishes us to use conceptual tools as vocabularies for scholarly conversations.

In my inquiry, the pragmatic method is not a distinct step or procedure, although it is more evident in the final chapter than in other chapters. Pragmatism is woven throughout my questions for inquiry. With each question about the experiences of disability I ask about the consequences of understanding disability in certain ways. Pragmatic analysis, then, is integrated into the heart of my inquiry process and can be found in my frequent questions about consequences.

My final strategy for analysis, heuristics, is a method of analysis based in discovery and invention, and is consistent with the interpretive tradition. Carl Moustakas, a humanistic psychologist, is a heuristic researcher. He notes that "the central characteristic of heuristic research is an emphasis on the internal process of inquiry in the individual person as the primary instrument for describing and understanding human experience" (p. 10).[30] Heuristic research, Moustakas writes, "involves self-search, self-dialogue, and self-discovery; the research question and the methodology flow out of inner awareness, meaning and inspiration" (p. 1 1).

In heuristic research the meanings given to concepts such as data, analysis, interview, and conversation are different than in other qualitative methodologies. In heuristics, data are:

> That which extend understanding of or add richness to the knowing of the phenomena in question. As in traditional research models, acquiring data involves a

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[30] Carol Moustakas, *Heuristic Research: Design, Methodology, and Applications* (Newbury Park, CA: Sage Publications, 1990).

> disciplined systematic series of methods and procedures designed to yield information. Unlike traditional models, however, heuristics permits and even encourages spontaneous creating of methods that will evoke or disclose experiential meanings. This license stems from the recognition of the contribution that subjectivity makes to knowledge and from the dynamic nature of subjective reality (p. 42).[31]

Analysis involves reflection upon one's ideas, creating mental images, examining one's notes, comparing ideas or concepts, and following the development of those ideas and concepts across time. Interviews are often done with oneself. The heuristic researcher has continual conversations with herself, asking questions and playing with ideas.

I conceive of heuristic analysis as a systematic thought process that asks the question: how can this thing or experience be imagined or understood differently? I use heuristic analysis in the development of my theory of an aesthetic of disability. As I develop that theory, I continuously ask how disability can be imagined differently and how experiences of disability can be differently understood. That question causes me constantly to refocus my attention on the underlying reason for my dissertation inquiry. Triangulated with conceptual analysis and pragmatic analysis, heuristic analysis allows me to construct a broadly applicable way of thinking about disability. I think of heuristic analysis as a creative process that builds something new after conceptual and pragmatic analyses evaluate and critique what is already in place. It is possible that heuristic interpretivists would argue that my use of conceptual blending is actually a heuristic exercise. If that is the case, I would not disagree.

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[31] B. Douglas and C. Moustakas, "Heuristic Inquiry: The Internal Search to Know," *Journal of Humanistic Psychology* 25(1985): 39-55.

Conclusion

The educational implications of a work like mine range from teacher education to pedagogy and educational policy. In chapter five I devote attention to those implications by utilizing pragmatic analysis to focus on the possible consequences of conceptualizing disability as an aesthetic pursuit. I imagine potential features of teacher education, pedagogy, and educational policy within a framework of an aesthetic.of disability.

Although my dissertation research can be placed within two distinct but related fields of study, I have been methodologically challenged by certain scholarly traditions. In an effort to find ways of analyzing the problems I identify, I attempt to apply research methods borrowed or revised from other traditions to these conceptual problems. I face multiple challenges in this endeavor. First, I face the challenge of making convincing and explicit connections between concepts and experience. Second, I face the dilemma of how to argue for the importance of the questions I raise, the materials I analyze, and how I analyze them. Third, I struggle to find ways of communicating highly abstract notions so that others understand my thinking. Fourth, I am challenged with the difficulty of imagining the practical applications of my theory of disability.

My work is an attempt to develop a theory of an aesthetic of disability. The ultimate goal in this attempt is to change the ways in which scholars and analysts understand disability so that future scholarship is influenced by my aesthetic of disability. To achieve my goal, I follow the interpretive tradition by identifying and using concepts and imagined experiences as tools for analysis and for imagining alternative understandings of the ways things appear.

The primary contribution of my work to the fields of inquiry into which it can be categorized is my theory of an aesthetic of disability that I believe to be applicable across a wide range of practical matters of everyday life. Potential practical applications in the field of education are the conclusion of my dissertation and will facilitate looking ahead to future research.

The following passage well summarizes my experiences conducting this inquiry and the hopes that I have for the readers with whom I share my work:

> Having made a discovery, I shall never see the world again as before. My eyes have become different; I have made myself into a person seeing and thinking differently. I have crossed a gap...which lies between problem and discovery (p. 143).[32]

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[32] M. Polanyi, *Personal Knowledge* (Chicago: University of Chicago Press, 1962).

Chapter 2

Disability

This chapter analyzes the first and most important of my conceptual tools, sets the stage for later analyses of more basic philosophical concepts (the body, identity, community), and prepares the reader for the development of my own theory of disability. Disability is, however, more than an intellectual concept. It is a topic of interest and investment for most people as can be seen in its use in newspaper articles,[33] as a theme in popular culture,[34] and as a booming business enterprise.[35] In addition to its presence in the media and business, disability is the central focus of the institution of special education. In some ways the existence of disability explains the existence of special education, although a case has also been made that special education

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[33] A few recent articles include the following: Alan Riding describes a writer who is paralyzed and who commands a word processor with his eye movement in, "A Tale Seen in the Mind's Eye, Told by the Body's," *New York Times*, March 18, 1997; the late Ennis Cosby, Bill Cosby's son, wrote about teaching learning disabled students and being learning disabled himself in "Teaching from the Heart," *New York Times*, January 26, 1997; Raymond Hernandez, "New York Seeks to Overhaul Special Education by Discouraging Segregation of Pupils," in which the New York City schools special education system is described as racially discriminatory and a failure from the perspective of student achievement, *New York Times*, November 8, 1996; and Douglas Martin, "Eager to Bite the Hands that Would Feed Them," *New York Times*, June 1, 1997, about disability rights activists and the author's perspective on their attitudes toward able-bodied individuals.

[34] Consider the media frenzy when Christopher Reeves was disabled in a riding accident, or familiar stories from childhood: the Hunchback of Notre Dam, Beauty and the Beast, the Elephant Man.

[35] See Gary L. Albrecht's, *The Disability Business: Rehabilitation in America* (Newbury Park, CA: Sage Publications, 1992), in which he lays out a case for the perpetuation of disability because of the institutionalization of rehabilitation services. In his argument, the demand for rehabilitation services is continued in order to keep the participants on the supply side of the market in business.

explains the existence of disability.[36] Regardless of the chicken and egg dilemma and in spite of its popularity as a topic and the prevalence of disability among children and adults in the United States,[37] disability is rarely studied by educational researchers outside the field of special education or educational psychology. With few exceptions, I am unable to find educational researchers that analyze disability from an interpretive social science perspective,[38] although there is a significant body of work by researchers outside the field of education that utilizes interpretive methods and frameworks.

Those of us doing interpretive educational research related to disability are examining the theories of disability with which we work and are mapping out new theoretical territories for future disability scholarship.[39] This chapter provides an overview and critique of the four main theories of disability currently in use in scholarship and practice. Each theory is derived from a larger scholarly body of work which, in a

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[36] See Thomas Skrtic, *Behind Special Education*; and Hugh Mehan, Alma Hertweck, and J. Lee Meihls, *Handicapping the Handicapped: Decision Making in Students' Educational Careers* (Stanford, CA: Stanford University Press, 1986). Both argue that special education itself is the institution that produces disability. Skrtic does this from an organizational theory perspective while Mehan, et al., do it from an institutional process perspective developed from empirical data.

[37] The U. S. Department of Education estimates that approximately "15 percent of the non-institutionalized United States population" have disabilities. See Laura Trupin and Dorothy Rice, "Health Status, Medical Care Use, and Number of Disabling Conditions in the United States," *Disability Statistics Abstract* 9(1995). In addition, "6.1 percent of the U.S. population under 18 years of age" have disabilities." See Barbara Wenger, H. Stephen Kaye, and Mitchell LaPlante, "Disabilities Among Children," *Disability Statistics Abstract* 15(1996).

[38] I am only aware of three: Susan Peters, Michelle Fine, and myself. Some of Phil Ferguson's work might be classified as interpretive.

[39] Susan Peters' work in a theory of disability will be discussed later in this chapter. My dissertation is obviously a work in theory of disability. I am unaware of other educational researchers working on theories of disability.

future inquiry could be utilized to inform the field of disability studies. For now, I have chosen to focus my analyses on the ways in which general theories are applied to disability. For example, when discussing disability as a personal deficit, I focus tightly on the ways in which I am aware that deficit thinking has been applied to disability. In the section entitled, "disability as a social construction," I analyze the constructivist theory of disability but do not explore constructivism in general and how diverse constructivist theorizing might inform disability. In other words, at this time I have not attempted to uncover the ways in which aspects of general theories have not been applied to disability. I close the chapter with an examination of what is missing in disability theory.

Disability as a Personal Deficit

Disability has been explained by deficit models for more than a century in the United States.[40] Deficit models are derived from empirical natural and social sciences and their appeal, according to Richard Valencia, "comes from the model[s'] wrapping: the scientific method" (p. 1). The long-standing debate about deficit models of thought was recently stirred again with the publication of *The Bell Curve*,[41] an explicit attempt to demonstrate a connection between intelligence and socioeconomic class. Implicit in that attempt was an argument for relationships between race and

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[40] Richard Valencia, "Conceptualizing the Notion of Deficit Thinking," *The Evolution of Deficit Thinking: Educational Thought and Practice*, ed, Richard Valencia (Washington, D. C.: The Falmer Press, 1997): 1-12. Although Valencia is referring to school failure when he dates the deficit model, the use of this date is relevant to disability for two reasons. First, the emergence of deficit models correlates with the emergence of deficit explanations of disability. Second, disability is an often cited reason for school failure.

[41] Richard Herrnstein and Charles Murray, *The Bell Curve: Intelligence and Class Structure in American Life* (New York: The Free Press, 1994).

intelligence. That text and the subsequent popular and academic debates were reminders that deficit models are still with us.

Deficit models explain school failure, disability, illness, and other phenomena as the result of something wrong within the individual. Some deficit models implicate socioeconomic conditions as contributing to individual deficits, but deficit models all share the assumption that there is an essential problem state within a person. Genetic pathology models, for example, attribute deficits to transmission through the genetic code. Cultural deficit models shift the cause of deficits to class and social stratification. Whether the cause of a disability is innate or environmental, deficit models have been applied consistently to explain disability as something wrong with the person who is perceived as having the disability.[42] Mehan, et. al., state this view as the view that "handicaps reside in students or in their conduct" (p. 45).[43] I refer to this way of conceptualizing disability as the "personal deficit" model, in which it is assumed that the deficit can be innate or environmentally induced. In special education, medicine, and psychiatry, the identification of

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[42] Richard Valenica refers to innatist views of disability in, "Genetic Pathology Model of Deficit Thinking," *Evolution of Deficit Thinking* (p. 41-112); Douglas Foley explains the cultural deficit model in "Deficit Thinking Models Based on Culture: The Anthropological Protest," *Deficit Thinking* (p. 113-131); as does Arthur Pearl, in " Cultural and Accumulated Environmental Deficit Models," *Deficit Thinking* (p. 132-160). Here I use innate to refer to traits physiologically originating within the individual, as in genetic pathology models. I use environmental to refer to disability that is the result of something outside the individual that impacts the individual, as in cultural deficit models.

[43] *Handicapping the Handicapped*. The authors use "handicap," a term that I use synonymously with "disability". The use of "handicap" connotes two possibilities for Mehan's choice of the term. First, it is the term used in federal special education regulations. Children in special education are labelled as "educationally handicapped." In addition, the word handicapped was commonly used by academics in the mid- to late-1980's. Use of the term "disability" is a reflection of more recent times and current views about what is "politically correct." In the past, there was quite a bit of popular and academic debate about the two terms and their use. I have chosen to avoid this debate because its resolution is not central to my theory. In chapter four, I hope to resolve any problems the reader may have with my choice of "disability" by more thoroughly analyzing the term.

disabilities is always based in deficit models. The very definitions of specific disabilities, sometimes referred to as "impairments" or "handicaps," are based in deficit discourses that describe those ways in which an individual thinks or performs or interacts that are considered abnormal.[44] Within deficit models attempts are usually made to treat disability. In medicine this may result in surgery, medication, genetic counseling and testing, or other forms of intervention. In psychiatry, therapy is sometimes added. In special education, students with disabilities are evaluated for placement in a separate educational system. Through treatment, it is hoped that disability can be cured or its symptoms alleviated. When conceptualized as a personal deficit, there is an urge to perceive disability as something that is wrong with a person, as a condition that requires treatment or cure. Individuals who have disabilities are viewed as sick or incompetent or weak. They are creatures of the disability.[45]

Within the personal deficit construct of disability, when I say "I am disabled," I refer implicitly to the scientific history that backs my statement. I view myself within a medical or educational institution that has diagnosed me and given my disability a name. I know I am disabled because others have told me so and because I believe them. I have had concrete experiences that validate what I and others think about disability. I have been evaluated. I have been diagnosed. I may have pain or some other condition that science is able to treat and my symptoms may be alleviated. I might find technology useful in supporting my independence. Perhaps I

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[44] *The Diagnostic and Statistical Manual of Mental Disorders*, published by the American Psychiatric Association and periodically revised (1952, 1968, 1977, 1980, 1987, 1991), is the reference text for identifying psychiatric disorders.

[45] Ynestra King, "The Other Body: Reflections on Difference, Disability, and Identity Politics," *Ms.*, March/April (1993).

use a wheelchair or speak with a computer. Regardless of my interactions with doctors or special teachers, therapists or technology, I clearly view my disability as a fundamental part of my very nature and I look to science and its institutions to address my condition.

Aside from the potential for incorrectly connecting all experiences of disability with pain and suffering and their cure or alleviation, there are several problems with viewing disability as a deficit. First is our inability to be sure that the science upon which the model is built is correct. Several critics of the science of measurement practiced in psychometrics,[46] and objective science in general, attempts to discredit science as the foundation from which deficit models are generated. Richard Valencia claims that deficit models are built upon "pseudo-science" (p. xii).[47] Stephen Jay Gould, in *The Mismeasure of Man*, his critique of measurement, reveals science as a social activity implying that it is a subjective pursuit:

> Science, since people must do it, is a socially embedded activity. It progresses by hunch, vision, and intuition. Much of its change through time does not record a closer approach to absolute truth, but the alteration of cultural contexts that influence it so strongly. Facts are not pure unsullied bits of information; culture also influences what we see and how we see it. Theories, moreover, are not inexorable inductions from facts (p. 21-22).[48]

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[46] Psychometrics is the discipline in which mental measurement, such as personality and intelligence testing, is practiced.

[47] Richard Valencia, "Introduction," *Deficit Thinking* (p. ix-xvii).

[48] Stephen Jay Gould, *The Mismeasure of Man* (New York: W. W. Norton and Company, 1981).

As a social activity, the deficit model and the science from which it is derived must be viewed within a cultural context. Cultural values and the stories told throughout culture contribute to the social context in which science operates. In this sense, then, the deficit model is a story of disability told by science. Another problem with deficit models is that they do not adequately account for the social contexts within which disability appears as a phenomenon. Even cultural deficit models maintain the belief that disability is a personal problem, regardless of its cause. A third dilemma for deficit thinking about disability is the question of essentialism. I use essentialism to refer to the belief that there are objective truths about what it means to be human and that these are known to us. If we accept the personal deficit theory of disability, we accept an essentialist argument. For non-essentialists, this is a serious problem. Finally, deficit models are coercive. In effect, powerful people and institutions control decisions about who is disabled. Deficits do not seem to give an account of people choosing disability for themselves, nor for people with disability constructing personal views about their bodies and identities. While the deficit model has contributed to advancements that have alleviated some of the limitations caused by conditions that are, indeed, personal and can be interpreted as innate, it is an incomplete way of understanding the richness of experiences of disability.

Disability as a Social Construct

If deficits may not in some cases be features that indicate something wrong with individuals, or if there may not be enough evidence to prove that deficits objectively exist at all, or if deficit thinking is merely an incomplete way of interpreting disability, then another way of thinking about disability is needed. A second theory of disability holds that it is socially constructed. Here I use social construction as did Peter Berger and Thomas Luckmann in their classic work, *The Social Construction of Reality*, in which they lay out one of the early cases for constructivism.[49] Berger and Luckmann's brand of constructivism holds that humans produce their world and themselves within their world through interaction with their environment. Production, for Berger and Luckmann, is distinctly cognitive in nature. Within their framework, language is a key adaptive tool. The way the world appears to humans and, in turn, the ways in which we conceptualize our world and talk about it among ourselves, is the productive force:

> ...the developing human being not only interrelates with a particular natural environment, but with a specific cultural and social order, which is mediated to him by the significant others who have charge of him (p. 48).

Numerous scholars have argued the case for the social construction of disability.[50] This interpretation of disability holds that there is no person who is essentially disabled, but that society creates physical, programmatic, or attitudinal barriers that subsequently shape perceptions of who is disabled and who is not disabled. Using Berger and Luckmann's theory of social construction, we could say that disability appears to us as

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[49] Peter Berger and Thomas Luckmann, *The Social Construction of Reality* (Garden City, NY: Doubleday and Company, Inc., 1967).

[50] A few such scholars include Mehan, et al., *Handicapping the Handicapped*, Robert Bogdan and Steven Taylor, *The Social Meaning of Mental Retardation: Two Life Stories* (New York: Teachers College Press, 1994); James Trent, *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley, CA: University of California Press, 1994); Harlan Lane, *The Mask of Benevolence: Disabling the Deaf Community* (New York: Vintage Books, 1992); Eds. Benedicte Ingstad and Susan Whyte, *Disability and Culture* (Berkeley, CA: University of California Press, 1995); and Carolyn Wang, "Culture, Meaning, and Disability: Injury Prevention Campaigns and the Production of Stigma," *Social Science and Medicine* 35(1992): 1093-1102.

the result of our interactions with our physical and social worlds and that it is interpreted to us by the humans who shape our lives and our thought.

An application of the Berger and Luckmann brand of constructivist theory to disability is demonstrated by the study conducted by Hugh Mehan, et. al., in which the authors investigated the "day-to-day practices of educators when they decide to promote students, retain them, or place them in special education programs" (p. 1-2). Their ethnographic account describes sorting decisions made in a small West Coast middle and upper-middle class town in Southern California. The study followed the decisions to promote, retain, or place in special education in the classrooms of thirty one teachers. Mehan, et. al., identify three categories of consequences of the practices of identifying students as disabled.

> (1) the conception of students in schools,
> especially handicapped students,
> (2)theories of decision making, and
> (3)theories of social stratification (p. 158).

Several of their findings are salient to the argument that disability is socially constructed, although their first category is perhaps most relevant to this inquiry. First, the authors note that the process of referring students for special education services constrains the educational options available to those students, particularly when a student is found eligible for and placed in special education. The result of such constraints is that "student identities are constructed by the institutional practices of the school" (p. 159). Educational labels also clearly mark students who are deviant, or abnormal. Not only are their choices of classes and curriculum constrained but referred students become stigmatized, after which teachers differently perceive them. For example, if someone is labelled "mentally retarded," teachers and parents and even the student himself begin to think differently about that student. Future goals are influenced. He may even appear physically different to others or himself. "Mentally retarded" often conjures up the visual image of people with Down's Syndrome or hydrocephalus (a condition that causes the head to appear enlarged). In either case, a label alters the ways in which others perceive a person with a disability. Finally, Mehan, et al., notice that a disability label changes the ways in which teachers talk about disabled students. In their study, when students were identified for special education, suddenly the descriptors of that student became medicalized.[51] In conclusion, they note that:

> Disability...exists neither in the head of educators nor in the behavior of students. It is, instead, a function of the interaction between educators' categories, institutional machinery, and students' conduct. That is, designations like "disability" and "handicap" do not exist apart from the institutional practices and cultural-meaning systems that generate and nurture them (p. 164).

Institutional practices, then, combined with categorical thought and student behavior construct disability in the school setting.

A seminal work in the social construction of disability comes from two sociologists, Robert Bogdan and Steven Taylor,[52] in an empirical study of families who care for severely disabled loved ones. Bogdan and Taylor define "severely disabled" as "people with severe and profound mental retardation or multiple disabilities" (p. 135), which means these individuals

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[51] Here they refer to the medical model, which is closely related to the deficit model. The medical model, of diagnosis-prescription-treatment is, in fact, a deficit model.

[52] Robert Bogdan and Steven Taylor, "Relationships with Severely Disabled People: The Social Construction of Humanness," *Social Problems* 36(1989): 135-148.

require total physical care. Their study focused on the caretakers of over one hundred people with disabilities living in the community in non-institutional settings. They found significant themes and similarities across caretakers that, as sociologists, they categorized as the definition of humanness. Here is an example of a typical severely disabled person in their study:

> Twenty year old Jean cannot walk or talk. Her clinical records describe her as having cerebral palsy and being profoundly retarded. Her thin, short--four feet long, forty pound--body, atrophied legs, and disproportionately large head make her a very unusual sight. Her behavior is equally strange. She drools, rolls her head, and makes seemingly incomprehensible high pitched sounds. But this is the way an outsider would describe her, the way we described her as sociologists encountering her for the first time...To Mike and Penny Brown, Jean's surrogate parents for the past six years, she is their loving and lovable daughter, fully part of the family and fully human (p. 138).

Bogdan and Taylor uncovered four dimensions of "humanness": "attributing thinking to the other," "seeing individuality in the other," "viewing the other as reciprocating," and "defining social place for the other" (ibid.). In brief, the caretakers of these significantly disabled individuals were able to see human qualities in people who interact very differently than most of us. They were able to perceive ways of knowing and were able to read meanings from movements and gestures that outsiders could not immediately perceive. They produced, in Berger and Luckmann's sense, humanness in their loved ones.

