

Abstract

WEEBER, JOY ELIZABETH. Disability Community Leaders' Disability Identity Development: A Journey of Integration and Expansion. (Under the direction of Dr. Herbert A. Exum).

The purpose of this study was to investigate the disability identity development process of leaders of the disability community. Specifically, this study examined the cultural values, beliefs and assumptions individual participants held about their disability, what and who were the major influences on how they viewed themselves as disabled people and how their views of their disability changed over time. The study employed the qualitative methodology of in-depth, semi-structured interviewing to gather the data. Interviews were coded, coded data was entered into and sorted by *Atlas ti*, a software program for managing qualitative data and a coding auditor confirm identity "positions."

The findings show that disability identity develops in a dual-dimensional process. The first process is integrating disability positively into one's sense of self and oneself into the disability community. The second process involves the expansion of understanding the disability experience to include an increasing variety of disabilities, other diverse communities struggling for equal rights, and finally, a spiritual sense of oneness with all of humanity. Factors that played an important role in participants' disability identity development were the cultural beliefs, values and assumptions about disability in their environments, education, disability community, personality traits, age of disability onset, new paradigm of disability, role models and gender/sexual identity. A time of bonding with the disability community was found to be essential for the development of a disability identity and a sense of wholeness as a disabled person.

**Disability Community Leaders' Disability Identity Development:
A Journey of Integration and Expansion**

by

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- Weeber, J.E. (2002). What Could I Know of Racism? In V.N. Gordon & T.L. Minnick (Eds.). *Foundations: A Reader for New College Students*. Belmont, CA: Wadsworth Publishing Co.
- Weeber, J.E. (2001), Front Porch: Post-cute. *Independent Weekly*. September, 2001.
- Weeber, J. E. (2001), Book Review: What Psychotherapists Should Know About Disability. *Community Mental Health Journal*, 37(5).
- Weeber, J.E. (2000), Book Review: A Celebration of Disability Culture. *Disability Studies Quarterly*, 20(4).
- Weeber, J.E. (1999). Belonging and understanding: Disability identity grounded in community. *Disability Studies Quarterly*, 19(1).
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TABLE OF CONTENTS

	Page
List of Tables	viii
Chapter One: Introduction	1
The Ecology of Disability Identity Development – The Problem	1
Researcher Disability Identity Development Profile	15
Chapter Two: Literature Review	20
Identity Development Literature	20
Erik Erikson’s Theory of Psychosocial Development	21
William Cross’ Racial Identity Development Theory	31
Vivienne Cass’ Theory of Homosexual Identity Development	33
Linda James-Myers Optimal Theory of Psychology	36
Disability Research Literature	43
Traditional Medical Model Research	43
Disability-Related Identity Development Research	45
Disability Identity Development Related Research	58
Guiding Assumptions	64
Chapter Three: Methodology	66
Participant Sampling	68
Disability Community Leaders Demographics	71
Ethical Treatment of Participants	73
Trustworthiness of Findings	74
Credibility	74
Transferability	77
Confirmability	79
Data Collection	82
Data Management and Analysis	86
Chapter Four: Results - Individual Disability Development Profiles	90
Phyllis	91
Lauren	101
Leslie	108
Carlota	115
Florence	123
Lucy	130
Gail	139
Frank	149
George	154

Garth	163
Lena	172
Claudia	179
Lennie	187
Don	194
Karla	202
Fiona	210
Clyde	217
Ray	226
Chapter Five: Results – Disability Identity Development “Working Model”	231
Position One	233
Position Two	234
Position Three	235
Position Four	236
Position Five	237
Position Six	238
Discussion	238
Chapter Six: Discussion	269
Patterns	269
Limitations of the Study	277
Directions for Future Research	280
Implications for the Field of Counselor Education	281
Concluding Remarks	283
References	285
Appendices	301
Appendix A: On-line Leader Focus Group Announcement	302
Appendix B: Demographic Description	303
Appendix C: Informed Consent Form	304
Appendix D: Interview Transcript Review Cover E-mail	305
Appendix E: Member Check Cover E-Mail	306
Appendix F: Individual Interview Questions	307
Appendix G: <i>Atlas ti</i> Codes	308

List of Tables

	Page
Table 1: Disability Identity Development Matrix	267

Chapter One

Disability Community Leaders' Disability Identity Development:

A Journey of Integration and Expansion

The sick role is...a mechanism which...channels deviance so that the two most dangerous potentialities, namely group formation and successful establishment of the claim of legitimacy, are avoided. The sick are tied up, not with other deviants to form a "sub-culture" of the sick, but each with a group of nonsick, his personal circle, and, above all, physicians.

T.A. Parsons

Introduction

The Ecology of Disability Identity Development –The Problem

Constructing a sense of self is a universal human endeavor that is shaped by the particularities of our lived experience. "Identity" as a subject of study is far more complex and fluid than the seemingly monolithic statement "I am X" or "I am X-American." Individual identities embody multiple facets of the universal human experience – gender, class, race/ethnicity, age, sexual orientation, national, religion, and of course, disability. Each facet of our identities can share a commonality with a group, while not sharing that characteristic with others. And which facet of ourselves we choose to identify collectively with is influenced by many external and internal factors, at different points in our lives. Constructing a sense of self, as a member of devalued group within a dominant culture, presents the paradoxical challenge of "embracing that part of oneself despised by society" and seeing oneself positively as a member of one's own community, as well as a part of all of humanity. The complexity of this identity challenge is amplified within the disability experience, as the majority of disabled people are not born into families or communities of other disabled people – they do not share that characteristic with anyone in their world.

Disabled Americans have been working collectively for social and political

change in society over the past thirty years, just as women, African-Americans, gay people and other culturally diverse communities have struggled for equality. As other culturally diverse groups have struggled to confront their social devaluation, disabled people have engaged in what Anspach (1979) calls “identity politics” - politics that endeavors not only to change society’s conception and response to disabled people, but also to change the self-concepts of disabled people themselves. In 1990, the political struggle to change how society views disabled people scored a political victory in the signing of the Americans with Disabilities Act; a law that established disabled people are, in fact, a discriminated against class and, therefore, deserving of civil rights protections under the law. While this hard-won victory has not withstood well the legal backlash in a court system still grounded in traditional cultural views of disability, the passage of the ADA has had a deep impact on the psyche of many disabled people and how they view themselves. Hahn asserts, “one of the most important problems facing the political struggle of disabled people is the necessity of developing a positive sense of identity” (1985, p.310).

The very idea of a positive disability identity flies in the face of long-standing cultural “wisdom” about disability and the disability experience. The reasons for this lie in how our culture, historically and contemporarily, has viewed the disability experience. How cultural beliefs, values, and assumptions can influence the identity development of disabled people is best illustrated by the image of a richly painted, nested Russian *matryushka* doll. Some of these dolls are even designed to tell a story, with each “un-nested” doll supplying the next element in the unfolding folktale. Frédéric Brenner, who set out to photograph the “authentic Jew,” ultimately concluded that Jewish identity is “like a game of Russian dolls...nested in layers of culture, race and nationality” (Goodstein, 2003). Community psychologist, Uri Bronfenbrenner, uses these dolls to illustrate his model of the “ecology of human development.” The five dolls represent the

four social environments that surround and influence the development of an individual - that smallest center doll (Bronfenbrenner, 1979). To the person “un-nesting” such dolls, the primary interest is on each unique new costume as it emerges and not on the shapeless, but structurally important, interior of each doll. Such is the nature of an “outsider gaze,” it is the viewpoint of someone looking at something from outside of it and only able to perceive the most obvious about it – the superficial surface. It is a gaze unable to imagine what may exist beneath that surface, because the “outsider” has not had the same life experience.

The importance of such an “outsider gaze” is significance when we understand that it the “outsider gaze” our society has traditionally directed at the disability experience and disabled people. Traditionally, our culture has only seen the “colorful” surface appearance of disability’s differences and imbued those differences with inherently negative characteristics believed to be the sum total of the disability experience – the very roots of the social science phenomenon of the “stigma of disability” (Frank, 1988; Goffman, 1963; Herman & Miall, 1990; Parsons, 1951; Zola, 1993). This “outsider gaze” has been neither curious about nor able to perceive the lived disability experience lying just beneath its colorful surface. Just as with the inanimate dolls, this “outsider gaze” has rendered disabled people non-actors in the developmental process of defining themselves and their roles in society. Bronfenbrenner’s animated, “storytelling” nested dolls underscores the fact that it is not all a one-way gaze. His model outlining the two-way interaction between an individual and their multiple social environments provides a structure for exploring how our culture’s beliefs, values and assumptions about disability influence the identity development of disabled people. In this interactive model, the surface appearance is not as important to identity development as the “meanings” an individual crafts within their social environments - “what matters for behavior and development is the environment as

it is *perceived* rather than as it may exist in ‘objective’ reality” (Bronfenbrenner, 1979, p.4). Those individualized meanings, then, determine the extent and type of development that occurs and the “reality” an individual constructs from his or her experiences.