At first this may appear to be an opposing argument. I initially stated that this second theory of disability is that it is socially constructed yet I give an empirical study where people with disability are socially constructed as human, not as disabled. With a closer look, however, the importance and relevance of my use of this work can be clear. Consistent with Berger and Luckmann, the constructivist perspective would hold that disability and humanness, and all realities that appear to us, are socially constructed. The fact that Bogdan and Taylor held the disabilities of their study participants to be a constant variable does not discount the importance of their study. They make a critical point about the construction of any reality: that even in the face of what appears to some to be one reality (severe and profound mental retardation preventing an individual from maintaining a loving, caring family bond), humans construct another reality. Mehan, et al., make a similar point when they note that in the face of what could be interpreted as the failure of the educational system or the failure of teachers to be able to support student success, disability is constructed by the system as a cause of school failure.

While Bogdan and Taylor demonstrate the power of constructivism in families and intimate social groups and Mehan, et al., do so using the educational institution as a unit of analysis, the theory of the social construction of disability is further illuminated by comparative studies of disability. For this, I mention Susan Peters' work, *Education and Disability in Cross-Cultural Perspective*, in which she and her contributing authors map out a different story of disability.[53] Here, disability is a phenomenon unique to a culture and having features that are reflective of the norms and values inherent to a culture. Whereas Bogdan and Taylor emphasize the constructive force of family and intimate relationships, Peters focuses on social struggle of a larger scale. Ideology is the

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[53] Susan Peters, *Education and Disability in Cross-Cultural Perspective* (New York: Garland Publishing, Inc., 1993).

language of construction here and politics is its venue. In the next chapter, further analysis will provide a closer examination of power and its influence in society. Comparative studies, however, serve as reminders of the broader contextual nature of interpretations of disability.

If I recognize disability as socially constructed and say "I am disabled," I am making a statement about the culture within which I live. At some level, I associate my disability with the institutional forces at work in producing it. I recognize, then, the role of medicine and education in creating disability. Or perhaps I reject an essential view of myself as disabled and my claim "I am disabled" is in reference to the way others view me. Then, I am actually saying "Others see me as disabled." Either connotation is a reference to the social contexts that have produced me and the others with whom I interact.

In the ways in which it has been applied to disability by disability scholars, constructivism generally explains disability as a result of others' perceptions and beliefs as the sole or primary informant of the self. Constructivist explanations of disability are relative. They differ depending on the culture in which phenomena of disability are observed and interpreted. Therefore, the constructivist claim about disability offers an explanation more comfortable to the non-essentialist and anti-structuralist than does the personal deficit model.[54] Unfortunately, it does not help us understand individuals as much as it helps us understand societies and culture. If we are interested in individuals and how they come to view

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[54] Here I use non-essentialism as the antithesis of essentialism, or the assumption that there is a basic objective truth about what it means to be human. I use anti-structuralism to refer to the stance that is opposed to structuralism, or the assumption that there are true categories to which all phenomena can be assigned or that accurately classify all phenomena. Disability could be considered a structure within certain models of thought.

themselves as disabled, though granted this view is influenced by culture, we need a theory of disability that promotes the individual. In addition, although construction is an active process, using it as an explanation for disability feels rather passive. Too little of the activity is given to the individual with a disability. The bulk of the responsibility for construction, it would seem, goes to culture and society. Constructivism, then, gives an answer to "why do we observe phenomena of disability?" questions but does not give a course of action. It does not respond to "what now?" questions. For greater focus on individuals and a more active stance toward disability, we can examine the next two conceptualizations.

Disability as Membership in a Minority Group

A typical critical response to thinking about disability as a personal deficit is to construct it as membership in a minority group.[55] On the other hand, viewing disability as membership in a minority group could be a more concrete way of saying disability is socially constructed. This would certainly be true if all minority group models adhered to a non-essentialist assumption. However, the model is not necessarily non-essentialist as I will further explore later in this section. First, though, I will briefly list the basic tenets of the minority group theory of disability as it is described by disability scholars.[56] This theory is borrowed from political

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[55] Robert Bogdan and Douglas Biklen, "Handicapism," *Social Policy* March/April(1977): 14-19. They use the -ism suffix to illuminate similarities between racism and sexism and discrimination against disabled people.

[56] Three important and representative references are Harlan Hahn's, "The Politics of Physical Differences: Disability and Discrimination," *Journal of Social Issues* 44(1988): 39-47; Michelle Fine and Adrienne Asch, "Disability Beyond Stigma: Social Interaction, Discrimination and Activism," *Journal of Social Issues* 44(1988): 3-21; and Mark Nagler, "The Disabled: The Acquisition of Power," *Perspectives on Disability*, ed. Mark Nagler (Palo Alto, CA: Health Markets Research, 1993): 33-36. I summarize their perspectives, all of which share the basic tenets I describe in this paragraph.

science theories that have traditionally been used with racial minorities. The minority group model was commonly used during the civil rights era to gain equal rights for African-American citizens of the United States. The model holds that people with disability are members of a minority group like racial minority groups, that they are discriminated against as are members of racial minority groups, and that people with disability have the same civil rights as do all other members of society. As a minority group, people with disability have a political visibility they do not otherwise have. The more members added to the group, and the more active the group becomes, the more likely that significant legal, social, and economic changes can be made to improve the lives of people with disability. Whereas the personal deficit model is primarily a medical and educational conceptualization, the minority group model is a political and economic one. It is the first model I have analyzed that allows for an element of choice by individuals with disability. In fact, it was initially used as a political tool by disabled activists and scholars.

In many ways, the minority group model can be appreciated by essentialists or non-essentialists. As an essentialist interpretation of disability, it could be compatible with deficit thought if members of the group are believed to have personal deficits, regardless of their cause. This is sometimes the belief about other minority groups. Race and gender are understood by some to be innate categories, or categories that are assigned or belong to the person. On the other hand, if disability is conceptualized as socially constructed, then the minority group model remains non-essentialist, although it still implies a weak form of essentialism in that it suggests that there is such a thing as a "minority group." Perhaps the risk of essentialism comes from the tendency of the minority group model to think and talk about disabled people as a group and, therefore, in somewhat stereotypical terms. In the end, the minority group model can be comfortable to essentialists and is more comfortable to non-essentialists than are deficit theories. Its ability to span these perspectives on disability give the minority group model wide appeal. As a model that can be useful in political action, this theory can be beneficial to people with disability.

If I adhere to this model as my conceptualization of disability, when I say "I am disabled," I am choosing membership as a minority in my culture. While this choice may have been forced upon me or may have been influenced by other people or events, I have made a decision to affiliate with my minority group. When I place myself or feel others placing me in minority status, I am generally saying that I feel marginalized in some way or that, regardless of my feelings, others are marginalizing me. I am finding allegiance with others who appear to be like me and who appear to experience similar marginalization. When I use deficit theories to explain my disability, I contextual myself within medicine, education, and science. Constructivism locates me socially. Contrastingly, when I use the claim of minority status, my claim situates me clearly within a political context, although that context could be shaded by deficit or constructivist thinking as well. Establishing myself as a minority group member, I have asserted my socio-political position in relation to others, some of whom are with me and some against me. My disability is a tool, a symbol of my oppression and an instrument in my fight against it. Unlike the constructivist stance, this view encourages me to take action. Unlike the deficit perspective, I, not others, have named my condition.

As could be expected there are problems with the minority group model. I highlight three here. First, there is the problem of the ease with which this model can slip into essentialism. Even if we reject the possibility that disability is innate, that there is something distinctly different between people with and without disability, using minority group status as a conceptual tool is risky. The very concept of "minority group" lends itself to essentialist ways of thinking about people or groups of people. Related terms that pose this problem are "majority group" and "lower class." In other words, what important things does belonging to the group "lower class" communicate about a person? Are there essential human differences between individuals who belong to minority and majority groups? I am not suggesting that the minority group model be cast aside. I am merely suggesting that it be used with caution and that its risks be evident. A second problem with this model is that it, too, groups people with disability into a class of personhood. Within deficit models, people with disability are grouped by the category of their disability sub-type. In constructivism, individuals are lost in the vast social milieu. And in minority thinking, people are classified by group. Since minority groups gain political power through numbers and activity, there is also a risk of pressuring people with disability into participation in the minority group. The coercion evident in the personal deficit and social construction theories of disability does not necessarily disappear in the minority group interpretation. Finally, and perhaps connected to both of the previous problems, there is a tendency in the application of minority group thinking to disability to situate people as either "us" or "them," as "disabled" or "able bodied." Categorizing people this way might politically be useful but it sometimes interferes with the goal of achieving equity and it often discounts people who either have less visible disabilities or who are avid supporters of the disability rights movement. Thinking in terms of "us" and "them" is exactly the kind of thinking that drives other theories of disability. The minority group model does not always escape this trap.

There is a need for a view that allows an individual to make his own claim about disability, that allows that individual to make such claims with less minority group pressure, that is consistent with a constructivist stance, and that still accounts for the political nature of disability. The next theory meets these four criteria.

Disability as a Personal and Political Identity

The timing of the arrival of this theory of disability coincides with the identity studies trend and entails a rather new dialogue in the disability studies literature. As with the minority group model, its proponents tend to be scholars who themselves experience disability.[57] This view of disability is related to the minority group model because both views agree that disability has social origins with political consequences. It differs from the minority group model in its ability to accept that disability might not be experienced as membership in a minority group for all individuals with disability. The personal and political identity model also agrees with constructivism in that both models adhere to the idea that disability is a phenomenon constructed by social processes. While the constructivist model provides an explanation for the existence of the phenomenon of disability, the identity model places a stronger emphasis on taking action as a response to the social problems that create disability and its negative

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[57] Simi Linton is an example of a disability studies scholar who has a disability. Her paper, "Disability Studies: Who are We and Where do We Want to Go?", The Society for Disability Studies Annual Meeting, in Minneapolis, MN, May, 1997, strongly supports the identity model of disability.

consequences. In this regard, identity thinking is closely aligned with minority group thought.

Disability as an identity, though, is a response to disability as minority group status. The following passage from Susan Peters' recent text reflects common themes in the work of identity theories of disability and echoes my own concerns about the ways in which we have conceptualized disability:

> The disability movement has often insisted on solidarity to advance our human rights. Our own disability community, including scholars of disability studies, needs to forge new relations between identity and difference...diversity is an overused concept which has become trivialised, and in combination with the pressure for solidarity, has thwarted our self-development. In addition, the concept of 'oppressed minority' points the finger at others, while neglecting our own conceptual weaknesses. Finally, the whole notion of difference is problematic because difference is always perceived in relation to some implicit norm. It perpetuates the illusion that individuals are measured from some universal standard of objective authority (p. 230-231).[58]

In viewing disability as a personal and political identity, more balance is struck between the individual and the group, between what one experiences as a self and what one experiences in common with others.

My critique of this theory of disability is twofold. First, it offers little more than the minority group interpretation of disability. Although I will admit that it attempts to respond to the problems of coercion and predominance of group membership in the minority model, identity models are in essence politically charged. So while identity theory strikes more of a balance with the personal, it does so too little. Claims that the personal

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[58] Susan Peters, "The Politics of Disability Identity," Disability and Society: *Emerging Issues and Insights*, ed. Len Barton (New York: Longman): 215-234.

and political are inextricable, while persuasive, neglect the impact of individual experience, apart from any particular group, on the development of the self. This leads me to my second critique of the identity theory of disability. It is that the personal aspect of the theory is undeveloped. It makes claims about identity as a private matter but has not explored that private self to a full extent. Although clearly a constructivist way of thinking about disability, identity thought does not deeply enough explore the self and the construction of the self. In many ways, my work is a response to this very problem.

Much more will be examined related to identity and disability in chapter three, but for now, if I understand my disability to be a personal and political identity, I have struggled to know myself and have achieved a sense of myself as a disabled person. I feel connected to others who have disability because I know that we share a place in society and life experiences in our world. Yet I also know that I am like no other and that I stand alone as a unique individual. My two selves, the private personal self and the public political self, are interrelated. One informs the other and in doing so, who I am is continually transformed. I have a dynamic view of my self that I have constructed together with the social forces around me and the people with whom I share my world.

Missing Theoretical Pieces

I have reviewed and critiqued four theories of disability. Each theory has conceptual and/or functional strengths. For some conditions associated with disability the personal deficit model is beneficial because the application of scientific advances to those conditions has improved lives. People with schizophrenia often find their symptoms lessened by medication. People who have paralysis benefit from the use of technologies that increase their independence and quality of life. Computers make it possible for some non-speaking people to communicate. The social construction perspective provides a more comfortable explanation about the cause of disability for many people with disability and for non-essentialists. Minority group thought is a useful political and ideological tool that has been instrumental in the disability rights movement. It often gives people with disability a sense of belonging and empowerment. Viewing disability as a personal and political identity expands the notion of minority allowing individuals to develop a sense of themselves apart from a group while continuing to feel connected but does not offer a distinctly different interpretation of disability than do the constructivist or minority group theories and it has not yet entered into a thorough exploration of the personal aspect of its claims.

In addition to posing problems, each of the four theories of disability has been shown to be connected to the others in ways that do not seem apparent with an initial reading. All four theories share coercive features that apply the label "disabled" from the outside. The identity theory, however, relies less upon coercion than do the other three. The problems of essentialism found within the deficit theory are not lost in the minority group model, nor are the problems entirely absent in the constructivist model, where disability is explained as socially produced but where it is not necessarily explained as non-essential. Finally, none of the theories of disability fully interpret disability from within experiences of disability, although the identity theory, again, attempts to do so more than do its predecessors.

All theories have problems and these four are no exception, as I have detailed earlier. What is needed is an interpretation that offers what present theories do not provide, either in their conceptualization or practice. This theory should be compatible, or should at least be able to co-exist, with other views of disability so people can utilize practices connected to theories that meet their needs. By this I mean that theories of disability can have function and I will be developing an argument for pragmatically choosing them for their function. A new theory of disability should be a useful way of understanding and appreciation disability and should have applications that improve the lives of disabled people from their own perspectives. For example, I have already argued that the constructivist theory is primarily an explanatory theory and that it does too little to map out action. What, for example, can we do with our knowledge that disability is socially constructed? What concrete changes can be made in schools in response to constructivist models of disability? While we might think of physical changes in school environments, such as ramps and other forms of access, it seems difficult to imagine changes in curriculum and pedagogy from a strictly constructivist model, as constructivism has been applied to disability. Personal deficit and minority group interpretations of disability, on the other hand, provide paradigms for action. Minority group thought has probably influenced the inclusion movement, where special education students are educated to the greatest degree possible in general education settings. As with any civil rights movement, understanding an experience from the perspective of a minority group can be systemically useful. Certainly we can agree that deficit thinking has influenced action. Special education and much of regular education have been built upon this model.

In the end, we need a theory of disability that is useful for understanding disability from inside and outside experiences of disability and that can do more than explain why we have phenomena of disability. This insider's view that allows for an outsider's appreciation would be useful because its outcomes would be the ends desired by disabled people. We also need a theory that is inclusive of other ways of thought so that people with disability and the institutions that serve them can utilize the models that make sense without negating other models that make sense in other situations. The risk with this type of inclusion is that institutions will continue to utilize models that are more coercive of disabled people than is necessary and that outsider views will continue to dominate conversations about and decisions for disabled people. The key to this type of inclusive thinking about disability is that it always respects individual choice and that, as much as possible, it considers disability and its consequences from an insider's point of view. This new theory of disability, then, needs to understand disability from the perspective of people who experience disability. I argue that this means it must be a non-essential and post-structural theory in the sense that it must not impose an essentialist or structuralist view of disability upon disabled individuals. Finally, a theory of disability must have clear educational applications. It needs to support reform in ways that present theories have not been able to do. A theory is needed that can alter the ways teachers think about curriculum and pedagogy for all students, the ways in which we prepare teachers for the field and for their students, and the ways in which we conceptualize experience in schools, including how students come to know themselves through the educational process.

In the next chapter I explore three more concepts that will prove fundamental to my theory of disability. After that, I map out the theory of an aesthetic of disability using the criteria described above. I conclude my dissertation with an analysis of the ways in which a new theory of disability can influence education and educational research.

Chapter 3

The Body, Identity, and Community

In chapter two I analyzed the various conceptualizations of disability currently found in theory and practice. Each way of understanding disability has conceptual strengths and some are functionally useful. My analysis highlighted those strengths. There are also problems with each conceptualization and those, too, are clarified in the previous chapter. Finally, I demonstrated that a close examination of each theory reveals that they are not as different from one another as they first appear. This is particularly true of the identity theory and its response to the minority group model because the identity theory of disability has not made a full enough accounting of the self and its relation to community.

In order to construct a theory of an aesthetic of disability, three other conceptual tools need exploration. In some ways, these concepts are philosophically more basic because understanding them is necessary for giving meaning to so many human experiences intellectually similar to disability: race, gender, sexual orientation. These other experiences, then, are used in this chapter as touchstones for understanding this chapter's concepts and how they relate to disability.

This chapter is organized in three sections. In each section I review and analyze some works related to one of my conceptual tools: the body, identity, and community. In my reviews, I identify and evaluate ideas from scholars from a variety of fields of study. My critiques function as a means of determining the ways in which the scholarly ideas I have reviewed are applicable to this dissertation and to disability and disability studies. Paired with the previous chapter, my conceptual analyses set the stage for my theory of an aesthetic of disability.

The Body

Until recent years, as Harlan Hahn observes, "scholars have tended to ignore the fact that humans are embodied creatures who frequently use their bodies as a means of organizing perceptions of the circumstances and events surrounding them" (p. 21).[59] Within the last two decades, however, social science research has increasingly focused on the body as an avenue of inquiry and as a central unit of analysis when examining gender, race, ethnicity, sexual orientation, and other cultural phenomena.

Since his concepts are touchstones for thinking about the body, Foucault is a good place to start in this exploration of the body. His concepts useful for two reasons. First, they are powerful in their explanatory potential. They offer an multi-level interpretation of the body that connect the body to society and society to the products of society. In Foucault's work, the important products of society are its institutions. Second, Foucault's concepts related to the body are highly relevant to disability studies, where themes related to the body and social control are always emerging. In *Birth of the Clinic*, Foucault continually reapproaches a central metaphor of that inquiry: the gaze.[60] In Foucault's theory, the gaze of the individual physician as he looks at and examines the body of

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[59] Harlan Hahn, "Towards Politics of the Body: Theory and Disability," *Disability Studies Quarterly* 2(1992): 20-23.

[60] Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception*, trans. A. M. Sheridan Smith (New York: Vintage Books, 1973).

his patient is symbolic of the institutional gaze of medicine as it monitors and regulates the bodies of members of society. At both levels of analysis the bodies of individuals are present, but at the level of society, Foucault is also implying that the social "body," or society as a whole, is the target and result of the institutional gaze. For Foucault, an "archaeology of medical perception," which is the subtitle of the book, is the act of uncovering the history of the development of the institution of medicine while simultaneously peeling away the layers of society to expose social processes that operate invisibly. Just as Mehan, et al., argue that institutional processes create the perception of disability in public schools and, therefore, its reality, Foucault's metaphor of the gaze can be applied to institutions in society. Medicine and psychiatry also construct disability and its categories. The gaze, the focused attention on a body that constructs that body as disabled in the eyes of the observer as he examines it through an institutional lens, is one way of understanding the relationships between bodies and society. In schools, as in Mehan's study, students' bodies are the object of the gaze. In medicine the gaze is directed at sick bodies. In psychiatry, the gaze is toward sick minds. In general, the gaze is a metaphor for the social processes at work constructing the world around us. Foucault's use of gaze is specifically concerned with the bodies of individuals and the ways in which those bodies represent the social body. In effect, he has proposed a theory of the construction of the body as it appears to social institutions. My suggestion, then, is that Foucault's metaphor of the gaze is applicable to the disabled body.

In a related work, *Discipline and Punish*,[61] Foucault accomplishes a similar task with prisons. Here, the gaze of authority is present in disciplining practices such as the use of prisons and other forms of punishment, but the concept of "discipline" itself is transformed into a new social theory. Discipline becomes not merely the correcting of individuals who stray from social norms. It is also the regulation of society members, as is the gaze of medicine, so that they behave according to institutional rules. Discipline, both in its individual and whole group contexts, is also relevant to my thinking about the body and disability. Just as the gaze could be explained as a social mechanism for constructing disability, particularly disability as a personal deficit, the concept of discipline assists in understanding the ways in which institutions, schools for example, construct norms and standards whereby individuals are measured and with which they are monitored. If discipline creates standards for normalcy, it also produces boundaries for what is abnormal. It is into the category of abnormal that disability is usually assigned.

Relative to his metaphors of the gaze and discipline, Foucault remains consistent with another social scientist who has used the body as a unit of analysis. Mary, Douglas, an anthropologist, argues that the body is a symbol system.[62] More specifically, she claims that the body and the ways in which we think and talk about the body represent culture to us and culture, in turn, reflects the body back to us. In Douglas' view, the body and culture are interacting symbol systems. In her work symbols

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[61] Michel Foucault, *Discipline and Punish: The Birth of the Prison*, trans. Alan Sheridan (New York: Vintage Books, 1979).

[62] Mary Douglas, *Implicit Meanings: Essays in Anthropology* (New York: Routledge, 1975); and *Natural Symbols: Explorations in Cosmology* (New York: Pantheon Books, 1970/82).

associated with culture begin with the human body and the ways in which humans represent their bodies to themselves. Applying Douglas to disability, we could understand disability as a notion or set of notions that are not only about bodies and individuals but that are at a deeper level reflections of cultural values and the ways in which culture members understand themselves and their world.

In their symbolic analyses of the body and society, Foucault and Douglas present persuasive arguments for understanding the body discursively, as a symbolic way of interpreting lived experience, but a discursive interpretation of the body does not go quite far enough. If does not integrate corporeal realities, or what appear to be realities to those experiencing them, with the discourses of the body. Discursive explanations focus so tightly on symbolic ideas referring to bodies and metaphoric behaviors directed at bodies that they tend to de-emphasize personal identities, experiences, and thoughts that shape individual beings. Other scholars offer such ideas, however, and it is to those scholars I devote the next part of this section. As I leave Foucault, please note that I will return to him in the last section of this chapter when social theories are presented that are related to the concept of community, where his views on the interaction between social institutions and members of society are relevant.

The examined body, the disciplined body, the body of symbols that represent culture, are all important concepts that construct a view of the body as a public entity, as something that belongs to society and its institutions. But what of the private body? How can we understand the body of the self? This thing is sometimes called the embodied self.[63] Bryan Turner notes that there is a need to look at the body as a lived body, as something that experiences, something that is "not located in a fixed space" but that is both socially constructed and objective, or is discursive and animated. This, then, is what I would claim is one missing element in discursive theories of the body. The body is certainly discursive, but it is also animated. Yet it seems to have less physicality when interpreted as text, except as the physical body is manipulated by authorities. Textual notions about the body and its relationship to society are enriched by Turner's reminder that the body is also a corporeal thing. The physicality of disability is a frequently used notion in disability studies, perhaps because disability so often appears to be a highly physical phenomenon involving the limbs or eyes, the ears or internal body systems. Even when disability may not seem physical in a conventional sense, as in mental retardation or mental illness, if we consistently adhere to either the connection between the mind and the body, or the oneness of the mind and the body, then mental experiences become physical experiences and mental disabilities are animated.

Another way of conceptualizing the body is to consider it an epistemic index,[64] which is a bit different than claiming the body is discursive. As an epistemic index, the body could be understood as a location of knowledge, or as a site upon which knowledge is projected. This way of understanding the body has value in disability studies that will

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[63] For an excellent review of the sociology of the body and embodiment, see Bryan Turner, *Regulating Bodies: Essays in Medical Sociology* (New York: Routledge, 1992).

[64] This phrase is taken from J. M. Berthelot, "Sociological Discourse and the Body" *Theory, Culture, and Society* 3(1986): 155-164. Berthelot does not strongly support this view of the body, but he does suggest that it is one view found in sociology.

be illuminated in the next section of this chapter during my analysis of identity.

More recent scholarship on the body from feminist works expands the possible conceptualizations of the body. Paula Cooey claims that there have been many ways of conceptualizing the body: as a "site of political struggle," as a "construct for understanding physical experience," as a"pedagogical resource," as a "location and artifact of human imagination." She writes that "the body lived in relation to the body imagined (is) a testing ground...for mapping human values, as these are informed by relations of and struggles for power" (p. 9).[65] In Cooey's framework, the body is "a site of the imagination as well as object of the imagination" (ibid.). Imagination, here, is what constructs the body. But imagination also plays with the body. It seems that Cooey is arguing consistently with Turner, that the body is both socially constructed or an object of the imagination, and that it is animated or a site of imagination. But Cooey's semantic choices yield different thought consequences than do Turner's. Cooey implies a highly creative force at work in and on the body. Through her word choices she suggests that human imagination is the fertile ground from which the body as object and metaphor grows. This use of imagination in the construction and interpretation of the body will prove important in later chapters when I develop my theory of an aesthetic of disability. Cooey offers an interesting application to disability. If the body is the site of imagination, the place from which metaphor is developed, then the disabled body could be interpreted as a metaphor, as

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[65] Paula Cooey, *Religious Imagination and the Body: A Feminist Analysis* (New York: Oxford University Press, 1994).

a way of understanding something less visible. As a metaphor, disability says something about the culture in which we live and with which we construct. Perhaps disability is a metaphor for social hierarchies. Or perhaps it is the result of creative minds at play. Maybe the game they play is sadistic. Maybe it is not.

A final note on Cooey is needed in order to be true to her work. Central to Cooey's claims about imagination and the body is her belief that "whatever else 'body' may mean, and its meanings are multiple, acknowledgement of gender must lie at the center of its definition" (19). While I value her connections of body and imagination, I must disagree with her claim that gender is necessarily central to any definition of the body. I view gender as a highly transmutative experience and I consider transgendered and intersexual people as evidence of this.[66] From my perspective, gender is a fluid category that only appears to be stable from the standpoint of some but certainly not all humans. Likewise, I would not argue that ability or disability are at the center of the construct of the body. Again, disability is a fluid identity that an individual may experience through part of her life or that some individuals may experience while others will never experience it. Because of the notion of fluidity, I am skeptical of any scholar who attempts to claim that one particular experience is at the center of the definition of the body or any human phenomenon.

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[66] I understand transgendered people to be individuals who, at some time in their lives, have crossed the gender boundaries to experience a gender different from the one by which they were identified at birth. I view intersexual people as those who, at birth, have genitals that cannot be distinguished as male or female, or perhaps whose genitals are both male and female.

The historian Carolyn Walker-Bynum has yet another answer to the question "what is the body?"[67] She writes that the body is "a locus of experience and expression." She claims that discourse of the body can generally be about the body rather than society, sexuality, or power. In making this claim, she disagrees with Foucault, Douglas, Cooey, and Turner but she refers to a conceptualization of the body that can accommodate these other scholars' views while improving upon their conceptualizations. The important concept I take from Bynum, then, is that the body can be understood as a place of experience and expression. It is both a construction and a discourse. It is an appearance but it might also be something real.

In contrast to Walker-Bynum's claim that bodies could be real bodies and nothing more, Jonathon Rutherford suggests that the body is "bereft of those spatial and temporal co-ordinates essential for historicity, for a consciousness of our own collective personal past" (p. 24-25).[68] Bodies are liminal, according to Rutherford. They are in between the real world and the constructed world. They are ambiguous possibilities. The world is "wide open," and so are our bodies. For Rutherford, the body is undefined and undefinable. In the future, I will refer to Rutherford's concept of the body as the "ambiguous body."

Rutherford comes close to my own view that the body is necessarily fluid and ambiguous. Here I use fluid as a metaphor while late in this paragraph I use fluid to refer to body products. There is a way of

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[67] Carolyn Walker-Bynum, "Writing Body History: Some Autobiographical and Historiographical Reflections" *Disability Studies Quarterly* 2(1992): 14-16.

[68] Jonathon Rutherford, "A Place Called Home: Identity and the Cultural Politics of Difference" *Identity, Community, Culture, and Difference*, ed. Jonathon Rutherford (London: Lawrence and Wishart, 1990): 9-27.

understanding the body as something that is not necessarily bound by flesh and held together by a frame of bones. Throughout one's lifetime, the body is ever-evolving and from birth to death it is not the same body. If I nurse my infant, my milk nourishes that child and something of my body becomes one with my child. Male sperm is exchanged in intercourse, as are female fluids, and bodies or body products are blended. Blood transfusions are also the exchange of body fluids, thereby bodies. But the idea that the body is not bound by the physical space it appears to us to occupy is not limited to the exchange of body fluids.[69] Consider the fact that the cells of the body are continually dying and multiplying so that from one moment to the next the physical composition of the body is not exactly the same. Also consider body growth, the pregnant body, the body that is injured, and changes in the brain over time. Even more imaginative, consider the possibility that one's thoughts are of the body and that thoughts shared are interacting bodies.

Each of these interpretations of the body can give us a different way of analyzing statements about bodies. For example, if I say "I am sick" I and others in my society usually understand sickness to involve my body yet each of the previous interpretations of the body would provide a different understanding of my statement. Discursive interpretations of the body might argue that while my statement may reflect some discomfort on my part, that discomfort may be constructed and the result of the control over my body exercised by medical institutions. A more anthropological yet still discursive interpretation might understand the statement to be an

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[69] Fluids are thought of as being shared between humans in some cultures. See Farley Mowat, "The Blood in their Veins," *Annual Editions in Anthropology* (Guilford, CT: The Dushkin Publishing Company, 1990): 60-65; and Elisa Sobo, *One Blood: The Jamaican Body* (Albany, NY: State University of New York Press, 1993).

indication of cultural values of good and bad inherent in the physical (or social) body. If the body is interpreted as animated, the statement might indicate that while there are probably symbolic reasons for my perception of sickness, there might be objective, physical reasons as well. If the body is understood as an epistemic index, then my statement reflects human knowledge about the body and sickness and indicates how I understand their connections. Gendered views of the body would counter that as a female I have a female way of experiencing sickness and that my perception of sickness is imagined (socially constructed) and that it is also an interpretation of an objective reality I understand in a certain, gendered way. But the body as history camp might suggest that my statement simply says that when I claim "I am sick," and I intend this to refer to my body, it is possible I am talking about just that. It is plausible that the statement, "I am sick," is a factual statement indicating a condition that anyone in any body from any culture would experience, although we might be able to argue that the experience could be perceived and communicated differently by different bodies in different cultures. This possibility of a body being understood apart from society, sexuality, power, or any other category normally associated with bodies is of interest to me and will appear again in the theme of resistance as my theory is more fully developed in chapter four. Finally, if the body is ambiguous, non-spatial and non-temporal, or if it is fluid, shifting and changing through time and space, then the statement "I am sick" holds infinite interpretive possibilities, none of which can be assumed to be correct or incorrect, even if the interpretation comes from me. I return to this notion of the body later in this section and in greater detail in my chapter outlining a theory of an aesthetic of disability.

What, then, is the body? How can it be conceptualized and why is it important to conceptualize it a certain way? First, the integration of body and mind has been assumed in this discussion because I understand the body to include the mind and its activities. In understanding the body this way, I agree with previous scholars who have critiqued and discredited the mind-body duality.[70] In addition, given the examples of the alteration of the body, through sharing body fluids, through changes in the body over time, or even through accidental body changes, I also interpret the body to be more than the flesh and blood that appears to us at any one moment. It seems possible to conceptualize the body as a living thing as well as a medium through which experiences are interpreted. As such, the medium of the body is in constant flux, as are the experiences it interprets or that are interpreted through the body.

By blending these concepts the body can be conceptualized as "lived experiences." The body as lived experiences is consistent with a discursive view of the body. It allows for human imagination in its construction but it is more than a construction, although it seems impossible to determine where the construction of the body ends and the physical body begins. Because infinite interpretations are allowed, lived experiences can be about the body isolated from society, or gender, or other constructions, but it is unlikely to be so, for these seem inseparable from the body. Yet, as mentioned earlier, it seems possible that individuals might resist the body images forced upon them by society, or gender, or other influences. When talking about the body as "lived experiences" it is

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[70] Warren Gorman, *The 'Mental and the 'Physical': The Essay and a Postscript* (Minneapolis, MN: University of Minnesota Press, 1969); William Betchel, *Philosophy of Mind: An Overview for Cognitive Science* (Hillsdale, NJ: Lawrence Earlbaum Publishers, 1988); Edgar Wilson, *Mental as Physical* (Boston, MA: Routledge and Kegan Paul, 1979).

implied that what appears to us as the physical realities of living, sensations and emotions for example, are indistinguishable from the meanings we make of those perceived realities. The body as lived experiences allows us to think about the body as fluid, transformed and transformative, and ever-evolving. The body is more than what we see and feel of ourselves, more than flesh and bones, more than blood and semen. The body is our thoughts and what we know of ourselves. It is the child we feed. The body is the aged one we bury. The body is what we think we see of ourselves and others. But it is also what we do not see. The body can be gendered and can be given a race. It can be disabled or not. It can be described in many cultural terms. This view of the body holds that these categories and the ways in which we imagine the body being bounded or not are culturally constructed and that those constructions are accomplished in relation to individuals who might resist particular ways of viewing their own bodies and who might opt for alternative interpretations of their selves. Living and experiencing together create a body and the words we use to describe those experiences of living, that body, that person, interpret the body to us.

The body as lived experiences provides several ways of interpreting statements about the body. Now if I say, "I am disabled," we can assume I am making a claim about my body because experiences of disability are necessarily interpreted through the medium of my body. My statement simultaneously refers to how I have experienced my body as I move through my world, as I interact with other beings in my world, and as I interact with myself. My statement also reflects the ways in which others have shown me they understand me. When I say "I am disabled," I say something about the culture within which I experience life, its values, its norms. I also consider my disabled-ness in light of my other body experiences (gender, ethnicity, race, sexual orientation) and how those are constructed and valued or de-valued in my culture. Finally, if my statement appears to disagree with the prevailing notions of my culture, then my claim is one of resistance to those notions and, in the end, my claim collaborates with my culture to construct my disabled body. In the end, my statement says much about me and how I view my body and my self but it also says much about the others with whom I experience my world.

As remarkable and interesting as conversations about the body can be, the body as a single conceptual tool is insufficient for understanding disability, although I would argue that disability is primarily a body based identity, or to frame it more consistently with my view of the body, disability is lived experiences that include a disabled identity. The next section of this chapter provides a review and critique of identity literatures that can be relevant to disability.

Identity

The meaning and nature of identity have long been examined by scholars in many disciplines. In this section I will provide a review of key ideas from those scholars whose work in identity I consider most relevant to disability studies. I select such works with the realization that others might argue with my decisions on the grounds that they are incomplete or inaccurate. With each work cited, I provide my rationale for having chosen the scholar and his or her work.

Philosophical scholars have produced some relevant ideas about identity. Philosophical works on identity are particularly helpful in framing understandings about whether or not there is a human essence, and how humanness, with or without essential features, can be understood. Such pursuits are inquiries into ontology (the study of what it means to be human) and epistemology (the study of the knowledge of humans). One philosopher who has published seminal work about identity and the essence of humanness is Martin Heidegger who claims that "the principle of identity is considered the highest principle of thought" (p. 23).[71] In making this claim, he is not suggesting that identity is merely the most interesting or important principle. This is an ontological claim indicating Heidegger's commitment to "Being." For Heidegger, "Being" is the essence of an individual's humanness, the true core of the human individual. This essential core is distinct from its related term "being," which indicates any conscious person or even a particular conscious person, but which does not refer to a specific individual's essence or individuality. A "Being" in Heidegger's philosophy is fundamentally different from all other "beings." All other qualities of the individual are subsumed under "Being." "Being" is a single object. It is at once a sameness or a unity with oneself and a difference from others that is so fundamental that the difference usually goes unnoticed by the self and other beings. "Being," in Heidegger's framework, is one's identity. Heidegger's "Being," though, can be interpreted as a purely mental phenomenon, as something that could theoretically exist without a body, because "Being" for Heidegger is an essence that need not be corporeal, although the body is implied gently in his theory of "Being." While "Being" has an ontological essence, it is an epistemological realization. Another

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[71] Martin Heidegger, *Identity and Difference*, trans. Joan Stambaugh (New York: Harper and Row Publishers, 1957/69).

way to understand this is to think about the possibility that "Being" does not need a body to know itself, while a being might need a body to be itself.

Heidegger's accounting of "Being" is intriguing, and the possibility that each living person could be essentially distinct from all other living individuals is engaging. However, in my search for concepts of identity that are relevant to disability and the disabled identity, I find several potential problems with Heidegger's construct. First, Heidegger's "Being," though necessarily grounded in real experience, does not make enough of an account of the body of beings and the importance of the body to identity. Integrating the body into identity constructs is particularly crucial for understanding disability since disability is an experience of the body, as I have argued in the previous section of this chapter and as I will continue to argue in chapter three. Second, Heidegger's assumption that there is an essence, which he labels as "Being," is questionable if one adheres to an interpretive tradition that is uncomfortable with objective categories. In such a tradition there is a value in having a variety of ways of understanding reality or what appears to be reality; therefore there can be no objective categories that truthfully describe anything. All categories would have to be subjective. Interpretively speaking, "Being" could be many things or could be nothing at all. Heidegger does not account for such possibilities in his theory. Third, Heidegger's concept of "Being" disconnects ontology from epistemology. More plainly, Heidegger considers what it means to be human separately from how a human knows he is human and how he understands his world. I view this as a distinction of content which is a distinction that is inconsistent with ways of understanding the world that de-emphasize objective categories. Heidegger, then, offers a theory of identity that focuses on a being, an individual, but that does not connect the individual's being-ness with his knowledge of being-ness. In addition, Heidegger's Being can exist disembodied, though he cannot exist ahistorically. In other words, he does not need a body to exist, but he does need experience, although that experience can be strictly or primarily mental.

Applying Heidegger to interpret the disabled identity is an interesting task. It seems plausible to use Heidegger in two ways. First, we could understand Being as something that is far removed from any one identity. In this view, disability would not be located at the core of the human identity. It would not define one's Being. However, disability or any other identity-marker could constitute the experiences that contribute to Being. In other words, experiences of disability might influence the character of Being but would not of themselves constitute a Being. A second way to apply Heidegger to the disabled identity is to claim that Being is essentially the identity or group of identities that form a person. In this application, Being is either disabled or abled, it is gendered and raced. It has a sexual orientation and an ethnicity. Specific identity markers are necessary for Being if Heidegger is applied in this way. Then disability lies at the core of what makes a person who she is. In chapter two I argued against claims of anything being at the core of anything else, particularly when talking about humans. Therefore this application of Heidegger is inconsistent with my purpose.

In addition to adhering too much to an essentialist view, this notion of Being feels incomplete. It is not dependent enough upon the body and experiences of the body. What is needed is a body-centered, non-structural, non-essentialist, interpretive view of identity. For that view, I find that another philosopher, John Dewey, has potential.[72] Dewey epistemologically views identity as "knowing" oneself but he also views it ontologically, as intimately connected to lived experience. For Dewey, an individual understands and recognizes the self through experiences of living, Dewey's claim depends upon an iterative view of identity. While Heidegger's notion of "Being" is primarily a mental experience, Dewey's idea of "knowing" the self is connected to the body and experiences of the body, and although he does not explicitly deal with the dualism of mind and body, Dewey's theory of experience implies that there is no duality. By linking lived experience, or "doing," to knowing the self, Dewey suggests a truly wholistic view of identity that blends the mental and the physical. Dewey's notion that knowing and doing as lived experiences of the body, as an example of the body being subject to and active within the influences of the social world, constructs a theory in which simultaneous social processes are at work in the development of the individual identity. Within Dewey's framework I know something from or while I am doing it, after I have done it, and even while I am thinking about doing it. Or, I might even know because my body responds to others' doings that somehow impact me through experience. Within Dewey's framework, my responses could be in agreement or in disagreement to the doings and knowings of others. Dewey is most persuasive at constructing an identity that is contingent upon mental and physical interaction with one's world. In the end, Dewey leaves room for Heidegger's "Being" but strongly contradicts the possibility that there is "Being" without a body.

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[72] Ed., John McDermott, *The Philosophy of John Dewey, Volume II* (Chicago: University of Chicago Press, 1934/81).

Dewey provides interesting application possibilities for disability. A Deweyan view of the disabled identity might hold that mental and physical experiences are necessary for constructing one's identity as a disabled person. Further, this view would insist upon the interaction between experiences of the body (in Dewey's thought these were mental and physical) and knowledge of oneself and others. Knowing one's self and others, doing those things that constitute experiences, knowing and doing together construct a view of the self, an identity, that can include disability. When using Dewey, it is imperative that we understand a disabled identity as something that is actively experienced and understood through the body and that is constructed by interacting with others in one's world while attempting individually to make sense of that world and those others.

Heidegger and Dewey hold identity as central to the human condition in any sense, but more recent scholars conceptualize identity as a public political enterprise rather than a private individual one. Kobena Mercer summarizes a current alternative view by stating that "identity only becomes an issue when it is in crisis...eagerness to talk about identity is symptomatic of the postmodern predicament of contemporary politics" (p. 43).[73] In this view, identity is a construct resulting from external social pressure. Crisis, according to Mercer, is the spark that sets the fire of identity discourse.

The idea that some type of crisis or conflict is required for identity to be at issue is echoed in current debates about race. Race theorists,

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[73] Kobena Mercer, "Welcome to the Jungle: Identity and Diversity in Postmodern Politics," *Identity, Community, Culture and Difference,* ed. Jonathon Rutherford: 43-71.

such as Anna Stubblefield, debate whether or not race and racial differences actually exist.[74] In her work, "Racial Identity and Non-Essentialism About Race," Stubblefield posits a theory about the development of the racial identity. First she notes the conflict of logic that exists between non-essentialist arguments about race and arguments for racial identification related to problems of social justice. Stubblefield suggests that the problem is not unresolvable but that the problem is in the "way in which race and groups based on race are conceptualized" (p. 346). In her reconceptualization of race, Stubblefield claims that "racial identification satisfies a desire to feel connected to others and to generate strength in numbers for political action" (p.360). In this theory, non-essentialism about race does not necessarily have to be inconsistent with racial identification if those making a racial identification for themselves understand that "there is a fundamental difference between being a victim (of labelling) and experiencing having an oppressive label applied to you" (p. 365). That experience of oppression, suggests Stubblefield, is the glue that binds racial or other minority groups together allowing group members to self-identify.

Popular authors, too, have debated the problems of racial identity. Lawrence Wright has suggested that increasing multiracialism has posed serious problems for racial labels.[75] How, he asks, do we know if census data are accurate, given the lack of multiracial categories at the same time that we have rising numbers of multiracial citizens?

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[74] Anna Stubblefield, "Racial Identity and Non-Essentialism About Race," *Social Theory and Practice* 21(1995): 341-368.

[75] Lawrence Wright, "One Drop of Blood," *The New Yorker* July (1994): 46-55.

Multiracialism, he claims, threatens to "undermine the concept of racial classification altogether" (p. 52). For example, think of the problems of the "one drop" rule that holds that any individual having "one drop" of black blood makes a person Black.[76] He asks whether this is a racist rule. Given our history as a nation, we must also wonder if it is a realistic rule. In the end, Wright's claims are disturbing for their lack of solutions when he writes, "Whatever the word 'race' may mean elsewhere in the world, or to the world of science, it is clear that in America the categories are arbitrary, confused, and hopelessly intermingled" (p. 53).