The first, outermost “doll” of Bronfenbrenner’s ecological schema is the repository of those inherent characteristics our culture has ascribed to disabled people. From this abstract and indirect cultural environment, we can “unpack” the cultural beliefs, values and assumptions about disability. These are taught to everyone in our culture, disabled and non-disabled alike, through images found in theater, movies, books, news media, art, TV, dance, music, radio, poetry, etc. The second “doll” of this ecological schema represents the laws and policies that are shaped by these cultural beliefs and values, i.e. building code councils, school boards, parks & recreation boards, transportation boards, employer personnel policies, etc. These laws and policies, then, shape the third “doll” which represents the local organizations and how they are structured. It is within these local organizations, i.e. home, schools, work, recreation centers, church, theaters, stores, public transit, etc., that disabled individuals are “taught” the kinds of activities and roles society assumes they are capable of doing or it is thought appropriate for them to do. The fourth environment, or “doll,” shaped by cultural values and beliefs are the very relationships disabled individuals have with family members, teachers, classmates, neighbors, friends, bus drivers, store clerks, etc. (Bronfenbrenner 1979). And, at the most subtle of levels, they also influence how a disabled person views themselves and their place in their families and in the world around them.

In order to understand contemporary beliefs, values and assumptions about disability in our culture, we must first examine their historical roots. For generations prior to the founding of the American colonies, the traditional European view of disability was a “moral view.” Seen as evidence of God’s displeasure at someone’s sin, disability was

a violation of the moral order of the universe and disabled people were morally deviant - incapable of physical, moral or sexual control (Longmore, 1993; Wolfensberger, 1969;). In short, disability was a “moral problem” embodied by the disabled person (Bryan, 1996; Goffman, 1963; Longmore, 1993; Treanor, 1993). Eileen Gardner, Reagan’s Assistant Secretary of the Department of Education, demonstrated that such attitudes did not evaporate with the Declaration of Independence and are still operating in the policies of our country today:

“there is no injustice in the universe...a person’s external circumstances do fit this level of inner spiritual development. The purpose and challenge of life for a person is to take what he has and use it for spiritual growth. Those of the handicapped constituency, who seek to have others bear their burdens and eliminate their challenges, are seeking to avoid the central issue of their lot. The order of the universe is composed of different degrees of development. There is a higher, more advanced development and a lower, less advanced. Man cannot, then, within a short lifespan, raise the lower to meet the higher. This artificial constraint is exactly what has happened over the past two decades -- what has happened in the civil rights movement for disabled people (as quoted in Longmore, 1993, p.4).

Disability and disabled people were also seen to cause many social evils, such as poverty, sloth, vice and crime (Bryan, 1996; Longmore, 1993; Treanor, 1993). A leading moralist of the late 19th century stated, “the deaf-mute is by nature fickle and improvident, subject to idleness and drunkenness, and debauchery, easily duped, and readily corrupted” (quoted in Longmore, 1993, p. 5). R.C. Elmslie, in a turn of the century orthopedic textbook, wrote that “a failure of the moral training of a cripple means the evolution of an individual detestable in character, a menace and burden to the community, who is only too apt to graduate into the mendicant and criminal classes” (quoted by Longmore, 1993, p.6). In literature and in the media, disabled people were represented as “grotesques,” a literary device that represented moral or sexual deviance through the “evil” character in the plot (Davis, 1997; Thomson, 1989; Winzer, 1997). Popular forms of entertainment, such as vaudeville, used depictions of disability as a

way to get laughs, as well as to ridicule disabled people themselves (Gallagher, 1996), while freak shows actually placed disabled people on display, exploiting their status as “deviant others” (Bogdan, 1988). Lon Cheney, in *The Hunchback of Notre Dame*, played a “grotesque” character who was assumed to be dangerous because of his appearance. The isolation of Boo Radley, in *To Kill a Mockingbird*, portrayed the social practice of hiding a disabled family member, as well as revealing its negative affect on the neighborhood children’s view of him. In *Jane Eyre*, Rochester hid his mentally ill wife in the attic, nearly obliterating the memory of her existence (Bryan, 1996; Gallagher, 1996; Shapiro, 1993).