Stubblefield and Mercer, and others who make similar claims, then, conceive of identity as saying something about one's environment, or about the self responding to the environment, but not about the self in addition to or in spite of the environment. I find the lack of attention to the individual self to be the major problem with applying such arguments to disability. If Stubblefield is correct and theories like hers can be applied to disability, then every individual who utters "I am disabled" does so in response to environmental stimuli alone. If this is the case, then it seems equally plausible to argue that in an environment where individuals are ascribed certain disabled identities, there could be no individual who refuses such an identity. If this is possible, then it would have to hold that the environment inevitably identifies individuals as disabled and that there are no individuals who could or would, in the face of such an ascription ever state, "I am not disabled." But this does not seem plausible, nor does it makes sense within the framework of Dewey's theory of experience,

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[76] I use the term "Black" to refer to a racial category and to differentiate it from an ethnic category often identified as "African-American."

where knowing and doing reciprocally interact. In chapter four I will elaborate upon the possibility that individuals might resist social pressure to self-identify. So, race theory, or at least race theories that attribute racial categories to the social environment alone, are important but insufficient for understanding disability.

Feminist theorists also contribute to conceptualizations of identity. One branch of feminist theory, standpoint epistemology, is a useful tool for understanding identity claims. Standpoint epistemology starts from the perspective of marginalized lives. While feminist theorists usually refer to women, standpoint epistemology can be utilized in understanding the experiences of other marginalized groups: African-Americans, the disabled, gays and lesbians. Standpoint epistemology refers to a preferencing of the experiences, knowledges, and beliefs of individuals having a particular perspective. Sandra Harding explains why marginalized lives are central for the standpoint epistemologist: they give insight into certain kinds of knowledge and they raise better critical questions about the social order.[77] In fact, Harding claims that the social order cannot be fully understood except from the perspective of the individuals who live marginally within it. Other feminist scholars implicitly utilize standpoint epistemology in their work. For example, Charlotte Bunch notes that the strength of this method "lies in providing an alternative view of the world (p. 173). This suggests an interpretive way of describing experiences or phenomena. Lisa Isherwood and Dorothea McEwann describe standpoint epistemology as changing the normative

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[77] Sandra Harding, "Rethinking Standpoint Epistemology: What is 'Strong Objectivity'?" *Feminist Epistemologies*, eds. by Linda Acoff and Elizabeth Potter (New York: Routledge, 1993): 49-82.

perspectives with which we view the world. Nel Noddings uses this as a methodological approach in her analysis of *Women and Evil.*[78] Isherwood and McEwan summarize the philosophy behind standpoint epistemology well when they note that the authority of the theoretician must be based in experience. Here they imply that experiencing the marginalization oneself is necessary for authoritative discourse about that phenomenon.

Understanding the world from the perspective of people with disability is exactly the view this dissertation attempts to take. In that respect, standpoint epistemology is a useful tool. It is also useful for thinking about norms from the experiences of marginalized individuals, either where those norms are theirs or others'. But if standpoint epistemology is understood to claim that a certain perspective on the world cannot and should not be appreciated by those who do not share particular marginalized experiences, then it is a divisive tool and one that is inconsistent with the framework within which I work. This risk of using standpoint epistemology, then, is taken with the caution that I use it to remind myself and the reader to keep the perspective of individuals with disability in the forefront of identity and all discourse in this dissertation. It challenges us to use our imaginations to try to envision life with different disabilities.

A rich and recently developing body of literature on identity comes from gay and lesbian studies. Empirical studies of gays and lesbians contain some of the most eloquent and persuasive claims about

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[78] Charlotte Bunch, "Not by Degrees: Feminist Theory and Education," *Modern Feminism: Political, Literary, Cultural*, ed. Maggie Humm (New York: Columbia University Press, 1992): 171-174; Lisa Isherwood and Dorothea McEwann, *Introducing Feminist Theology* (Sheffield, England: Sheffield Academic Press, 1993); and Nel Noddings, *Women and Evil* (Berkeley, CA: University of California Press, 1989).

identity that I have found. There are several possible reasons for disability studies scholars to be drawn to gay and lesbian literatures. First, both types of studies focus on highly marginalized people who have only recently begun to be studied by themselves. Disability studies is even younger than women's studies, placing its development more in line with gay and lesbian studies than with women's studies. Second, there are compelling similarities between gay and lesbian and disability studies as they are related to the body and identity. Both groups of people have been assumed to be abnormal, have been submitted to clinical treatments in attempts to "cure" them, and are discriminated against for their "conditions." The parallels between gay and lesbianism and disability are most compelling when considering the fact that we rarely hear about individuals of minority races or genders to be clinically treated for such "conditions;" however gays and lesbians and people with disabilities often are treated clinically in an effort to make them more normal.

Representative of gay and lesbian studies of identity, Judith Schuyf conducted a study of lesbians in the Netherlands.[79] She observes that there appears to be infinite possibilities for lesbian identities and that there is no one way in which all or most lesbians come to know themselves as lesbian. She identifies a variety of identity formation processes that emerged from her work, noting that there are many ways of "being" lesbian, and that the lesbians she studied have not experienced one lesbian identity throughout their lives, rather, they have experienced a variety of identities and ways of knowing themselves.

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[79] Judith Schuyf, "The Company of Friends and Lovers: Lesbian Communities in the Netherlands," *Modern Homosexualities: Fragments of Lesbian and Gay Experience*, ed. Ken Plummer (New York: Routledge, 1992): 53-64.

Recognizing one's self as gay or lesbian and then identifying that to others is important in the homosexual community. Peter Davies notes that "coming out is a central feature of the experience of lesbians and gay men in the Western world" (p. 75).[80] He claims that in the gay community coming out means becoming a different person but he also claims that the centrality of coming out to the gay identity does not necessarily indicate the centrality of sexual identity as central to the gay identity. For Davies, coming out is the process of coming to know the self and then telling others what one knows. Davies writes that "...identity is a process of accommodation to a social world rather than a dominating and pre-disposing psychic force" (p. 83).

Davies' work on the significance of coming out to the gay identity highlights a possible difference between the experiences of gay identity and the experience of identity for most people with disabilities. This difference can be understood by using the metaphor of "coming out." Davies' research reminds us that coming out is a significant process in the development of the gay identity. Coming out appears to hold ritual importance, but as a ritual it can be interpreted. Coming out appears to hold ritual importance, but as a ritual it can be interpreted in two ways. One interpretation could explain coming out as a significant series of events that hold special meaning for individuals who are transforming their self-knowledge. In this view, coming out is a response to changing meanings of self-hood. But another way to view coming out is to see it as a

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[80] Peter Davies, "The Role of Disclosure in Coming Out Among Gay Men," *Modern Homosexualities*: 75-83.

confession of sorts, a necessary confession in a "dysfunctional" society where it is considered bad to be gay.

In connecting the metaphor of coming out to disability and the disabled identity we can look pragmatically at the metaphor from several angles. With one angle, we could claim that most people with disability do not have the opportunity to "come out." They are "outed" by others: teachers, parents, doctors. This view suggests that if coming out is important to the process of claiming one's identity, then people with disability are generally denied that opportunity, unless they have invisible disabilities.

Another angle with which to view coming out in the context of disability is to ask if something like it might have meaning to people with disability. Would the process of "coming out," including the agency and the intentional decision making that coming out requires, be beneficial to people experiencing themselves as disabled? If not, what is essentially different about the experience of coming out as a gay person from coming out as disabled? An obvious difference is in the self-revelation of gayness whereas many people with disabilities find that their disabilities are revealed for them regardless of their personal intentions. But understanding disability merely as it appears to others feels incomplete. I argue that revealing oneself to the world as one is understood by oneself is important for individuals with any identity. This matter is connected to the problems of self-definition in the various theories of disability analyzed in chapter two. It also implies some type of resistance to the beliefs of others when those beliefs conflict with one's own views. The matter of resistance is discussed in this chapter and is more fully explored in chapter four. Finally, it is related to ethical decisions and the challenge of honestly presenting one's self to the world.

A third way of viewing the coming out experience is to ask not only whose right it is to "out" a person with a disability, and not only whether the process of coming out can be important or useful to people with disability, but whether or not we can imagine an example of someone who, in the face of overwhelming physical evidence of disability, exercises her freedom to choose her own identity by refusing to accept a disabled identity for herself. In this case we would be imagining someone who resists being "outed" by others by holding on to self-knowledge in the face of powerful evidence and social pressure to the contrary. In a sense, we are asking if it is possible to resist powerful social processes that attempt to identify people as disabled when they, themselves, do not feel disabled. We need not imagine this person. She lived and died as a non-disabled person. She was my daughter. At a recent conference of disability scholars, I remembered her:

> My daughter, Tiffany, died last summer. She was fifteen at the time of her death. Her official medical diagnoses in life included: spina bifida, hydrocephalus, severe mental retardation, Arnold Chiari syndrome (a brain stem malformation), sickle cell trait, and epilepsy. By all observers' accounts, including my own, Tiffany was disabled. And Tiffany knew what it meant to have a disability. But not once in her life would she allow anyone to call her disabled. And not once did she ever admit to being "disabled." Up to the day she died, Tiffany viewed herself as a non-disabled person. She maintained this view even in the face of having two other siblings with disability, of having a mother who is disabled and who has been an advocate and a disability scholar, and of living in a home where disability and civil rights are the favorite topics at the dinner table.
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> Tiffany's persistent self-knowledge, her clear indication that she did not have a disabled identity and

> that therefore others should not view her as disabled, have made me think about identity in a very different way. If Tiffany could, as a child, choose to resist even her own mother's identity for her, what does this tell us about identity and disability in general? I think it shows us that coming out may be as important for the disabled identity as it is for the gay identity.[81]

The theme of resistance is strong in this example and it makes the metaphor of coming out more complex. Gay men face similar, though opposing, social pressures to those experienced by many disabled people. For gay men, the force is in the direction of remaining closeted. Coming out as a gay man resists that force. For most visibly disabled people, the social pressure is to be outed and it is difficult for an individual who appears disabled to others to resist that process even if she feels strongly that she is not disabled. Tiffany's view of her self is a good example of this pressure and her resistance to that pressure. A less often observed social pressure can be found within the disability community. There, individuals who are not visibly disabled and who do not live openly as disabled people are often perceived as "passing", or as pretending to be non-disabled when they are actually disabled. The term "passing" comes from the gay and lesbian communities, in which individuals who are gay or lesbian but who are living openly are perceived as "passing".[82] Within the disability community, then, there is pressure for people with invisible disabilities to stop passing and to live openly as disabled. Again, if there is any possibility that individuals have some choice in whether or not they are disabled, there is likely to be some resistance to pressures to

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[81] From a paper, "Community and Disability in Schools: Alternatives for Policy Thought," presented at The Society for Disability Studies, in Minneapolis, MN, May 1997.

[82] Corbett O'Toole and Jennifer Bregante, "Disabled Lesbians: Multicultural Realities" *Perspectives on Disability*, ed. Mark Nagler (Palo Alto, CA: Health Markets Research, 1993): 261-273.

stop passing. It also seems likely that, if the disabled identity is constructed as are other identities, then it is not something that is static or easily interpreted by the self. It is more likely that the disabled identity becomes progressively stronger over time, or that it ebbs and flows, or that, as in the example above, some individuals with significant disabilities will not be comfortable claiming, "I am disabled." When we consider two other possibilities, that some individuals believe themselves to be disabled but still choose to pass in society, or that some individuals will use the disabled identity in certain situations where it achieves desired outcomes, we are faced with the ethical dilemmas of identity. The ethics of an aesthetic of disability will be addressed in chapter four.

What, then, is identity? How can it be consistently understood and used throughout the remainder of this report? Identity is a complex weave of how a person views herself and how others view her and how those views influence each other. Identity is some level of understanding of how an individual is both the same and different from others. Identity is a lived experience that is informed by one's cultural context and by experiences of relationships with others, physical and kinesthetic sensations, thoughts, and emotions. In claiming that identity is a lived experience, I am clearly arguing that identity, in some way, is intimately connected with the body. The body and identity are joined. When I say, "I am a woman," I am making a claim that I have constructed from the appearance of my body as I and others perceive it, the experiences I have had with my body that cause me to believe this about myself, and the ways in which my body is shared with others or the ways in which my body flows through my world. Identity is one way of interpreting the experiences of living in the world with a body. As with the body, individual beliefs about identity can appear resistant to culture and can confuse constructivist theories. For some scholars, identity is a political interpretation while for others, it is a philosophical one. For still other scholars, identity is socio-cultural. All interpretations of identity, however, begin with the body and conceptualizations of the body, if the body is conceptualized the way in which I propose in this chapter. Even Heidegger's account of identity, as an essential feature he labels "Being," begins with the body, although he would claim that the body experiences being while the mind recognizes and has knowledge of "Being."

Using this interpretation of identity, when I say "I am disabled," I am making a statement about who I believe I am, in part because of the ways in which others view me, and in part because of how I view myself. I am making an ontological claim. I am indicating that I consider myself very much like other people with disabilities and that my similarities are important enough for me to affiliate with them in this way. My statement indicates that I view myself as distinct from others whom I do not perceive as disabled, or who do not perceive themselves as disabled. I am also saying something about the ways in which I experience social and physical life through my body, or about my lived experiences. I am making a claim about what I know about myself and others. It is an epistemological claim. My claim of identity as a disabled person reveals me to myself and the others with whom I interact. My knowledge of my disabled identity grows, ebbs, flows, evolves, as do my lived experiences, as does my body. By giving myself this identity, or by accepting it when others give it to me, I am saying that there is something about me that is real enough for me to experience it, understand it, and make statements about it.

Community

Analyses of concepts of the body and identity can lead to thoughts about community. Perhaps this is so because humans experience life in groups and this makes it difficult to conceptualize about our bodies and identities without thinking about the people with whom we interact. In this section, I discuss community as a body experience with some experiential features that are both different from and connected to individual identity. Our perceptions of identity are dependent on the sensations we feel in our bodies as we either experience ourselves or others as disabled (or gendered, or raced, or sexual). Identity is formed through interacting with others but it is, to a great degree, one's own, as are one's perceptions of the identity of an other one's own.

In contrast, community is dependent on some type of real experiences or perception of shared experiences in combination with either a choice to belong to those shared experiences or being assigned to belong to those experiences. By its very definition, community is something that a group of people do or share, whether by choice or not, although experiences of community certainly influence experiences of identity and affect the body or perceptions of the body.

A disability community might be composed of individuals who believe they share an identity and body experiences or who have been assigned by others to a community based on social values and processes. Although the external perceptions might be that there are shared identities and experiences, the ambiguity of this all suggests that community members cannot be sure that this is, indeed, the case. Even individuals with what appear to be the same disability experience their bodies very differently. The power of social processes is binding, though, and somehow a disability community, or any community, develops. Perhaps even more so than individual identity, community is dependent on certain social processes that designate the community and its members and that establish its values and customs.

One way of understanding community is through a metaphor of ritual. For this dissertation, a simple definition of ritual will be sufficient. Let ritual be understood as routinized, habitual actions that have their roots in cultural beliefs and symbols. Rituals are often conducted in ceremonial public style; however there are also private rituals.[83]

Victor Turner, Bruce Lincoln, and David Kertzer have developed models of ritual that imply that rituals are one form of "social glue," one way of binding groups of people together into community.[84] These three scholars have all approached ritual somewhat differently; however it is their common themes that are important in this dissertation and to my analysis of community. Turner's model of ritual is based upon extensive anthropological field work in which he identified distinctive ritual stages that comprise a ritual process. Turner's stages of the ritual process roughly follow this pattern: it is recognized that something or someone needs to be fixed, a ritual is performed on or related to the object or individual needing to be fixed, if the ritual is effective the object or individual is believed to be returned to its proper state. Lincoln takes a historical and literary view of ritual, claiming that social categories mark what is normal or acceptable,

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[83] Catherine Bell, *Ritual Theory, Ritual Practice* (New York: Oxford University Press, 1992), offers a nicely constructed and recent overview of ritual theories.

[84] Victor Turner, *The Ritual Process: Structure and Anti-Structure* (Ithaca, NY: Cornell University Press, 1969); Bruce Lincoln, *Discourse and the Construction of Society: Comparative Studies of Myth, Ritual, and Classification* (New York: Oxford University Press, 1989); and David Kertzer, *Ritual, Politics, and Power* (New Haven, CT: Yale University Press, 1988).

thereby automatically delineating what is abnormal or unacceptable. In Lincoln's model, these categories are taxonomies. In creating taxonomies, Lincoln argues, social hierarchies are established. Ritual, he further claims, perpetuates hierarchies and taxonomies. Kertzer approaches ritual from a socio-political perspective that is compatible with Turner and Lincoln. For Kertzer, ritual is a social act that continues the political structure of society.

Blending these three views of ritual and applying them to disability and community offers many interpretive opportunities. We can understand ritual as routinized actions that produce and reproduce culture, where culture is understood as the values, norms, beliefs, and socio-political institutions of a particular group of people. Rituals are enacted rather habitually; they symbolize cultural beliefs about what is normal and where individuals fit within society. They maintain social and political stability. In essence, they identify community members and non-members. They indicate the social groups to which individuals belong.

If this is the case, then there must be clearly identifiable rituals of disability, routinized acts that mark individuals as belonging to a community of disabled or non-disabled people. It could be argued that there are numerous rituals of disability and that most of them have been oppressive to people with disability. Consider several acts that are performed when an individual has or is suspected of having a disability: intelligence testing in schools, various therapies (physical therapy, psychotherapy, occupational therapy), certain routinized pedagogics used in special education (direct instruction, for example).

A more careful description of the ritual nature of intelligence testing and its effects on children may be helpful here. Intelligence testing has been used in the Western world for nearly a century.[85] Today, intelligence test results are a key tool for determining many types of educational or psychological disabilities, for example the diagnosis of learning disabilities, emotional impairments or behavioral disorders, and mental retardation are all partly contingent on how a person functions on an intelligence test. As do other rituals, intelligence test results produce symbols of status within society. For example, intelligence testing identifies people with mental retardation, who are not highly regarded within the culture of the United States. Most people with mental retardation, if employed at all, are employed in jobs that make less than the minimum wage. They are usually educated separately from other children who have "normal" intelligence and when they reach adulthood, if they leave home, they are usually sent to "group homes" rather than to their own homes. Intelligence testing also functions as ritual as a form of social control:

> Standards for normal intelligence translate into standards for normal behavior, and abnormal intelligence is believed to be correlated with abnormal behavior. Social responses to abnormal intelligence and behavior serve to establish social control over those considered to be abnormal and those who are perceived to have the potential for abnormality. Social control through intelligence testing is exerted through several social systems: educational, political, medical, and psychological. Once testing has been deemed necessary by one of these systems, the individual being tested is seldom given the choice of whether or not to participate...Social norms are [also] maintained by the cover threat that if an individual does not conform with

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[85] Stephen Jay Gould, *The Mismeasure of Man* (1981). When I use the term "Western," I generally mean the western hemisphere, but more specifically, I refer to North America, England, and other western European countries, where intelligence testing has most systematically been used.

> social expectations, that person may be tested for intelligence.[86]

Viewing community through the lens of the metaphor of ritual assists in understanding one way in which communities are defined and continued. However, there are problems with using ritual as the only way of understanding community. Since rituals "have a political aspect to them and may embody and transmit certain ideologies or world views" (p. 49),[87] and since rituals are implements of culture that can function oppressively if the individuals on whom rituals are conducted are devalued culture members, other interpretations of community are needed.

In attempting to expand the notion of community, we could look for other social theories and in doing so we can use the theory of reciprocity, or reciprocal relations. Marcel Mauss' theory of reciprocity holds that a community maintains social stability when all members have reciprocal relations.[88] Reciprocity is a form of social relations in which all social members or institutions comprised of social members contribute to the good of society, each playing his or her role in good faith. In a nation such as the United States, according to Mauss, this means that the government promises to protect its citizens, who in turn promise to cooperate with government officials and rules, including rules of giving and receiving. In a tribal society, it could mean that the chief provides protection to tribe members who pledge their support and who present the

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[86] Susan Gabel, "Intelligence Testing as Body Ritual" *Insight and Outlooks: Current Trends in Disability Studies*, eds. Elaine Makas and Lynn Schlesinger (Portland, ME: The Edmund S. Muskie Institute of Public Affairs, 1994): 29-36. I have not found any other examinations of intelligence testing as a ritual act.

[87] Peter McClaren, *Schooling as a Ritual Performance: Towards a Political Economy of Educational Symbols and Gestures* (New York: Routledge, 1986).

[88] Marcel Mauss, *The Gift: The Form and Reason for Exchange in Archaic Societies* (New York: W. W. Norton, 1950/1990).

chief with goods and services that he wants or needs. In families and smaller social units, reciprocity requires that material or social gifts be evenly exchanged. Although not explicit in Mauss' work, reciprocity is also evident in a school community. Just as nations grant rights and responsibilities to those who follow the rules of reciprocity (even if the rights or responsibilities are differently conceived and understood across different nations), school communities do too. And as in tribes, individuals in schools who are shut out or who opt out of reciprocal relations are marginalized and do not participate in the social interactions and benefits that occupy the rest of society.

There are clear applications to disability here. If people with disability are either not expected to participate in reciprocal relations, or they are shut out of such relations, then they cannot be fully participating members of the community. Their inability, for whatever reason, to participate in the "social economy" (the exchange of social "goods and services" for the return of the same) marginalizes them. For example, when students are assigned to the separate educational system of special education, they are sometimes placed in segregated classrooms. There, they are shut out of the reciprocal relations of the larger school community. They no longer participate as full community members. Even if special education students are "mainstreamed" or "integrated" (terms used to describe attempts to keep students with disabilities at least part time in general education classrooms), less reciprocity is often expected of them. Consider the youngster who, because he is believed to have mental retardation, is excused from following the rules of etiquette that other students must follow. In making what appear to be appropriate and reasonable accommodations, adults are actually symbolically placing him in the margins of his school community. If he does not reciprocate the social graces, he will not be a full community member. Or think about this child when he becomes an adult and cannot earn a competitive wage because most adults with mental retardation, if they work, are paid below minimum wage. He will not be able to participate fully in adult reciprocal relations, tax paying and gift giving for example. Reciprocity is a way to understand the give and take of relationships in community. Ritual and reciprocal relations conceptualize community by defining its members and their ways of interacting.

What, though, is propelling community along? What social force keeps things moving? Can community be conceptualized as the result of large-scale social processes? For this I return to Foucault. Foucault has a large body of work that examines the interactions between individuals and social institutions.[89] His theory is often identified as body power or power relations. I prefer the use of "body power" since this use is consistent with my view that the body is the key site of the exercise of power relations. Foucault's theory holds that power flows through society and social institutions, controlling the lives or bodies of individuals. It is a theory that is at once personalized, focusing institutional attention on the bodies of people, and generalized, reminding us that social institutions can be understood through the metaphor of agency, or intentionality, where intentionality refers to actions that produce anticipated outcomes.

Understanding community in light of Foucault's theory of body power and applying this to disability has been a topic in some of my

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[89] I have previously cited two: *The Birth of the Clinic* and *Discipline and Punish*. Also see *Madness and Civilization: A History of Insanity in the Age of Reason*, trans. Richard Howard (New York: Vintage Books, 1965/88); and *Mental Illness and Psychology*, trans. Alan Sheridan (Berkeley, CA: University of California Press, 1954).

previous work.[90] The applications may seem rather apparent, especially since disability is intimately connected to each of the institutions Foucault analyzes. Medicine, psychology, and psychiatry diagnose and treat disability. Prisons, as we have often heard in the popular media, are full of people with disability, especially when disability is defined broadly.

The previous works of social theory feel incomplete as analyses of community, perhaps because they feel disconnected from the emotions of real people. They provide possible explanations for why things appear the way they do, but they do not get at the feelings associated with the way things appear. It seems that community could also be interpreted at a more emotional level. Whereas ritual, reciprocity, and body power are explanations for the social processes that form and define community, it also seems important to understand how members of a community recognize that they belong to one another. While community membership can be imposed or assigned, it also seems possible that community is a feeling or a commitment. Elizabeth Fox-Genovese describes it as a fellowship.[91]

This feeling of fellowship or commitment might be the result of social processes, but it also seems plausible that it meets individual needs as well. Here I see at least two possibilities. First, the commitment to community could meet the need of marginalized individuals to have

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[90] Susan Gabel, "Intelligence Testing as Body Ritual", in which I utilize Foucault's theory of body power to interpret consequences of intelligence testing; and "Inclusion and Issues of the Disabled Identity" *Disability Studies Quarterly* 16(1996): 13-17, in which I analyze the problems of identity in inclusive education from the Foucaultian perspective.

[91] Elizabeth Fox-Genovese, *Feminism without Illusions: A Critique of Individualism* (Chapel Hill, NC: University of North Carolina Press, 1991). In her book she lays out a case for community as something one feels, as an emotional attachment. She also constructs community at almost a spiritual level, by suggesting that it is a "fellowship," since fellowship has religious connotations. Within her theory, community is antithetical to individualism.

political or intellectual efficacy and strength. Jo Anne Pagano notes that in her life as an academic, being an "exile," working in the fringes of the academic mainstream, is a necessary experience for finding her scholarly voice.[92] Stubblefield's work on race theory echoes Pagano's observation that membership in a community of people who share experiences of marginalization has political overtones. Second, and consistent with my earlier discussion of Dewey, participation in community allows an individual to grow into a knowledge of herself. This reflects back to the knowing-doing connection, a phrase that represents Dewey's notion that action and knowledge mutually are informative.

The final concept of community I utilize in this dissertation, and one that enriches the concept of community, is to view it as the collective enactment of human ethics. For this view of community, I borrow Nel Noddings' theory of an ethic of caring.[93] Noddings defines caring as a reciprocal relationship between a carer and a cared-for, where the cared-for recognizes that caring has taken place and is able to reciprocate with caring. Noddings' ethic of caring enhances Mauss' theory of reciprocity in this respect. Both theories require reciprocation but Noddings assists in interpreting community as a place where caring occurs. When understanding community as the enactment of a caring ethic, emphasis is

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[92] Jo Anne Pagano, *Exiles and Communities: Teaching in the Patriarchal Wilderness* (Albany, NY: State University of New York Press, 1990). She argues that the status of "exile," being on the margins of academic life, has significantly contributed to her ability to be a feminist theorist. Without experiencing marginalization, Pagano argues, she would not have the opportunities to construct knowledge about marginalization.

[93] I find two of her works on caring helpful. See *Caring: A Feminine Approach to Ethics and Moral Education* (Berkeley, CA: University of California Press, 1984) and *The Challenge to Care in Schools: An Alternative Approach to Education* (New York: Teachers College Press, 1992).

placed on the commitments of community members to one another and the ways in which they meet each others' needs.

As with reciprocal relations, some individuals are not participants in caring, as Noddings defines caring. One possibility is that an individual could live and work among community members and not receive care. If community is the enactment of an ethic of caring, then an individual who does not receive care would not be a community member. Homeless people could be examples of such individuals. Another situation is the individual who receives care but does not recognize it as caring. Perhaps this is an individual who is mentally ill, who is hallucinating or delusional. If we remain consistent with Noddings' theory, we must admit that such a person would not be a member of the community because the caring relationship is not present. A final possibility is the individual who receives care, who recognizes it as caring, but who does not reciprocate, or is not allowed to reciprocate, or whose reciprocation is not recognized by the carer. This, too, seems plausible, and examples related to disability are illuminating here.

Consider an adult with mental retardation who cannot speak and who does not have control of his limbs and hands. This young man's only form of communication is through eye contact and some blinking in response to questions asked of him. We will assume he recognizes caring when others give it to him. He understands that when his mother feeds him she is caring for him. He also understands this when she gently massages his leg cramps away. The very fact that she is meeting his physical needs now that he is a full grown man could be viewed as a caring act. His mother is aware of his recognition of her caring because she sees something change in his eyes when she is caring for him. They sparkle. He appears more alert. His vocalizations are of a different quality when she is caring. She intuitively knows that her son recognizes her caring. In fact, the sounds he makes and the way he looks at her feel caring to her. They feel as though he is returning her love. To an outsider, he is communicating nothing. The outsider cannot perceive the sparkle in his eyes, nor can the outsider hear the difference in vocalizations when he is receiving a massage. Yet the two of them, a mother and son, a family community, recognize caring in their relationship.

What if this mother did not recognize her son's subtle actions as caring? What would we say about their community if she did not feel cared for by his interactions with her? Does a theory of caring hold up in a situation like this, a situation in which some people with disabilities find themselves? It seems that the answer is complex. One response might be that if we remain consistent with Noddings' theory and my application of it to conceptualizing community, then caring that is reciprocated but that goes unrecognized does not constitute a community built upon an ethic of caring. Another response, however, might be to suggest that the inability to recognize a caring response in an individual with such a significant disability does not, in the first place, constitute a caring relationship. How can someone who cares not recognize its return, even when the individual reciprocating has significant disabilities? Still another way to understand the situation is to suggest that whether or not caring is recognized by one or more members of the community, the intention of caring even without the possibility of receiving care in return is what constitutes community. This is unselfish caring, it would seem.

On the contrary, it could be selfish to not expect people to care. If a person who communicates through eye contact can be a carer, why not expect it of anyone? Why limit the pleasures of caring community to some, but not all, humans? Some of the most caring interactions can be done by almost anyone: touching, holding, looking.

As with the body and identity, community can be conceptualized in a number of ways. It can be defined by its members and the ways in which they interact through ritual and other forms of exchange. It can be understood as constructed by power. It can be interpreted as the collective enactment of human ethics. I previously stated that in this dissertation I would conceptualize community by conceptually blending it with the previous concepts in this chapter. Community, then, can be understood as a feeling of commitment to others with whom one shares lived experiences. Perceptions of shared lived experiences is a perception informed by interacting with others inside and outside the community and by living in one's body and interpreting one's experiences through that body. Such perceptions are mediated by beliefs and experiences of identity. Community members are those individuals who participate in the symbolic and physical life of the community, through ritual, through exchange, through ethical interactions. Community members are also defined by the social processes that enter the community from outside the community and that intermingle with community processes. Institutional power is an example of such a process. Since we are drawn to communities where we perceive shared lived experiences, there is a body connection in community. It is both a connection of knowing and doing. Community members share similar body experiences; therefore they share ways of understanding those experiences.

Within the context of community I can say, "I am disabled" and it communicates more than how I view my identity and my body. It is a claim about to whom I feel connected and with whom I want fellowship. It is a commitment of some degree to a community of disabled people, perhaps people with my same disability, or perhaps anyone who is disabled. These people are not necessarily individuals with whom I have daily contact but they are individuals in my thoughts and my awareness. Because my community may be geographically dispersed, my community may exist mostly in my thoughts. "I am disabled" means I believe that I experience a disabled body as do other disabled people. It means I understand how it feels to have institutional power exercised upon me in certain ways. It shows that I understand something about the ways non-disabled people view me and others like me. In a sense, it is a coming out to myself and to others. "I am disabled" is a claim about my personhood, about some things I know of myself, and about those others to whom I want to be connected. It is a claim about my body, my identity, and my community. It is a claim about an aspect of my being.

Chapter 4

An Aesthetic of Disability

In the previous chapters I analyzed four concepts central to this dissertation. In chapter two I examined ways in which disability is interpreted, each of which originates from a certain thought tradition. Each interpretation was criticized for its usefulness and problems from the perspective of people with disability. I ended chapter two indicating that a new theory of disability is needed that meets specific criteria that include, at the minimum, co-existence with other theories, usefulness to individuals and institutions, and potential for educational application. I also noted that a new theory must be non-essentialist and non-structuralist, and must be developed from the perspective of people who experience disability. Chapter three was devoted to the larger task of analyzing the body, identity, and community. As I waded through the intellectual puddles of those ideas, I formulated my own interpretation of each concept and applied each formulation to the statement, "I am disabled." In doing so, I attempted to provide multiple interpretations of that statement, making use of each conceptual tool and integrating the concepts as much as possible. My conceptualizations of these last three tools and the ways in which disability can be understood from those perspectives will become important in this chapter.

While I developed the body, identity, and community to a point where I could interpret them for the reader and for myself, I ended my analysis of disability without such a development. Instead, I made claims about what is needed in a new theory of disability. This chapter returns us to disability theory but only after I piece together a way of understanding aesthetics that is applicable to disability and other experiences of the body. For the moment, let us accept that aesthetics is the appreciation of meaning in art, and that art is an object that produces a meaningful experience. I realize the circular sound to these simplistic definitions, but for now, they will suffice. Later, a more sophisticated and useful understanding of aesthetics will emerge. This chapter, then, is my response to the problems of current conceptualizations of disability. It is my attempt to map out a new way of understanding disability that meets the criteria mentioned above. It is the synthesis of everything that came before, a way of putting together the pieces of the conceptual puzzle of disability, as I have spread those pieces on the table.

In this chapter, I review and briefly critique three influences on my understanding of aesthetic theory. I then construct a way of interpreting aesthetics that is useful for educational research. By this I mean that, in its traditional form, aesthetics seems less relevant to educational theory and practice but by reconceptualizing it, or rather, by conceptualizing it as do certain scholars, aesthetics can be a useful tool for analysis, including interpretive analysis. I close this chapter with my proposal for a theory of an aesthetic of disability. This theory will be examined for its implications for education and educational research in the final chapter.

Traditional Aesthetics

Monroe Beardsley well represents the perspective of the traditionalist in aesthetic criticism.[94] Here I use traditionalism to refer to a

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[94] Monroe Beardsley, *Aesthetics: Problems in the Philosophy of Criticism* (Indianapolis, IN: Hackett Publishing Company, Inc., 1958/81) is his seminal work in aesthetics.

brand of aesthetics that holds conservative views about the nature of art and aesthetic value, or the importance of the work of art.[95] Beardsley, for example, writes that art is an

> arrangement of conditions intended to be capable of affording an experience with marked aesthetic character...an object (loosely speaking) in the fashioning of which the intention is to enable it to satisfy the aesthetic interest played a significant causal part (p. ixi).

Art, for Beardsley, is intentionally produced to elicit a certain kind of experience with a specific character: an aesthetic character. Within this mode of thought, an artwork is a perceptual object, a thing that can be experienced through the human senses. It has aesthetic qualities that can be objectively defined, or "that can be named and talked about that characteristics can be attributed to" (p. 17). Art by itself, though, is not aesthetic. The aesthetic affirmation of art occurs when someone tries to understand a work of art.[96] The questions in aesthetics, according to Beardsley, are about what is true about art, or "what reason is there to believe that it is true" (p. 8)? Art, a work of art, is an aesthetic object when it

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[95] Peggy Zeglin Brand , in "Revising the Aesthetic-Non-Aesthetic Distinction: The Aesthetic Value of Activist Art," in *Feminism and Tradition in Aesthetics*, eds. Peggy Brand and Carolyn Korsmeyer (University Park, PA: Pennsylvania State University Press, 1995): 265-289, agrees that Beardsley is a traditionalist as I use the term. She notes that Beardsley adheres to several traditional notions about aesthetics. First, he assumes an aesthetic/non-aesthetic distinction. Second, he argues that there is an objectively described "aesthetic character" to an experience with art. Third, he adheres to the primacy of aesthetic value. By this she means that he believes in the importance of aesthetic value over emotional or political or psychological values of art. Finally, his evaluation of aesthetic value is traditionalist in that only the aesthetician can judge aesthetic value. Or, only the observer of art who uses the criteria established by the aesthetician can evaluate art.

[96] Here, Beardsley distinguishes himself from other traditionalists, who argue that aesthetic criticism includes attempts to understand the creative process itself. Beardsley, though, disagrees with that view. He argues that there is a difference between a work of art and the artist's intentions, thereby making the two distinct things that do not give evidence of each other. For Beardsley, aesthetics is criticism of a completed work.

is distinguishable from "other perceptual objects...by [its] own characteristics" (p. 63). This, then, is an objective definition for Beardsley, and is sufficient for understanding the nature of an aesthetic object, or an object that perceptually presents itself to humans and that can be evaluated for its artistic worth.

The aesthetic object itself, which for Beardsley is a work of art with objective characteristics, can have aesthetic value. In fact, in order to be art there must be some aesthetic value, if Beardsley's theory of aesthetics is utilized. The art must be beautiful to the critic and its beauty must be objectively supported, or it must have some intrinsic value or meaning independent from a relationship to any other object (including humans), in order to have aesthetic value. Saying that a work of art is "good" is really making a claim about its aesthetic value, according to Beardsley, but it is essentially saying that, regardless of how the work is related to anything else in the world, it has some kind of inherent worth, whether that worth be in its beauty, its form, or some other meaning. Beardsley admits the possibility that aesthetic value might be subjective but he classifies it as objective by comparing it to psychological or emotional values that could be attached to art, where the value of the work is in its relation to a human being who utters a statement about it. For Beardsley, any relational value is a subjective value and is a lower value than are objective ones.

In his development of the notion of aesthetic value, Beardsley makes a claim that will later prove to be closely connected to a theory of aesthetics that intimately informs my dissertation research. He writes, "The capacity of an object to evoke an aesthetic experience is not, properly speaking, a value unless the experience itself has value" (p. 557).

Experiences of value, then, are the effects of the aesthetic object on humans who perceive and evaluate them. In the simplistic sense in which I introduced aesthetics, as the appreciation of meaning in art, Beardsley would both agree and disagree. To him aesthetics is, indeed, the determination of meaning in art, but it is not the interpretive enterprise that I have implied. It is more objective than interpretation tends to be. As for my overly simplistic claim that art is something that produces meaningful experience, Beardsley would again hedge. He might agree that meaningful experience constitutes aesthetic value, but he would disagree about whether everything that produces meaningful experience can be said to be art. He would likely argue that art is one object of many that, when interacting with humans, produces meaningful experiences, though he would disagree that anything could be called art the value of which is defined in relation to humans.

Art, for Beardsley and fellow traditionalists, is defined by those philosophers of criticism whose training and role it is to validate and evaluate art. In this sense, Beardsley's accounting of aesthetics is most useful for its intellectual categories (e.g. aesthetic object, aesthetic value). These cognitive tools make it possible to use the vocabulary and ideas of aesthetic criticism and apply it to disability. A traditional view of aesthetics, though, is too dependent upon objective truth and formal definitions of art. It is helpful for the art critic but not very applicable to education or to disability. It is an essentialist proposition, an activity that requires the assumption that there is something basically artful about certain intentionally produced objects. To be art, an object must have certain characteristics, as defined by the aesthetician. To hold aesthetic value, the object must produce certain types of experiences, again as defined by the philosopher.

Aesthetic and Experience

I intentionally chose to begin this chapter with a traditionalist perspective on aesthetics because it sets the stage for a remarkable contrast with the next scholar's theory of aesthetics. The scholar is John Dewey and the work is *Experience and Nature*, in which he lays out a theory of experience and an aesthetic of experience.[97] He notes that "the things which a man experiences come to him clothed with meanings which originated in custom and tradition" (p. 26). These events are historical, temporal, and even spatial. They are events in nature. Further, he claims that "respect for experience is respect for its possibilities in thought and knowledge as well as an enforced attention to its joys and sorrows" (p. 39). Experience is a method of analysis for Dewey a way of understanding something from the inside. It is particular to an individual. It is an episode, an event captured in one moment but that is never fully completed nor fully realized.

Dewey implies that our humanness comes from the artful meaning of experience. This, then, is the foundation of his theory of experience and aesthetics. Whereas Beardsley views art as a perceptual object that could be classified into an objective category named "art," Dewey views art as meaningful experience. When humans view an aesthetic object, in Dewey's theory, they are giving meaning to an experience of something "immediately enjoyed and suffered" (p. 87).

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[97] John Dewey, *Experience and Nature* (Chicago: Open Court Publishing Company, 1926).

While Beardsley's aesthetics places the aesthetic object in a passive role of being assessed, Dewey implies that the object is the experience itself, if the experience has meaning to the one having the experience. In this sense, the object (art) and the subject (person appreciating art) are joined. Object and subject become one.

Aesthetic experiences, for Dewey, do not only occur at a moment in time. They are pursuits. They are ends-in-view, aims, "things viewed after deliberation as worthy of attainment and as evocative of effort" (p. 104). In Dewey's model, aesthetic experiences are not necessarily the result of viewing fine art, as they are in traditionalist frameworks. Rather, they are any experience to which a human assigns meaning. Therefore, aesthetic objects are not necessarily objects of fine art. They may be useful arts, such as cars, or buildings, or tools. Aesthetic objects are defined as such from the perspective of the one experiencing them and Dewey is careful to iterate several times that meaningful experiences are both joyful and sorrowful.

Art is practice in this theory of experience. It is

> the doings and sufferings that form experience ... a union of the precarious, novel, irregular with the settled, assured and uniform--a union which also defines the artistic and the esthetic (p. 358).

Human activity is a purposeful search for meaning and when meaning is achieved, art is formed. In the end, even ideas are a work of art, a conscious act of producing meaning.[98] Dewey's theory of experience holds that the

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[98] Dewey is clear about ideas being works of art. See p. 371 and 378. Cognition produces art.

> distinguishing feature of conscious experience is that in it the instrumental and the final meanings that are signs and clews [sic] and meanings that are immediately possessed, suffered, and enjoyed, come together in one (p. 359).

This, then, is art and its value can only be determined by the one who produces it, who has the artful experience.

Dewey's work is helpful because it produces a general theory of experience that can be applied to many particular experiences. It is the foundation upon which my own theory of an aesthetic of disability is constructed. It implicitly accepts that one's specific influences affect one's knowledge but it does not strongly enough pursue the likelihood of perspectival knowledge, or knowing that comes from having a certain perspective. The next section introduces a strand of aesthetics in which perspectives on experience are essential.

Feminist Themes in Aesthetics

Two feminist philosophers develop relevant arguments about aesthetics that enhance what Dewey has constructed. First, Mary Devereaux reconstructs a familiar argument about power when she borrows Foucault's notion of the gaze and applies it to tradition in aesthetic criticism to illustrate the gendered way in which aesthetics is typically conducted.[99] She notes that the gaze is male gendered because

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[99] Mary Devereaux, "Oppressive Texts, Resisting Readers, and the Gendered Spectator: The 'New' Aesthetics," in *Feminism and Tradition in Aesthetics*, eds. Brand and Korsmeyer: 121-141. Devereaux constructs a Foucaultian account of traditional aesthetics and argues that it can be resisted by the female aesthetician. She writes, "At the heart of recent feminist theorizing about art is the claim that various forms of representation--painting, photography--assume a male gaze. The notion of the gaze has both a literal and a figurative component. Narrowly construed, it refers to actual looking. Broadly, or more metaphorically, it refers to a way of thinking about, and acting in, the world" (p. 123). She continues by using gaze as a metaphor, as does Foucault, to critique tradition in aesthetics and to argue for resistance to that tradition.

aesthetics, and scholarship in general, is male dominated. She further argues, though, that "...no vision, not even artistic vision, is neutral vision," and that "all seeing is a 'way of seeing'" (p. 121). Art, and every other object of analysis, is political and ideological. Devereaux's argument is related to one developed by Peggy Zeglin Brand, who writes that the aesthetic values to which we adhere are the result of the political and ideological tradition in which we are immersed.[100] She argues against Beardsley's placement of aesthetic value as distinct from and above cognitive, moral, political, or other values. In effect, she argues against the traditionalists' subjective/objective distinction when she writes that:

> we must become accustomed to relying upon more than one single monolithic sense of "aesthetic" as established by the tradition. If a feminist sense of aesthetic value emerges as well as a black sense as well as a Native American sense, then so be it (p. 268).

If Brand can be believed, then we must also add that there can be a disabled sense of aesthetic value. In the end, argues Brand, art must be evaluated and aesthetic notions must develop from the context in which the art is produced. While Devereaux makes a Foucaultian case within a feminist framework, Brand applies standpoint epistemology to aesthetics and aesthetic criticism.