The ensuing social policies and laws directed at such “deviants” were based on the belief that disabled people were less than fully human, with nothing to contribute to society (Goffman, 1963; Safilios-Rothschild, 1976; Fowler, O’Rourke, Wadsworth, & Harper, 1991; Zola, 1983). The policies and laws were designed to “protect” society from the “violence” of disabled people’s “deviant” appearance and behaviors. Coastal colonies did not allow disabled people to disembark at ports, because they were viewed as unable to live up to the Protestant work ethic and, therefore, potential economic and emotional burdens to their communities (Bryan, 1996). Later, ship captains had to post bond for such passengers should they ever require public assistance. That public assistance, eventually, took the shape of asylums which warehoused disabled people at the same subsistence levels found in English “poorhouses” (Bryan, 1996; Crewe & Zola, 1983). People with mental illness, epilepsy and retardation were demonized and jailed in 4x4 cells resembling kennels (Bryan, 1966; Oberman, 1965), before such times as they were placed in asylums themselves (Rothman, 1990). These asylums used physical, and later, chemical and surgical restraints to control residents’ behavior. While any inmate deemed to have a minimal level of functioning was auctioned off as indentured servants to reduce the public burden of maintaining them in the asylums

(Crewe & Zola, 1983). Later, state-run residential training schools replaced asylums for the “deaf, blind, mentally retarded and crippled,” purporting to provide a developmental structure for inmates, though the activities were never assumed to prepare anyone for social roles in society (Bryan, 1996; Crewe & Zola, 1983; Shapiro, 1996). Such institutions were thought to be the most humane option society had to offer families – keep their disabled family member out of sight by institutionalizing them (Hubbard, 1997).

In many cities in America, laws creating “ugly wards” were passed, such as Chicago’s that was only repealed in 1973 (Treanor, 1993), prohibiting any “...person with diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object or improper person to be allowed in or on public ways or in other public places in this city or to expose himself to public view” (quoted in Longmore, 1993, p. 5). Such laws were based on the belief that the very appearance of disabled people would disrupt and interfere with the mercantile focus of our cities. Other laws prohibited disabled people from marrying, bearing children, serving on juries, attending school, holding public office (Bryan, 1996; Longmore, 1987; Shapiro, 1993; Weeber, 2003). Assumed disability status assigned to people with non-northern European features also formed the bedrock of exclusionary immigration laws for decades (Baynton, 2001).

Another variation of the “moral deviant” belief was that disabled people were “defectives” and, therefore, subjected to forced sterilizations to keep them from reproducing and further corrupting society (Duffy, 1981; Kirschbaum, 1991; Wright, 1983). Maintaining social purity was the ultimate aim of the eugenics movement of the 1920s and 1930s (Hubbard, 1997; Longmore, 1993; Shapiro, 1993; Treanor, 1993; Wolfensberger, 1969;). Contributing to this perception of disabled people was the work of Sir Francis Galton, who was an active proponent of the eugenics movement and the theory and practice of statistics. The statistical concepts he developed, such as “normal

distribution,” “bell curve,” and “ranked order” were used to establish scientific proof that disabled people were not normal and therefore (Davis, 1997). In the early 1930’s, German doctors took the eugenics goal of social purity to its horrific, but logical conclusions by murdering over 200,000 disabled people living in state asylums (Czuczka, 2003; Gallagher, 1995;). Such inmates were viewed as unable to be rehabilitated by modern medical science and therefore characterized as “useless eaters” and “life unworthy of life.” These doctors actually saw themselves as saviors of those they perceived as wanting to be released from their tortured existence by mercy killings. The killing methods the doctors developed were later adopted by the Nazis’ to protect the purity of their Aryan race by ridding Germany of it’s other social undesirables (Czuczka, 2003; Gallagher, 1995; Lifton, 1986; Shapiro, 1993).