Aesthetics is a tiny field of inquiry within philosophy and is even less often pursued in other disciplines. Therefore it should be no surprise that it is difficult to find much feminist literature on the topic.[101] Although I

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[100] Brand, "Revising the Aesthetic-Non-Aesthetic Distinction," *Feminism and Tradition*: 265-289.

[101] Two texts on the topic are available in the Michigan State University libraries. I use one of them in this dissertation.

was not able to locate feminist scholarship addressing multiple aesthetic themes relevant to my dissertation, I believe that there are other themes in feminist theory that are applicable to aesthetics and my theory of disability. I mention two possibilities. The first is an epistemological claim that subjective experiences result in certain ways of knowing that emerge within the context of experience. This is the standpoint epistemologist position, or the perspective that holds that humans construct knowledge from their particular experiences in the world. For disabled people, ways of knowing are uniquely "disabled ways." They are also gendered and racial ways. They could even be ways informed by religion or philosophy. Yet, using this theory and remembering standpoint epistemology, a disabled person will understand and interpret his world from his perspective as a disabled person and in combination with his other ways of knowing.

For example, think about the young man described in chapter three who has cerebral palsy and whose mother cares for him. She massages his limbs when they spasm. She feeds him. She sometimes rocks and sings to him. He particularly likes it when she does this because so few people touch him. In fact, only his mother, his doctor, and his physical therapist touch him. Of those three individuals, only his mother touches him in loving ways. And his mother is the only person who ever sings to him. He suspects it is because whenever there is music, he sings along, but his singing just sounds like guttural noises to other people. They do not appear to recognize his noises as singing. Or, if they recognize him as singing, they do not seem to appreciate it. His mother seems to be the only person who understands that the noises he makes when she sings or plays the radio are his way of singing. Through his unique experiences of touch and song from another human being, this young man has learned many things about himself. He has ways of knowing. He knows that there is one person in the world who appears to understand and appreciate him and his interactions. He experiences singing in the back of his throat, with lots of lip and jaw movements he cannot control or that he tries to control. There is much salivating when he sings and he spits. His mother often tucks a towel in the neck of his shirt when they sing. That way, he does not have to change his shirt afterwards. Singing, though, is a most pleasant thing to do and music takes him out of his body and makes him feel like flying. He closes his eyes when he sings, partly because it helps him concentrate on the movements he makes to sing and partly because it helps him make the visual images that go with the music. This young man experiences singing in a certain way, as noises and movements that are different than those made by others who sing, and as extremely wet. He enjoys the activity, as do many people, but he enjoys it in his own way. He experiences his body and the song as only he can experience them. He has a way of knowing music that is interpreted through his body when he joins his mother in song.

This example and the claim that standpoint epistemology is relevant to aesthetics are related to the Deweyan notion that action and thought inform each other, that knowing and doing are connected. It is clearly related to standpoint epistemology, the theory claiming that experiences and knowledges are best understood from the perspective of the one having a certain experience. Yet it is slightly different than standpoint theories in that a Deweyan "way of knowing" is directly related to experiences of the individual in and through her body. Whereas standpoint theorists would tend to generalize to all women, Deweyan experience theory would find it difficult to use such a large unit of analysis. Feminist theory, though, informs aesthetics if we think of the meaning given to art as a way of constructing knowledge from a certain subjective perspective.

The second possibility for applying feminist themes to aesthetics is if we remember Paula Cooey, whose work on the body was highlighted in chapter three.[102] Cooey argues that the body is both the site of and the result of the human imagination. Again, an example can be useful to elaborate on her theory of the body. Here I again use my daughter, Tiffany, as an example. I earlier explained that during her life, Tiffany refused to call herself disabled. She did not think negatively about disability, she merely did not view herself as disabled. She agreed that she had some conditions that she found rather bothersome. She did not enjoy hospitals and doctors and therapies. She did, however, completely resist the notion that her physical or mental conditions made her disabled. At the time I did not realize that Tiffany was enacting what Cooey identifies as the body that is the site of and the result of the imagination. Her life was, however, evidence of powerful imagination. Tiffany had a distinct body image, a view of her physical body, that included her wheelchair as part of her body. She lived in her wheelchair as though she were born with it. She sometimes wanted out of it, to sit near her grandmother, or to get into a position her chair would not allow, but she knew the value of her chair to her freedom to move and make decisions and be in control of her life. In effect, she exercised her imagination to make the chair part of her body. Her body, including her chair, was the result of her imagination. With her imagination

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[102] Cooey, *Religious Imagination and the Body* (1994).

focused on her body and the ways in which the chair was integral to her body, she used her body as the site of her imagination. In living in her chair and imagining it as part of her body, Tiffany was experiencing ways of knowing that people who do not use wheelchairs can never understand. She had a knowledge of life in a chair, of moving about her world with that chair, of the contours and squeaks and creaks of that chair, and that knowledge contributed to the ways in which she viewed her self as a non-disabled person, even though it seems unlikely that a full time wheelchair user would view herself as non-disabled. I cannot imagine life in a chair nor can I imagine experiencing a wheelchair as part of my body. I am not able to do so because I do not live in a wheelchair, therefore I have no experience from which to construct that knowledge of myself. As an outsider to life in a wheelchair, I can appreciate Tiffany's way of knowing life with a wheelchaired body but I cannot appreciate how that might feel for me. I only have partial imaginative capabilities in that sense.

Imagination, then, is key to an understanding of experience, the body, and aesthetics. In the next section, imagination becomes important to disability as I develop a theory of an aesthetic of disability.

An Aesthetic of Disability

If imaginative activity and its products are useful at all in scholarly pursuits, it seems that aesthetics is a good place to start. Aesthetics implies an analysis of some type of art and art suggests creativity. Imagination, then, is first related to aesthetics in the creative force that drive both art and imagination. Finally, imagination generates the aesthetic object, which is the human body. The object, then, is the body, and the body is lived experiences. This brings us back to Dewey, for whom experience is art.

If experience is art and the body is lived experiences, then aesthetics is the meaning constructed through lived experiences. As I argued in chapter three, these meanings include the ways in which we understand identity and community but they are most importantly body meanings. Experience becomes art when the individual is attuned to what is happening with her body, when she acknowledges the struggles and joys that constitute her life, and when she uses her imagination or her creative forces to make sense of those experiences. When meaning is given to experience, an aesthetic moment has occurred and an individual, or something about that individual, is appreciated in some way. Burying a son or daughter, an accident resulting in injury, the anticipation of waiting for one's first electric wheelchair, being enveloped in the arms of one's spouse, all become opportunities for an aesthetic experience or possibilities of making meaning out of life. Sometimes the meanings are tragic, as when a parent loses a child. And sometimes the meanings are joyful or climactic. If meaning is present, though, the experience is an aesthetic one and artful meaning is given to life.

A theory of an aesthetic of disability adheres to the centrality of the body and the importance and relatedness of identity and community to the body. The body is understood as a fluid construct, as a medium through which experiences are interpreted. The body is a living, breathing object but it is also a conception, an imagined and imaginative subject. We metaphorically write upon the body the meanings we give to it and to ourselves. We interpret ourselves to ourselves and others through and with the body. We share bodies. In a caring community, bodies are naturally shared because it is in the sharing of bodies that caring is an observable phenomenon. Significantly disabled people are fed, clothed, given medication, or assisted in the bathroom. In turn, disabled people give affection and admiration to their loved ones, or their community members. They contribute to the chores of community life. They add to the joys of community life. They tell jokes and laugh at the jokes told by others. For example, the only joke Tiffany ever told was one that she composed herself. The first day she told the joke we were all stunned and delighted. She said, "Knock, knock." We responded, "Who's there?" She said, "Ants." By now we were quite curious, never having heard this joke before. We asked, "Ants who?" Then she laughed so hard she could hardly finish, "Ants in your pants!" Tiffany thoroughly enjoyed our reaction and continued to tell that joke to anyone who would listen in her remaining years. Our family still tells that joke and we always laugh at it, less so because it is funny and more so because it is a symbol of Tiffany's caring efforts to humor us. This said, in spite of her deep emotional connection to her family and her school communities, and in the face of years of special education placements, Tiffany continued to use her resistant gaze to declare who she was as an individual within her social groups. She intuitively knew the need for balance between knowledge and perceptions of the self and the community. She practiced the sharing of her body in her care giving and care receiving yet she always understood the boundaries between her self and others.

The language we use to describe our bodies and the sharing of our bodies includes the vocabularies of identity and community. Identity falls into the class of concepts I label as body concepts. Identity is the meanings given to the ways in which we perceive ourselves as similar and different from others within or related to the culture in which we live. Identity is a political marker but it is also a social symbol. It signifies connections with and separations from others like or unlike us, as we perceive the self and the other. While body identity is influenced by others and can be intellectually shared by individuals who similarly perceive themselves, it is necessarily one's own. Community, too, can be placed within the class of body concepts and feels like a natural complement to identity. It is a concept necessarily related to connectedness with others, a feeling of commitment and a process of social exchanges. I have previously defined community as collective ethical action. Within community the body alone becomes the body shared with others.

An aesthetic of disability holds that the statement "I am disabled" is the result of a pursuit of the self, that it is, in Dewey's words, something known "after deliberation as worthy of attainment and as evocative of effort" (p. 104). More than a pursuit of the self, the statement is an account of the self, a way of claiming that one's "doings and sufferings" have formed one's self, so that "I am disabled" is an accurate claim, from one's own perspective.

When interpreted as an aesthetic pursuit, it matters less whether disability is a personal deficit or socially constructed. It can be both. It matters more whether the individual. has made the claim without coercion, or with as little coercion as possible. In other words, when viewing disability as an aesthetic, as an appreciation of the self, it makes little sense to identify someone else as disabled. That is not possible within this framework, nor is it useful. It is not possible because disability, as an aesthetic, is understood as one's own meanings given to one's own lived experiences. It is not useful because we must each decide for ourselves who we are and the meaning that can be created from our lives. We must be as free as possible to choose our identities and our communities.

Although others and their ideas about us inform our self knowledge, what we do and know about ourselves, in the end, is uniquely our own knowledge.

Interpreting disability as having aesthetic meaning allows for the probability that it can be an experience of some individuals while accepting that it can be appreciated by those who do not have disability. Put another way, an individual who does not have a disability, by his or anyone else's standards, can still use imagination to appreciate experiences of disability and to imagine life with disability. Sometimes an individual with one disability attempts to imagine and appreciate life with an entirely different kind of disability that affects the body in different ways. Just as the artist and the art lover differently appreciate a work of art, disabled and non-disabled people can differently appreciate disability. Or, people with different experiences of disability can appreciate those experiences they do not share. Whether or not disability is the experience of a minority group, and whether or not that group experiences something in common, such as oppression or discrimination, an aesthetic of disability invites open discourse between people with and without disability in the hope that many people without disability will come to understand and appreciate it.

This aesthetic of disability recognizes the flow of power through society but rejects it as informative of the self, or at least rejects it as the primary informant of the self. In rejecting power as informing the self and in claiming that individuals must be as free as possible to choose their own identities and communities, an aesthetic of disability is not a naive theory, rather it is a theory of resistance. It remains sturdy and uncooperative in the face of exercises of power. It insists that choice and respect are critical in knowing the self: choice because who one is becoming cannot be completely understood from outside one's body or outside one's lived experiences, and respect because those who cannot thoroughly know another must allow an individual to know himself. An aesthetic of disability faces the forceful gaze of the other with opposition, even defiance.[103] It looks directly in the eye of power and refuses to submit to power's conceptions of a self if in doing so the self is acting honestly, and even when that refusal is only possible in a private way within the self.

As a theory of resistance, an aesthetic of disability necessarily values the experiences and perspectives of people with disability. In an aesthetic, resistance comes from the perspective that is most valued within this framework. It is the insider's perspective. An aesthetic of disability resists the imposition of the outsider's view on the insider even while it recognizes the probability that insider views, as well as outsider views, are socially constructed and influenced by body power. Resistance in an aesthetic of disability can be understood from several angles. From one angle, resistance comes from the individual who, although influenced by the beliefs of others, finds something within herself that rejects the body or identity beliefs of others when those beliefs are imposed upon her. My description in chapter three, of Tiffany and her self-knowledge, is an example of this type of resistance. It is a resistance that presents itself even in the face of strong evidence to the contrary, and when that evidence comes from something as intimate as one's own body or one's own significant others. Resistance can also be understood from the perspective

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[103] Here I use other to symbolize any individual or institution that might attempt to dictate disabledness to someone. In this sense, the other could be education, or medicine, or psychiatry. It could also be parents or doctors our spouses or even one's culture as it metaphorically fixes its gaze upon the body of a person perceived as disabled.

of community. We can anticipate some resistance to community pressure by some individuals. The example of passing used in chapter three is relevant here. While the disability community might be critical of individuals who pass for non-disabled, it seems plausible that some individuals are not passing but merely do not feel disabled, or do not choose disabled-ness for ethical reasons.

An aesthetic of disability does, in fact, have an ethic. It is not a license to pick and choose disabled-ness or abled-ness from one moment to the next to serve superficial purposes. It would not support an individual presenting himself as disabled to an institution to gain social welfare benefits for the disabled and then denying a disabled identity to his friends. If he believes himself to be disabled but sometimes pretends to be non-disabled he is, in fact, passing, and is acting unethically. An aesthetic requires individuals to live honestly and to behave ethically. It expects openness whether or not one views one's self as disabled. While the aesthetic supports freedom of choice, it also recognizes the responsibilities that come with freedoms. Within the aesthetic, the responsibility is to be honest to the true self, as the self interprets that truth, and to present that self to others whenever possible or necessary.

The aesthetic also holds the community to an ethic. Here, the ethic is to avoid coercion whenever possible and to be supportive of individuals' choices related to their selves. Because an aesthetic is necessarily one's own view of the self, the community should recognize the power it holds and should do anything possible to protect the freedom of its members to choose the disabled identity. Within this ethic, it would be inappropriate to out someone whom the community views as passing because it can never be completely clear to the community whether an individual views herself as disabled or not. Coming out is, by its very definition, an individual act, a presentation of the self to the self and others. The community cannot present a self. Only the self can do this. While the community is ethically bound to protect individuals from as much coercion as possible, the community is also responsible for creating a safe environment in which individuals can flourish and with which individuals can live honestly and openly. Safety, then, is an important ethical consideration for the community, and is a key characteristic of communities in which individuals feel comfortable living honestly, whether they are disabled or abled individuals.

Within an aesthetic of disability a community is understood as collective ethical action, or as a caring community within which reciprocity is expected of all community members. This expectation is not viewed coercively, however. Rather, giving and receiving care is considered a basic human need, even a human right. Therefore, disabled people, even significantly disabled people who are typically not expected to give care to others, are supported in being care givers. The community intentionally seeks ways in which all members are care givers as well as care receivers. Carried further, caring relationships are not only human needs or rights. Caring is a responsibility entrusted to members of a community.

An aesthetic of disability is a contextualized and particularized theory. In this sense, then, disability could be viewed in multiple ways because just as all people do not share the same lived experiences, disabled people also differently experiences themselves. One person with schizophrenia may desperately hope for a cure while another finds her unique perceptions curious and pleasant. One paralyzed individual may wish to walk again while another enjoys his skills as a wheelchair athlete and would not choose to walk if he could. One youngster with mental retardation may feel anguish over her feelings of incompetence while another could find focused pleasure in her caring relationships with family and friends.

This theory recognizes the social influences that produce perceptions of self while at the same time strongly urges the individual to know herself and choose or reject the disabled identity on the basis of the meaning of her life and experiences and whether or not she views herself as a disabled person. An aesthetic of disability attempts to strike a balance between knowledge of the self as an individual and knowledge of the self in fellowship with others in one's communities. The aesthetic recognizes the difficulty in striking this balance because group life tugs at humans and we feel drawn to sharing perceptions with those with whom we feel connected. It accepts the inevitability of tension between self and other, particularly when the other wields power.

If I hold an aesthetic view of disability and say, "I am disabled," I am making claims about my own aesthetic value as I interpret it. Within an aesthetic of disability, I appreciate the meaning of my life through the struggle to know my self. That struggle, that pursuit of the aesthetic moment, the goal of appreciation of my body as a disabled body, is the content of the art I am producing. As such, when I say, "I am disabled," I am indicating that my experiences hold particular meaning for me and that the concept of "disability," a concept that refers to experiences of my body that contribute to the meanings I construct of my self and my community, accurately symbolizes those meanings, or some of those meanings. I may use other words to represent concepts that describe other meanings associated with my experiences, and those, too, may have aesthetic value for me, but when I use "disabled" to describe myself, I am valuing disability and the disabled parts of me. I am saying that experiences of disability are important in the struggle to know my self and my place in my world.

As an aesthetic pursuit, disability is an integral aspect of being. It says things about how I experience and understand my body, how I interpret the bodies of others as they interact with me, and how I view myself in relationship to others. If I use this theory of an aesthetic of disability to understand my self, I do not say, "I have a disability." That would suggest that I view my disability as a superficial aspect of my being, as something of which to be ashamed, or as an experience that is not crucial in knowing my self. I would likely not agree with others who say, "She has a disability," because that would suggest that they, too, do not view my disability as an integral feature of my self, or that they, too, believe that disability is shameful. With an aesthetic of disability, if I view myself as disabled, I proudly proclaim, "I am disabled," as I also claim, "I am female" and "I am mother," and in my resistance to shame and my positive construction of my self, I want others similarly to interpret me.

If I aesthetically view my disability, I feel supported by social rituals that give attention to my disability, or that enhance me with my disability, or that celebrate my disability. I enjoy rituals that, when performed with others in community, bind us together through common experience, or experiences we interpret as being in common. I would be unlikely to participate in rituals designed to cure or fix me unless such a cure would alleviate pain and suffering that I prefer to avoid. Nor would I involve myself in treatments that alter my physical appearance or cognitive processes unless that alteration improves my ability to do something I want and need to do. I would search for a community where the rituals of disability symbolize the meanings of the disabled life, where the joys and sorrows of disability are symbolically enacted through performance, liturgy, and physical interaction.

An aesthetic of disability holds that there is no essential experience we can label as "disability." There is no objectively defined disabled identity, nor can there be a way of thoroughly explicating the disabled community. This is a theory of experience and the self and the self in relationship to others. It is an interpretation of a category of experiences we call "disability" for lack of a better term. As an interpretive theory, it necessarily holds that there is no one way of experiencing disability; rather, there are infinite experiences of disability. The self, however, is the point from which the perspective of disability must emerge if we adhere to an aesthetic view of disability. In the end, "I am disabled" can only be true if I utter it from the depth of my being, if I claim it as my own, whether I find joy or sorrow in that aspect of being. Others may attempt to assign me to the category of "disabled," but those attempts merely reflect how others view me or how I interpret others as viewing me. As a theory of experience, an aesthetic of disability is a theory of how I experience my self, how I would categorize my self, and the others with whom I prefer to fellowship. It is what I call my self, regardless of what others call me, yet it is influenced strongly by the perceptions of others. It is who I perceive my self to be and to whom I perceive my self to be related. Then, when I say, "I am disabled," my utterance is at once a self proclamation and a declaration of community. It is my coming out to the world as a disabled person, regardless of what others have said about me, or whether others have outed me. "I am disabled" is the artful appreciation of experience. It is the recognition of art in life.

Basic Premises and Clarification

For simplicity, this theory can be summarized in two statements. They are as follows.

1. "Disability" is a set of body-based experiences that can be appreciated for their meanings and contributions to the construction of the self and community.
2. "Disabled" is an interpretation of the self constructed from one's own lived experiences.

Inherent to these premises are some implicit assumptions. First, there is the assumption that "disability" is a term used to refer to multiple phenomena that present themselves to humans. People with and without "disability" can point to a phenomenon and call it "disability." The phenomenon may appear as mental retardation, sickle cell anemia, cystic fibrosis, or some form of mental illness, but as a perceived phenomenon, it is a cultural notion, a construction using the tools of social values. "Disability" is identifiable, as are race, gender, and sexual orientation, and it is at least as amorphous. Disability, as a phenomenon that appears to the senses, is an object of varied perception and opinion.

As experiences that contribute to the formation of community, disability is, again, multiple phenomena that all have one thing in common: at least some of the community members have disability, or identify themselves as disabled. Some disability communities could be comprised entirely of disabled people, as is often the case with the deaf community. Other disability communities could include abled and disabled people.

In contrast to "disability," which is more applicable to communities of people or to phenomena outsiders might interpret a certain way, "disabled," as an interpretation of the self, is necessarily one's own.

Within an aesthetic of disability, it cannot be assigned to another. Whereas "disability" is a phenomenon that can correctly or incorrectly be pointed out by one's self or another, "disabled" is an identity and community affiliation to which only the self can claim connection. This mirrors the difference between saying, "I am disabled" and "She has a disability." When I claim a disabled identity for myself, as in the second premise, I am making an ontological claim for myself. As such, it is also an epistemological claim if we are to believe Dewey. This, however, is something only I can claim. When someone says, "She is disabled" in reference to me, it must be with my consent. Without my consent, without my agreement that "I am disabled," the statement is false from my perspective. In comparison, if another says, "She has a disability," that person is making a statement about the observation of a perceived phenomenon from outside that phenomenon. That statement is not necessarily true or false. It is primarily an epistemological claim. It is a claim of knowledge about appearances of disability, just as if I said, "I have a disability." This last statement would be consistent with the first premise. I would be making a claim about the appearance of disability from my perspective or from what I believe to be the perspective of others. Nevertheless, when someone says of me, "She has a disability," it is not a claim about my identity, nor about how I experience my self. It is more a claim about how I appear to another person. In that sense, a statement of that nature is less objectionable within an aesthetic of disability than is the statement, "She is disabled," when made without my consent.

This dissertation is not an attempt to eradicate other theories of disability nor is it an attempt to claim that an aesthetic of disability is necessarily a higher theory than its counterparts. That would indicate absolutist thinking and would be inconsistent with an aesthetic of disability. This dissertation is an attempt to provide another understanding of disability that has importance and application that current theories, or rather that current applications of theories, may not have. An aesthetic of disability fleshes out experiences of disability in ways that other theories have not done. Therefore, within an aesthetic of disability, I would not claim that the aesthetic is the only way of understanding disability, although I might claim that it is a more inclusive way of understanding.

I would expect that every person, particularly every disabled person, would utilize the theory of disability that makes functional sense at a point in time and that functionally selecting theories when they make sense means that a disabled person could, throughout his lifetime, utilize all theories. By this I mean that, if a disabled person aesthetically viewed herself but chose to use medicine or another deficit-based discipline to treat a condition she wants remedied or alleviated, then an aesthetic view would appreciate her need to do that. In fact, an aesthetic view of disability would understand this choice as critical to her individual freedom. Similarly, if a disabled person disagreed with the aesthetic and viewed her disability strictly from a deficit model, that individual's freedom to choose a deficit view of herself would be consistent in an aesthetic of disability. It could even be consistent because of both premises. First, others can appreciate experiences of disability whether or not a particular individual is disabled or whether or not a disabled individual adheres to an aesthetic. Second, a disabled person who interprets her disability as a personal deficit is, in one sense, still adhering to an aesthetic of disability. She is identifying herself as disabled and she is making that distinction from the perspective of her experiences, even if her interpretation of those experiences is a deficit interpretation. This is not to suggest that her perspective is less valid than it would be if she adhered to an aesthetic. It is merely to indicate that an aesthetic of disability is as inclusive as possible, perhaps in an effort to counteract other theories of disability where disability is usually defined in terms from particular perspectives that are not necessarily the perspective of the one to whom the definition is directed. This same individual may at some time in her life join a disability rights campaign attempting to influence the funding of health benefits for disabled people. Then, she is functioning within the minority group model and is doing so for a specific purpose.

Where, you might ask, is the aesthetic in all of this? It is both in the perceptions of and meanings constructed by the outsider observing the phenomenon of disability and in the insider experiencing being disabled. For the one observing disability from the outside, an aesthetic is the appreciation of the contribution of disability to the development of the self and to our knowledge about what it means to be human. For the one experiencing disability, or the one who claims to "be disabled," the aesthetic is the intimate knowledge of the self. It is appreciation of the contribution of disability to the self and the self's interpretations of experience. For the one experiencing disability, or the one who claims to "be disabled," the aesthetic is knowledge of the self. It is the appreciation of the self as a disabled person.

Remaining Problems

While the next chapter maps out the educational applications of an aesthetic of disability, this section focuses on the problems that remain now that a theory of an aesthetic of disability has been proposed.

I see at least six dilemmas still facing disability studies and disability scholars in light of the addition of another interpretation of disability. First, there is the realization that we still cannot get away from the problem of power and its influence on people with disability. A theory of resistance, as is mine, cannot ignore the results of power. It can merely attempt to thwart them, if only in the minds of those upon whom the power is exercised. Even Paulo Freire developed a resistance theory in light of the recognition of power and its effects.[104] Yet, it must be realized that as humans we are greatly influenced by the power surrounding us and even when we do not recognize ourselves as cooperating with it, in some ways we are doing just that. So, claiming that experiencing one's self as disabled and being free to self-identify, although a resistive act, is still a response to the exercise of power by institutions and individuals in one's culture. None of the theories of disability examined in this dissertation erases power from the social landscape. All of them recognize or use it in some way. Power, then, seems to be an intractable problem for disability studies and for those of us theorizing about disability.

The second persistent problem is related to the power issue. It is the complexity of the socio-political importance of identity and community for people with disability, illustrated by the understandable tendency for identity or community activists to expect everyone who appears disabled to join forces. Two slices of the political issue can be examined. First, an aesthetic of disability might be misconstrued to be apolitical. If disability activists understand it to be lacking any political implications, then they

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[104] Paulo Freire, *Pedagogy of the Oppressed* (New York: Continuum, 1970); and *We Make the Road by Walking, Myles Horton and Paulo Freire: Conversations on Education and Social Change*, eds. Brenda Bell, John Gaventa, and John Peters (Philadelphia, PA: Temple University Press, 1990).

may be unsupportive of this view of disability. In that case, the intense need for politically useful theorizing could outweigh the need for new interpretations of experiences of disability, even though such a decision would be made on the basis of incorrect assumptions. We can, however, slice this issue a different way. If an aesthetic of disability is viewed as political, as I believe it should be, particularly in its support of resistance to beliefs about the disabled body and identity that are constructed from outside the experiences of disability, then this theory is problematic from two angles. It could result in fewer individuals choosing to identify themselves as disabled. This is possible if people with disability recognize the aesthetic's support for resistance to popular beliefs and decide to stop identifying themselves as disabled. If enough individuals make this choice, it could decrease the numbers of disabled people, thereby limiting the political strength of the disability rights movement. If, on the other hand, an aesthetic of disability supports resistance to being labelled by others and supports individual choice and the coming out process, then this theory could be perceived as supporting the civil rights of people with disability to self determination. In any case, although an aesthetic of disability might be perceived as apolitical, I do not believe it is nor do I believe it has no political function. More to the point, as a theory of resistance, an aesthetic of disability is strongly political in its support of the individual's freedom to choose to interpret the self as a disabled body with a disabled identity, and having fellowship with the disabled community.

A third problem for which I can find no solutions is the inability, at this time, of this interpretation to be applied to policy that allocates resources based on categorical membership.[105] Unlike the personal deficit model, which can appear objective and measurable and which lends itself well to policy decisions and resource allocation, an aesthetic of disability does not promote measurement or objectivity. As a theory of experience and the self in relation to others, it is necessarily particular to each individual. The process whereby a person comes to know herself as disabled is not generalizable. This is not a universal theory of human development, except in its suggestion that meanings as basic as body, identity, community, and disability are universal experiences to which we have assigned terms that construct the self. In the end, this is not the typical discourse of policy nor are these vocabularies of objectively identifiable things. In the next chapter I construct some ways in which an aesthetic of disability is applicable to educational policy, however those ways are qualitative in nature and are related to schools as communities of learners.

Still another set of problems, to which an aesthetic of disability attempts a response, is the entrenched belief that people with significant mental retardation are not capable of having a sense of the self. The logical next assumption if one adheres to the first is that individuals who cannot develop a sense of the self cannot construct meaning from experience. This claim was recently purported when a bioethicist working on national genetic testing policy claimed that adults with significant mental retardation, who might always function at the level, for example, of a three year old, would never develop a "sense of self" and therefore it

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[105] In the next chapter I address some ways in which this theory can be applicable to particular types of policy.

would be ethical to abort a fetus expected to have this level of mental retardation.[106] I do not use this example to argue for or against abortion. Rather, I use it as evidence that scholarly people who are making public policy decisions have conceptions about disabled people that may be inaccurate or are, at least, non-aesthetic.

A fifth problem is with general theorizing about disability. Or perhaps it is a problem of any theoretical work. When something is proposed to be a theory, it is suddenly perceived in absolute terms. This is understandable but to a theorist, it feels like getting stuck in quicksand. No sooner has the theorist mapped out what seems consistent and solid than a reader finds an inconsistency or points out an ideological mess. The problem is that it is impossible for any theory to be interpreted by every reader in the ways in which the author considers it. Therefore, the theorist is always standing on a precipice barely balancing at the edge of that quicksand. Theorizing is tricky business and this is an intractible problem.

The final remaining problem, and one for which I have some proposed solutions in the next chapter, is the dilemma of when and how to use an aesthetic of disability. For what ends is it functional? How can it assist us in policy decisions, and can politicalization solve problems of power in society and in schools? What are the practical consequences of a theory of an aesthetic of disability for real people in real school communities?

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[106] In using the term "significant mental retardation" I intentionally alter the bioethicist's comment. She used the term "severe mental retardation", which typically refers to people who have a measurable IQ (intelligence quotient) below 25. The reference to "severe" is often considered offensive in the disability community because it connotes a personal deficit when the disabled individual may not believe herself to be deficient. "Sense of self" was Bonnie Steinbock's exact phrase, in "NIDRR Sponsored Plenary: Variation? Discrimination? Can We Put Limits on Genetic Testing?", The Society for Disability Studies Annual Meeting, in Minneapolis, MN, May 1997.

Chapter 5

Implications for Educational Thought and Practice

In previous chapters I lay out a theory of an aesthetic of disability that utilizes conceptual tools in order to interpret disability a particular way. In this chapter, I produce an argument for the useful ends of this theory of an aesthetic. In order to develop an argument for the consequences of an aesthetic of disability, I use the two basic premises of my theory as a heuristic tool by applying these premises to the first three categories mentioned above. Later I will explain how I approach implications for educational research. In my application, I imagine ways in which these categories might be transformed by an aesthetic of disability. To review, the two premises of my theory are as follows:

> 1. "Disability" is a set of body-based experiences that can be appreciated for their meanings and contributions to the construction of the self and community.
>
> 2. "Disabled" is an interpretation of the self constructed from one's own lived experiences.

In my clarification of these premises, I make an explicit distinction between the multiple phenomena any of us might perceive as "disability" and the actual experiences of disability that signify a person who is "disabled."[107] Disability, then, is a view from both inside and outside of the experience. Statements can be made about disability, regardless of whether or not the

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[107] For the remainder of this dissertation, I will not set these terms in quotes but my use of them will connote this distinction.

individual uttering the statements experiences disability. If one is disabled, however, the view is from within the experience. Statements ascribing it to another can only be made from the outside of the experiences of the individual to whom the statements refer. This necessarily makes the statements outsider interpretations. With this in mind, I now turn to four broad issues for which there are potential applications of my theory: educational policy, teacher education, curriculum and pedagogy, and educational research.

Educational Policy

As previously stated, an aesthetic of disability is difficult to apply to many problems in educational policy. This is especially true for policies that allocate resources based on categorical numbers. Special education is an example of a program for which funds are allocated, at least in part, by numbers of students assigned to specific categories of disability. To support such a funding system and to make allocation decisions fairly, policy usually requires objective measurements to determine eligibility for programs and resources. In chapter two I briefly described some problems with current ways of identifying students with disability because they depend upon what appears to be objective science.[108] If one believes that the science of psychometrics and other forms of measurement used in educational policies that identify students with disability is a social act generated from cultural values about disability and normalcy, then special education eligibility policies are questionable on the grounds that they

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[108] In schooling, this science often involves psychometrics, or the measurement of mental activity. It is utilized in intelligence testing. Intelligence test results are required for eligibility for most special education services. Stephen Jay Gould's claim in *The Mismeasure of Man* is an argument that science is "a socially embedded activity" that does not necessarily produce "absolute truth."

cannot objectively allocate resources. Regardless of what one believes about the science of measurement and its objectivity, quite a bit of research has been done on the subjective ways in which special education eligibility is determined across the United States. Much of the research indicates that special education eligibility is often assigned by race, gender, ethnicity, and class.[109] If these studies are to be believed, then they pose serious questions about the basic nature of special education as an institution and disability as an educational diagnosis. Thomas Skrtic has an intriguing perspective on the nature of disability as an educational category that is relevant to the problems of race and class in special education eligibility:

> Student disability is neither a human pathology nor an objective distinction; it is an organizational pathology, a matter of not fitting the standard programs of the prevailing paradigm of a professional culture, the legitimacy of which is maintained and reinforced by the objectification of school failure as student disability through the institutional practice of special education (p. 178-179).[110]

For Skrtic, then, disability is actually a label attached to a person that results from the failure of schools to meet the needs of students. In one sense, this is a specific account of the social construction of disability and

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[109] Some of the most powerful arguments related to this problem come from within the field of learning disabilities. Critics of that field have argued that it appears to be a more comfortable special education category for many parents and teachers than is the category of mental retardation. Therefore, political pressure is exerted on schools to label students learning disabled if a label is applied at all. To further complicate this problem, the label of learning disabled is by far the most commonly used special education label. See Christine Sleeter, "Learning Disabilities: The Social Construction of a Special Education Category," *Exceptional Children* 53(1986): 46-54; Gerald Sent, "Learning Disabilities as Sociologic Sponge: Wiping up Life's Spills," *Research in Learning Disabilities: Issues and Future Directions*, ed. S. Vaughn and C. Bos (Boston, MA: College-Hill Publications, 1988): 87-101; and Kenneth Kavale and Steven Forness, "Learning Disability and the History of Science: Paradigm or Paradox?" *Remedial and Special Education* 6(1985): 12-23.

[110] *Behind Special Education.*

against the objectivity of scientific methods for identifying disability. In chapter two I summarized the results of an empirical study by Mehan, et al., in which they reached conclusions similar to Skrtic's.[111] In conclusion, this first problem for policy is an ideological one because it poses questions about the nature of science, the nature of educational institutions, and the beliefs that serve as their foundations.

On the other hand I can differently pose this policy problem as it relates to the nature of science and social institutions by using Foucault's metaphor of the gaze. In chapter three I summarized Foucault's gaze as his metaphor for the ways in which social and institutional power is exercised upon the bodies of individuals. This way of viewing policy, as an instrument of power, suggests that policies that force people to be called disabled are instruments of social control. This places an even greater emphasis on the risks to individual freedom inherent to educational policy related to disability.

Whether or not arguments against the objectivity of the sciences and their applications used for eligibility are credible, and whether or not understanding special education as an institution that exerts social control over the lives of students is persuasive, if disability can be viewed as an aesthetic, then policies that label people as disabled are still problematic. This claim stems from applying the second premise of to policy. That premise holds that the label "disabled" is an interpretation of the self developed by constructing meaning from one's own lived experiences. Unlike disability, which I have stated is any number of experiences that can

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[111] *Handicapping the Handicapped.*

give meaning to the self and community, to any self or community, or to the human condition in general, disabled is a self-revelation. The realization, "I am disabled," requires me to come out, even though my coming out is informed by the beliefs others have about me. Whereas disability, or the experiences commonly believed to be disability, can be perceived and appreciated by people inside and outside those experiences, disabled is something I must claim for my self. It is a knowledge of the self that comes from within experiences of disability.

If educational policies were constructed from this perspective, policy would not be supportive of the fundamental practice in special education of evaluating students to determine if they are eligible for special education. More specifically, it is the practice in its current state that is the problem. The problem is theoretical and practical. On the practical side, special education eligibility decisions are often misused and can result from systemic pathologies rather than individual deficits, as was cited earlier in this section. Theoretically, an aesthetic of disability requires self-identification and insider appreciation of experiences of the self. It does not anticipate treating disability as a disease or as something that needs to be corrected, particularly in an educational setting. If, on the other hand, an individual who says, "I am disabled" requests educational support to experience success in school, then an aesthetic of disability would hold that the student should have support, although that support might not have the characteristics of special education as we know it today. Viewing disability as an aesthetic emphasizes phenomena of disability as ways of knowing and being as are other ways of knowing and being, as are racial or gendered or sexual ways. It adheres to the belief that we come to know ourselves through experience with the self and others and that knowing the self and proclaiming that self to others is a crucial process in constructing the human. An aesthetic of disability would never dehumanize students by identifying them as disabled unless they first self-identify.

At this time, I cannot extend my theory to the concrete consequences for policy analysis; however I can think of some questions and basic ideas that policy analysts using the aesthetic could consider about policy in order to be consistent with this view of disability. First, analysts could ask whether or not the policy in question supports an educational environment free from as much coercion as possible. By this I mean that school should be a place where children have experiences that allow them to grow into a knowledge of their selves and their communities. For policy to support this endeavor, it must use as little force as possible upon the body of the child. It must avoid assigning labels to children and find other ways of funding support systems for children who need help. Policy should avoid the segregation of children based on disability characteristics and should find ways of meeting students' needs that allow them to remain fully participating members of the school community.

Although my rationale for making these claims is novel, claims against special education as it is practiced today are not new.[112] Policy

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[112] Two current critics of special education from within the field include Thomas Skrtic, *Behind Special Education* and *Disability and Democracy: Reconstructing Special Education for Postmodernity*, ed. Thomas Skrtic (New York: Teachers College Press, 1995); and Douglas Biklen, who was a critic of special education during the early years of mandated special education, "Let Our Children Go" (Syracuse, NY: Human Policy Press, 1974), in which he argued that the structure of service systems actually discriminates against disabled people. Biklen still critiques the field. See, "Handicapism" with Robert Bogdan, *Perspectives on Disability*, ed. Mark Nagler (Palo Alto, CA: Health Markets Research, 1993): 69-76. Skrtic uses a systems approach, arguing against special education as a "dysfunctional" system. Biklen currently takes a community-based perspective, arguing for the full inclusion of students with disability into school communities.

analysts need to ask whether their decisions allow children to come to know themselves to the greatest extent possible, or whether their decisions ascribe characteristics to children that the children may not otherwise accept for themselves, if given the freedom to choose.

Finally, tools for policy analysis should be developed that can sort out the issues raised by an aesthetic of disability as it is enacted in school community. These tools may look and feel very different from analysis tools currently in use. They would likely have a qualitative flavor and would require the development of relationships between analysts and school communities for analysts to be able to determine the effects of policy on identity and community in the school environment. Policy tools are needed that can describe, if not measure, the effects of policy on schools as caring, reciprocal communities. Tools are also needed that can observe the ways in which policy supports experiences of the self and the self's communities.

There remain, then, practical problems of applying an aesthetic of disability to policy because policy is, of necessity and as much as possible, an objectivist's activity while the aesthetic is strongly subjectivist. One example of the objectivist nature of policy is in the ways in which scholars tend to categorize policy thought. In a previous preliminary study university professors were asked to list the policy texts they consider important to the field of educational policy.[113] Their responses indicated a

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[113] Susan Gabel, "Reconsidering the Distinction between Special Educational Policy and other Educational Policies," unpublished manuscript in the author's possession (1996). This qualitative study was conducted during my research practicum under the supervision of Professor Doug Campbell. I utilized a combination of participant interviews conducted with professors who teach policy courses at at a major state university, combined with textual analysis of an article, Richard Weatherley and Michael Lipskey, "Street Level Bureaucrats and Institutional Innovation:Implementing Special Education Reform," *Harvard Educational Review* 47(1977): 171-197. One theme directly related to my claims in this section of my dissertation emerged from my data analysis. It was clear that some of my

tendency to either implicitly or explicitly assign special education to a category separate from all other educational policy scholarship. Of four respondents, two individuals explicitly described special education as a separate policy category, or category of scholarly literature. The other two respondents implicitly did this through their interview responses. Each participant was asked an open ended question: "What are the policy texts you consider important to the field of educational policy?" The two respondents who did not explicitly deal with special education as a policy category only mentioned one special education-related policy text while they each spent one hour listing and discussing policy texts.[114] My interpretation of these results is that at least these four professors in a school of education at a major university understand policy in clear categories, to which special education is assigned its own category. It seems likely that this would be true of many professors of education, since educators have long interpreted special education, or matters related to disabled students, to be distinct from general matters of education. These professors' views are consistent with the ways in which education is organizationally and intellectually structured.

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participants understood a distinction between special education policy texts and other policy texts. The "other" texts were typically referred to as general education policy texts. Following is a quote that represents this view. "I" represents me as the interviewer and "R" represents my respondent. This quote follows a lengthy response from my participant about the texts that my participant considers important in the policy field, particularly in educational policy. "I: What about Skrtic. Where would you place him? R: I guess I don't think of it as policy. I: You don't? What do you think of him as? R: Special ed. He is policy, but it's so specialized. That's why." In my study, when I used the term "policy text," I referred to any written scholarly product that was published in a scholarly journal or in book form that was related to policy in the view of the respondent answering my question.

[114] All participants referred to Weatherly and Lipskey's article, "Street Level Bureaucrats," suggesting that it is a seminal work in policy scholarship.

An aesthetic of disability, however, can be useful in illuminating the problems with policy in general, or policy viewed wholistically, to which scholars and policy analysts can focus their attention: problems of the effects of policy on the school community and an ethic of caring; problems of the lack of policy tools to describe community life; problems of the inability of policy to describe and support children's explorations of self; problems of the coercive nature of policy and the social effects of power on school children and school communities. If schools are viewed as communities, particularly if they are viewed as caring communities,[115] it is impossible to imagine policy that affects one group of students having no affect on other students in the same community. All educational policy affects all students in some way, if only in the trigger effect of policy. Policy is only one influence on children's selves and their communities, although its influence should not be underestimated.

The next section turns to the people with whom children interact daily, their teachers.

Teacher Education

Teacher education prepares future educators to interact with students as learners. One way of examining the implications of an aesthetic of disability for teacher education is to conduct the examination at the level of values or beliefs. John Goodlad has claimed that the beliefs teachers have about students and learning are a significant influence upon the ways in which they behave as teachers in schools.[116] Therefore, it

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[115] This refers to Nel Noddings' theory of caring and my application of it to a conceptualization of community as collective ethical action.

[116] John Goodlad, *Teachers for Our Nation's Schools* (San Francisco, CA: Jossey-Bass Publishers, 1990), where he makes the connection between values and beliefs and teaching practice. By "unpeeling the layers of the complexities" of teacher education, he

seems to follow that the theory ortheories of disability inherent to the content of teacher education influence(s) the ways in which future teachers are prepared to interact with disabled students and the curriculum and pedagogy related to disabled students. If we can agree with Goodlad that there is, in teacher education, an "implicit curriculum of values and beliefs" (p. 298), then that implicit curriculum should be subject to inquiry, criticism, and analysis. Such an analysis would make sense if it focused on the discourse of teacher education, since discursive analyses can be empirical and could reveal beliefs or values underlying discursive evidence.[117]

A previous analysis of the influences of the personal deficit model of disability on special education teacher preparation texts and the values implicit in those texts is also relevant to applications of an aesthetic of disability. In my analysis of four introductory special education texts,[118] to which teacher education students would be exposed early in the special education preparation program, I found three distinctive value themes emerging from all four texts. First, there was the theme of the importance of history and tradition. Each text situated its particular special education

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gets at what he considers to be the foundation of teacher preparation: the values behind what teachers do and the decisions they make.