The public policy of institutionalizing disabled people followed the community and family responses to disabled people. Seen by the community and the church as primarily the family’s burden to bear in isolation and silence, disabled family members were kept out of sight, in the attic or basement, to spare the family the shame of the moral stigma of disability. But even this overwhelming weight of social negation could not completely stifle the voices of some disabled people publicly resisting that socialization. Between WWI and WWII, when Roosevelt’s New Deal was being implemented, the League of the Physically Handicapped organized to publicly protest job discrimination in New York City and in the WPA projects, in particular, which had a stated policy not to hire disabled people (Longmore, 1993; Treanor, 1996). While unsuccessful in getting jobs, this group demonstrated the beginnings of a new consciousness in disabled people themselves about their assigned deviant role in society.

After WWII, medical and vocational rehabilitation services designed to return injured veterans to return to work began to change the cultural perceptions of disability

from moral defects to physical defects. Disability became medicalized, rather than demonized, with disabled people being assigned the “sick role” (Parsons, 1951; Zola, 1993), their bodies or behavior pathologized. Prior to rehabilitation services being extended to non-veterans, the sick role assigned disabled people assumed them to be childlike, pitiful, dependent, helpless, emotionally unstable, weak, incapable of making decisions about their lives, passive, unattractive, asexual, unintelligent (Deegan and Brooks, 1985; Fine & Asch, 1988; Hillyer, 1992; Kirschbaum, 1988; Longmore, 1993; Rousso, 1988; Phillips, 1990). Most certainly, disabled people were incapable of adult roles in society, such as spouse, parent or employee (Goffman, 1963; Kirschbaum, 1991; Parson, 1951). The promise that rehabilitation medicine held out to an increasing number of disabled people was that disabilities could be overcome, with the proper medical interventions. Such a promise gave disabled people their first socially acceptable role in society - negating the stigma of the sick role by demonstrating a willingness to work hard to become as normal as possible (Herman & Miall, 1990; Longmore, 1993; Parsons, 1951; Phillips, 1985). It was the standard of normal functioning that became the yardstick rehabilitation professionals used to evaluate all physical and psychosocial adjustments to disability and society - a standard that communicated disability could only be a negative factor in a person’s life (Davis, 1995).

The rehabilitation promise of overcoming and normalization, then, became society’s new prevailing beliefs and goals for mentally and physically disabled children and adults (Longmore, 1993; Phillips, 1985). Federal government policies developed the field of rehabilitation through its funding of massive training programs for medical rehabilitation professionals (Scotch, 1984). The focus of rehabilitation medicine was on ameliorating the functional limitations of “the physical and psychological experience of biological defect, deriving from any series of illnesses or injuries and located exclusively within the body of the afflicted individual (Longmore, 1993, p.4).” The goal of reducing

such functional limitations was to enable disabled people to adapt themselves to their disabilities and their environments and, ultimately achieve independence through employment (Treanor, 1993). This medicalized view of disability-as-personal-defect placed the responsibility of adapting to society's standard, or norm, solely on disabled people (Linton, 1998), with acceptance in this rehabilitation framework consisting of gainful employment that indicated you were no longer considered disabled according to Social Security Administration criterion. It was believed that only highly trained, non-disabled rehabilitation professionals were qualified to determine the service needs of disabled people, while disabled people were expected passively accept such services. In this overcomer role, it was assumed that disabled people would be perpetually in need of rehabilitation services, dependent on professionals to guide their efforts at "trying harder" to overcome their functional limitations (Longmore, 1993; Phillips, 1985). The overcomer myth became necessary, because the older cultural belief that disability renders one universally unable could not co-exist with the accomplishments of these disabled people – the disability had to disappear (Asch & Fine, 1988). Some of the more famous overcomers society lauded as role models were Franklin Delano Roosevelt, Helen Keller, Wilma Rudolph, and more recently, Itzhak Perlman and Mark Wellman, a paraplegic park ranger who scales the granite peaks of Yosemite National Park in his wheelchair. These people achieved such renown in their chosen field that their disabilities virtually disappeared in the face of the public's adulation of their accomplishments.