[117] Here I use discourse to refer to any communicative interaction between people or between people and texts (or authors of texts) during teacher preparation experiences.

[118] This analysis resulted in a paper, "Implicit Content: The Link Between Textual Discourse and the Development of Values of Practice in Special Education," presented at the American Educational Research Association conference in Chicago, IL, March 1997. I used the following texts in my analysis: Linda Hickson, Leonard Blackman, and Elizabeth Reis, *Mental Retardation: Foundations of Educational Programming* (Boston: Allyn and Bacon, 1995); Mary Beirne-Smith, James Patton, and Richard Ittenback, *Mental Retardation, 4th Edition* (New York: Merrill, 1994); Ed. Bernice Wong, *Learning about Learning Disabilities* (New York: Academic Press, 1991); and Jane Lerner, *Learning Disabilities: Theories, Diagnosis, and Teaching Strategies* (Boston: Houghton-Mifflin, 1993). Similar work has previously been done by Christine Sleeter, "The Social Construction of a Special Education Category", who conducted a study of fifteen special education textbooks published between 1980 and 1985.

category (learning disabilities or mental retardation) within a categorical tradition and within special education history early in the text. This could suggest that one value in special education teacher preparation is that the field is best understood within its historical and traditional contexts, as those contexts are interpreted by the field itself. Or perhaps this placement suggests something consistent with Thomas Skrtic's claim that the field of special education, along with its sub-fields, operates much like other fields of knowledge. There is an adherence to what Skrtic identifies as communal knowledge. In other words, teacher candidates who participate in the discourses that include introductory special education texts like these are involved in the construction of "communal knowledge," or ways of understanding the practice of special education that is shared with other practitioners, all of whom have been enculturated to certain value systems.

A second value theme, the role of the special education teacher, is consistent throughout all four introductory texts. This view of the teacher holds that she is an expert clinician, someone who drills students to learn skills, who trains students, who treats and hopes to repair their disabilities, or at the very least, helps them "cope" with disability. All four texts remain remarkably consistent in this view and it is a familiar view to me as one who was trained in special education two decades ago. In each text, the educational environment is described as expertly shaped by the teacher. According to one text:

> Effective teachers use diagnosis, prescription, monitoring, interactive teaching, and record keeping to adjust instructions to meet the particular needs of individual students (p. 359).[119]

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[119] Beirne-Smith, *Mental Retardation, 4th Edition.*

Another text notes that "clinical teaching," a term often used to describe the diagnostic-prescriptive approaches in special education, is not just a procedure, it is also "an attitude on the part of regular or special teachers" (p.115).[120] I argue that this "attitude" could also be interpreted as a value. It is the value that disabled students need teachers who play an expert clinical role in the educational system.

The third theme that runs consistently through all texts analyzed is the value of the disabled student, or special education student. In each text, students are presented as deficient, disordered, and dependent. Each text adheres to a deficit model of disability, similar to the personal deficit model discussed in chapter two of this dissertation. It takes a clinician with special knowledge and skills, the texts indicate, to administer the educational treatments needed by disabled students.

This analysis of four introductory special education texts is not summarized to suggest that these texts and their values are unequivocal representatives of the values across all of teacher education. This analysis does, however, provide an example of the claim I made in the beginning of this section: that the values supporting any teacher education program have the potential to influence future teachers and those future teachers will one day have an impact on the lives of students. If an aesthetic of disability and its values were one foundation from which teacher education operated, we would likely find very distinct themes running throughout our conversations and texts, or our discourses. Teacher education candidates would come to understand disability as a set of experiences that construct the self, as something to be appreciated for unique contributions to self

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[120] Lerner, *Learning Disabilities*.

knowledge and to the ways in which the individual lives in his community and his world. Teachers would be unlikely to perceive students with disability as needing to be taught by expert clinicians because there would be an understanding that all students share the need to experience educational opportunities that support them in growing to know their selves. Teachers would be prepared to provide educational environments in which all children are given the chance to explore the world, the community, and the self and in which children are encouraged to develop their own identities and communities.

If knowing the self and one's relationship to others in community can be a value in teacher education, then there are implications beyond texts and other discourses of teacher education. If it is possible that disability is a set of experiences that can be appreciated by those who do or do not experience disability, then teacher education must find a way of instilling that value into future teachers. This may be a difficult task, given the dual nature of teacher education today, in which general and special education teachers are usually programmed into separate tracks and are enculcated with the belief that disabled students require specialized teaching strategies in order to learn. On the other hand, if disability were viewed as an aesthetic, as experiences that construct meaning and interpret the self and others, then teacher education would be more likely to prepare teachers to facilitate such construction and interpretation by school children. Teacher education programs would guide future teachers in developing strategies for experiential learning for all students. In developing such strategies, future teachers would be given opportunities to learn to teach all students and to develop ways of teaching that support all students in coming to know themselves.

In this section, I argue that the values underlying teacher education influence ways in which future teachers formulate their views about students. I further argue that those views will affect real children when teachers leave teacher education programs and enter the classroom. There, the values to which they adhere are enacted daily. An aesthetic of disability has fundamental values and I have suggested a few ways in which the aesthetic could be applied to teacher education so that teachers are prepared to think about all students as needing the freedom to explore the self and to construct selves as free from coercion as possible. Here I use "all students" to refer to the full range of diversities in a school community, including the range of abilities and interests in curriculum and achievement goals. In other words, I am suggesting that all teachers need to be prepared generally to be good teachers to all students and that such preparedness requires teachers to respect all students, to appreciate their individuality, to celebrate their differences, to provide learning experiences that accommodate the range of interests and abilities in schools, and to support students' explorations of their selves through educational opportunities in inclusive settings. I am proposing that all teachers be prepared to be generalists and that classroom teachers who are specialists in disability or special education are not consistent with an aesthetic of disability. This line of thought is compatible with teachers who gained expertise in experiential learning, or other teaching methods that could support all students.

Teacher education and policy are not the only categories relevant to an aesthetic of disability. Teachers do not teach without the tools necessary for their work. Curriculum and pedagogy can be considered tools for teaching and it is to that topic that I turn now.

Curriculum and Pedagogy

Curriculum and pedagogy can be viewed from two perspectives: the theoretical and the practical. On the practical side, the movement toward inclusive education, or the education of students with disability within the general education setting, establishes new intersections between the curriculum and pedagogy of general and special education. In the future, general and special educators are unlikely to spend their careers devoted to entirely separate groups of students, curricular content, policies, and pedagogical strategies.[121] Using an aesthetic of disability when thinking about the practical aspect of curriculum and pedagogy requires educators to consider the possibility that teaching methods and materials, curriculum tools and policies, and the ways in which teachers interact with learners inform students about who they are as people. The activities in which children engage in school, the things they do and come to know, transform knowledge of the self. Applied to disability, this suggests that the curriculum and pedagogy we use with students can actually create disabled identities within them.

In practice, general and special education are merging, at least in part, and in so doing, their curriculum and pedagogics are blending and connecting. This merger makes conceptualizations of disability a critical aspect of reform. Not only do educators need to be aware of the ways in which they understand disability if we are to believe that experience instructs the self and the self is an important thing to know, but they need to

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[121] M. Pugach and J. Johnson, *Collaborative Practitioners, Collaborative Schools* (Denver, CO: Love Publishers, 1994).

be clear about the impact of beliefs about disability on curriculum and pedagogy, and in turn, on students.

The premise that disability is a set of experiences that can be appreciated for their contributions to the development of the self and the community has another practical implication for curriculum. It links disability to multiculturalism and the importance of expanding the curriculum to include cultural studies. If disability can be appreciated for its meanings and contributions to the self and society, it can also be studied as a way of life. When students interact with curriculum that examine ethnic, racial, gendered, or other ways of living, they can also study disability and its impact on ways of living. An aesthetic of disability is supportive of including disability studies in the multicultural curriculum because within this theory, disability is, indeed, a way of experiencing one's world, as an individual and a member of social groups.

The movement toward inclusive education and the possibilities for including disability in multicultural studies also establishes new theoretical intersections, particularly in curriculum theorizing. If an aesthetic of disability is viable, then there are clear implications for curriculum theory. First, an aesthetic of disability necessarily transforms the ways in which curriculum theorists view learners in classrooms. No longer would learners interacting with curriculum necessarily be assumed to be disabled or non-disabled. Rather, curriculum theory could account for the possibility that learners are exploring their selves and their relationships to others and are constructing interpretations of the self through the process of interacting with curriculum. Put another way, if a theory of experience and the disabled self is incorporated into curriculum theory, it would entail attempts to alternatively understand the ways in which students construct the self through experiences with curriculum. In addition, by understanding the nature of experience, as viewed through the lens of experiences of disability, curriculum theorists have an opportunity to understand curriculum and its function differently in the development of the disabled self through experience. Finally, by conceptualizing disability as an aesthetic, and by including it in the curriculum category of multiculturalism, curriculum theorists expand the ways in which the full range of human diversity is represented in the curriculum.

Curriculum and pedagogy can be understood from practical and theoretical perspectives. The practical view focuses on the trend toward inclusion and the blending of general and special education curriculum and pedagogy as a response to inclusive education. The multiculturalism movement, too, is related to an aesthetic of disability, because within the aesthetic disability is another way of experiencing life, as are race and gender. Therefore, experiences of disability should be placed within the multicultural curriculum. Finally, an aesthetic of disability offers unique perspectives for curriculum theory. It suggests new ways of thinking about learners in classrooms. It requires the incorporation of a theory of experience and the development of the disabled self into curriculum theorizing. It indicates that curriculum can be reconceptualized through the lens of aesthetics, experience, and the disabled self.

Educational Research

In this section, I map out the ways in which this inquiry might influence future educational research. These influences fall into four categories: novel units of analysis in research, non-traditional forms of research methodologies, a new theoretical perspective for educational research, and topical categories in educational research.

First, I argue that educational researchers have not explored the full range of rich units of analysis in their work. Units of analysis are the fixed object or distinct set that is the focus of the researcher's methodological attention. In educational research the unit of analysis is often a particular school, classroom, student or teacher. Sometimes units are plural: schools, classrooms, or teachers, or students in general. Sometimes the unit of analysis is an idea. Curriculum, pedagogy, school in society, and multiculturalism are all conceptual units of analysis. In this project I use disability as a unit and interpretively analyze it from a variety of angles. A number of other researchers also have used disability as a unit of analysis.[122] Special education is sometimes the unit of analysis, as in Skrtic's work. Another scholarly literature comes from the use labels of identity or community as the unit of analysis. A variety of scholars who use such units for analysis were cited in chapter three.

The body has been a commonly used unit of analysis used by certain scholars from particular social science disciplines. In chapter three, I cited numerous scholars who use the human body, or particular conceptualizations of the body as a unit of analysis. The body as a unit of educational analysis offers a rich field of inquiry that has not been fully explored in educational research. Conceptualizing the body and applying

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[122] Following are some examples of the use of disability as a unit of analysis: deafness is the unit in Harlan Lane's *The Mask of Benevolence*; mental retardation is the unit in James Trent's *Inventing the Feeble Mind*, disability in childhood is the unit in Philip Safford and Elizabeth Safford's *A History of Childhood and Disability* (New York: Teachers College Press, 1996); learning disability is the unit in Hugh Mehan, et al.'s, *Handicapping the Handicapped*. Susan Peters uses disability in general as a unit of analysis throughout her work.

conceptualizations of the body to analyses of the social contexts of education could give fresh insight into schooling, teaching, and learning. Even the subtle ways in which the body is conceptualized, as described in chapter three, could have fascinating and useful applications to educational research. It seems as though it is possible that the very way in which we implicitly conceptualize the body can influence the interpretations we give to the phenomena we study. For example, viewing the body as a fluid subject sharing itself with other bodies, understanding the body as thoughts and the imagination, as physical experience and the interpretation of that experience, establishes an entirely different perspective for analysis than does viewing the body as an object made of flesh and bones. As a relatively unexplored field of study, the body offers novel ways of collecting and analyzing qualitative data, and rich interpretive possibilities for theoretical research. Understanding culture and schools from the perspective of bodies gives researchers the opportunity to make new intellectual and practical discoveries that could be beneficial to education in general.

Fresh units of analysis, however, are not the sole contribution of this dissertation. My work also provides educational researchers with a new theory of disability that addresses the problems of current theories, that is consistent with experiential learning theory,[123] and that interprets disability in a way that can be useful to educational policy, teacher education, and curriculum and pedagogy. Its usefulness will be detailed later in this section. Although the practical applications of an aesthetic of disability must be worked out through arduous intellectual processing,

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[123] Here I primarily refer to Dewey's theory of experience, as analyzed in chapter four.

debate, and field research, it can become a helpful conceptual tool to enhance teachers' understanding of disabled students, to improve curriculum and pedagogy for all students, to improve educational policy and policy analysis and thus, to improve educational experiences for all students.

In addition to units of analysis and a new interpretation of disability, this inquiry demonstrates that there are varied ways of doing educational research and that preferencing empirical studies could stifle both the creativity of researchers and the expansion and enrichment of educational thought and practice. We must support theoretical exercises in education. We cannot know whether or not the next creative, imaginative inquiry will spark the fire of important reform. The abstract forms of analysis I have utilized in this inquiry and the interpretive nature of my endeavors have allowed me to use imagination to achieve results that would have been unlikely had I been limited to empirical work. Yet even though this is not an empirical inquiry, in the end, it will benefit real people. In making this claim, I am convinced that theoretical experiments in thought, as was this dissertation, definitely have practical potential, even if the practicality is not fleshed out until years after the theorizing has begun.

Finally, educational scholars need to review the ways in which topics are categorized in educational research. Studies of disability traditionally have been categorized into special education or educational psychology. Scholars in teacher education, curriculum, and even educational policy leave disability inquiries alone, perhaps because they narrowly view disability issues as falling into special education or educational psychology practice, or perhaps because they do not believe they have the knowledge or expertise to study disability, or even perhaps because they view disability as irrelevant to their research and their field site contexts. On the other hand, special education and educational psychology scholars sometimes behave territorially and imply to their colleagues that the study of disability should remain in special education and educational psychology. There are theoretical and practical problems with each of these reasons.

First, if an aesthetic of disability is the theory with which we interpret disability, then disability easily falls into all categories of educational research. Teachers certainly need to understand theories of experience and the ways in which experiences influence the child's development. In a climate of inclusive education, teachers need to be prepared for and accepting of disabled students in their classrooms. For both reasons, studying disability is the responsibility of teacher educators.

Second, I earlier made a case for the relevance of an aesthetic of disability to curriculum studies. I mentioned the trend toward inclusion and the blending of curriculum from general and special education. It appears that future teachers will be using curriculum for all students, or at the very least they will need to be familiar and comfortable with curriculum for the wide range of learners in inclusive schools. I also developed an argument for the relevance of an aesthetic of disability to curriculum theory, including the ways in which theorists view learners, the multicultural curriculum, and the influence of a theory of an aesthetic of disability on curriculum theory, design, and policy. Curriculum scholars, then, are also connected to disability.

Finally, educational policy has typically ignored disability, or has relegated it to a category called "special education policy." I claimed earlier that all educational policies affect all children, even if the effects are indirect. I argued that if policy is influenced by an aesthetic of disability, then the entire school community must be understood as collective human interaction. In communities, what happens to one member affects all other members. Within this perspective, policy targeted toward disabled students affects their non-disabled counterparts. At the very least, the effect is in the diminishing of their experiences of caring interactions with people representing the full range of diversity in society. At the most, the effect is to indoctrinate all students into cultural beliefs about normalcy and abnormality that an aesthetic and other theories of disability question. In the end, if schools are in any way small communities, then it is a misconception to believe that general education policy does not affect disabled students and that special education policy does not affect non-disabled students. Therefore, policy scholars, too, should not ignore disability studies.

Future Inquiry

This inquiry has opened up a number of possibilities for future work. At this time, one theoretical exploration stands out as needing to be done. I have claimed consistently that an aesthetic of disability is a theory of experience and the interpretation of the self in relationship to others. In making this claim, I have relied partially upon Dewey's theory of experience and aesthetics because my objective was to map out a theory of the self with disability or the disabled self, rather than a general theory of experience. Although Dewey is known for his theory of experiential learning,[124] and his thesis *Experience and Nature* supports an argument

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[124] See John Dewey, *The School and Society* (Chicago: University of Chicago Press, 1900/1943); and *The Child and the Curriculum* (Chicago: University of Chicago Press, 1902), in which he develops a theory of education that holds that children should have educative experiences that grow from their lives and their own relationships. He writes that schooling should not be separated from society or the social life of children. The

for the relationship between experience and the construction of the self, I believe there are other ways of interpreting experience and its role in the construction of the self. While the analyses I have used in this inquiry are a good start for mapping out a new interpretation of experience and the disabled self, they are merely a start. It is necessary to consider the possibility that experience is the self, or that without experience there could be no self. In addition, the knowledge of experience and its relationship to the self would be enhanced by comparative research. What, for example, can we learn from Hindu philosophy about Indian ways of knowing the self? Is there an Indian theory of experience, or what is the Indian concept of experience? A clearer and more fully developed theory of experience and the disabled self would be insightful for a wide range of scholars, including disability scholars. It is an inquiry that needs to be developed.

On a practical level, several avenues for future research emerge. It is necessary more clearly to uncover the applications of an aesthetic of disability to curriculum, pedagogy, and teacher education. Even in the face of challenges in conceptualization, educational policy can benefit from this inquiry. At a minimum, policy scholars and analysts could be more sensitive to the ways in which policy affects community life and identity development. Perhaps that sensitivity can only be demonstrated by policy scholars and analysts asking questions about the experiential consequences of policy. It must be possible to imagine other ways that an aesthetic of disability can be applied to policy. For example, I argue that there is no distinction between educational policy and special education policy because disability is an experiencing of the self as are other

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curriculum, for Dewey, is a set of experiences that are real and meaningful to children. Experience instructs and is the material of learning.

experiences of the self. How else, though, is an aesthetic of disability applicable to policy? Finally, and most ideally, it is possible to imagine that at some time in the future we will develop ways of conceptualizing policy that allow us to apply theories of subjective experience to its analysis.

Conclusions

In my dissertation, I utilize several concepts in order to construct a novel theory of disability. My framework is interpretive and my methods include conceptual, pragmatic, and heuristic analyses. I am interested in a theory of disability that explains phenomena of disability[125] from the inside of disability as experiences that inform the self and the self's communities but that also allows those who do not experience disability to appreciate it for its contributions to the construction of the self and community and for the things it reveals about what it means to be human.

In order to develop a theory of disability I use several conceptual tools, all of which were selected because of what I understand as their relevance to the phenomena we label "disability." My methodological choice of the use of concepts as tools referred me to inter-disciplinary scholarship including sociology, feminist or gender theory, race theory, homosexuality theory, anthropology, educational research, history, and philosophy. I intentionally avoided psychological literatures for a specific methodological reason. Psychology has long been the foundational discipline for the theory of disability I label as "personal deficit." I looked to other literatures to explore other possibilities for conceptualizing disability.

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[125] I have consistently used "phenomenon" to refer to a thing that appears to humans but that is not necessarily an object about which true statements can be made. In this use, a phenomenon could also be subjective. It could appear differently to different people. Or, we might each describe the phenomenon differently. A phenomenon can be perceived by the senses, A phenomenon could be an experience or set of experiences. In this way, I have classified disability as a phenomenon or as multiple phenomena.

Although my primary goal is to construct a viable theory of disability, my secondary goal is to establish ways in which it can be useful when usefulness is established from the perspective of disabled people. My theory of an aesthetic of disability is useful from that perspective for several reasons. First, it constructs a view of disability from inside the experiences of disability. As a view from the inside, it has the potential for being a more adequate way of understanding disability, where adequacy is determined from the perspective of people who self identify as disabled. Second, my theory is useful because it allows for the appreciation of disability as a lived experience. In other words, it interprets disability as experiences that one can find meaningful and important to the construction of the self and communities with which the self finds fellowship. Here its usefulness is in the positive way in which disability is understood, even when the disability imposes limitations, or what are perceived as limitations, upon the disabled person. Third, as a theory that attempts to explain experience and the self, my theory is connected to all participants in the educational process. It is not a theory with relevance isolated to disabled students. It says things about teachers, and the experiences they facilitate in their students. It speaks to the ways in which any student constructs the self and the influences on that self construction. There are also implications for educational policy, especially if we view schools as communities in which students can experience caring and reciprocity. Finally, an aesthetic of disability has potential for practical application to curriculum and pedagogy because students experience curriculum and they interact with teachers through pedagogy, and because the ways in which curriculum and pedagogy frame those experiences have consequences for students' knowledge of their selves and their place in the world.

In the end, an aesthetic of disability reveals more work to be done. It suggests that the hard work will be in figuring out how this theory can become meaningful for teachers and students. For example, how should an aesthetic of disability and its implications in the school and classroom be presented to teachers? If necessary, how can it be reformulated for the practitioner? An aesthetic of disability also demonstrates the inadequacy of current theories of experience. It does not unpack all the nuances of how humans conceptualize "experience," nor does it fully explain the impact of those conceptualizations on our knowledge of ourselves and the relevance of conceptualizations of experience for educational thought and practice.

Chapter one concluded with a quote that represents my journey toward an aesthetic of disability. Now that the journey is completed, at least for the moment, I feel compelled to return to that quote and to feel satisfied that I have contributed to disability scholarship and to ways in which humans can interpret lived experiences.

> Having made a discovery, I shall never see the world again as before. My eyes have become different; I have made myself into a person seeing and thinking differently. I have crossed a gap... which lies between problem and discovery (p. 143).[126]

Indeed, I will never see the world again as before.

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[126] M. Polanyi, *Personal Knowledge* (Chicago: University of Chicago Press, 1962).