At the community level, charity organizations formed to fill gaps in existing government-sponsored rehabilitation services. Generally organized around specific medical diagnoses, such as the March of Dimes, Muscular Dystrophy Association or Easter Seals, these charities created the powerful cultural image of the poster child to raise money. The poster child was a variation on the overcomer image that used

images of pitiful disabled children cheerfully and bravely struggling to overcome their disability or longingly asking for a cure (Longmore, 1993; Phillips, 1990; Shapiro, 1993)! No longer the perpetrators of social evils of the moral view of disability, the poster child played to the new medicalized model's belief that disabled people were tragic victims of viruses, diseases or birth defects that needed to be relieved of their burden of disability (Asch & Fine, 1988; Deegan, 1985; Hillyer, 1992; Longmore, 1993; Kirschbaum, 1991; Phillips, 1990; Rousso, 1988). The fund-raising telethon is a more contemporary version of the poster child/overcomer icon that uses images of attractive, yet pitiable, disabled children and adults longing for a cure. The Muscular Dystrophy Association's Labor Day Telethon, the most widely-known telethon, portrays the plight of disability as unbearable, a sentence worse than death - an existence that must either be prevented or cured, because disability renders people unable to fully participate in life, i.e. employment, school, recreation, etc. (Shapiro, 1993). Jerry Lewis (1990), the perennial MDA telethon host, described his belief about living with a disability as, "if I were stuck in a steel entrapment" [wheelchair], I would be half a person!" The overcomer/normalization image reinforced society's belief that disabled people are, in fact, outside the norm, but created the first culturally accepted role for them in society that of overcoming one's disability and achieving as near a normal state as possible. Popular culture movies communicated these new overcomer beliefs in films like *Born on the Fourth of July*, *My Left Foot*, *Forest Gump*, *Waterdance*, and *Rainman*; while biographical films like *The Other Side of the Mountain* and *The Terry Fox Story* presented real-life stories of disabled people who overcame great odds to achieve hero status (Treanor, 1993). Redemption, in this medicalized view of disability's defects, was only found in eliminating or hiding one's disability from society's sight.

In the 1960's, as other culturally diverse communities were collectively and publicly struggling for equality in society, disabled individuals began to publicly challenge

their own status in society. Influenced by the civil rights movement, these disabled people began to attribute their limited opportunities for participation in society to discrimination, not their disability. They began to reframe disability as a socio-political phenomenon, not a personal defect, and began to hold society was responsible for the second-class status of disabled people. Their individual struggles of challenging the social pattern of discrimination laid the initial groundwork for developing their own positive disability identities, as well as organizing and educating other disabled people about a new social model of disability (Shapiro, 1993; Weeber, 1999;). Gill (1995) articulates the core values of the disability community's new social model of disability as:

1. Disability is a difference from the average;
2. Being disabled, in itself, is neutral;
3. Disability derives from the interaction between the individual and society;
4. The remedy is changing the intersection between the individual and society;
5. The agent of remedy can be the disabled individual or an ally that improves; the interaction between disabled individual and environment.

Other disability community values and beliefs include the acknowledgement of a common disability experience that transcends medical diagnostic categories and creates a community of common understanding, shared history, humor, language and culture. It includes people with psychiatric, orthopedic, sensory, cognitive, chronic health conditions, as well as learning disabilities. While the foregoing Introduction delineates an overwhelming negative social construction of disability by society, the common disability experience extends beyond the collective experience of social oppression. The disability community has come to honor the interdependence our lived experience requires and treasures the perspectives our disabilities have given us on the universal human condition. It has redefined cultural values of attractiveness, health and power to include our variations and relishes the creativity and flexibility that living with a disability by necessity engenders. The disability community has reframed the legal social contract of "equal treatment under the law" to be "equal opportunity under the law" and is finding

artistic ways to communicate those values to the larger culture (Gill, 1994, 1987; Hahn, 1988)

Anspach (1979) describes this politicizing process of community building as “an attempt to wrest the definitional control of identity from the “normals (p.768).” All of the participants in this study have been leaders of the historical process of building a disability community where previously one did not exist. They have participated in the shaping and articulating the community’s cultural beliefs and values, drafting laws that reflect those beliefs and values and creating disability community-based organizations that reflect those beliefs and values. Some of the participants in this study were the very individuals who first publicly challenged society’s discrimination, while others benefited from those struggles and became the second generation to carry on the work in new ways. Some created local and regional disability organizations that reflected the new disability community values, while others carried on in their leadership roles. Others contributed to the national struggle to shape the initial laws and policies protecting the civil rights of disabled people, while others have come along to be a part of the effort to implement them.

This study is, in fact, part of a much larger national study to investigate disability identity development from a very broad spectrum of the disability community. It is funded by a three-year Field-Initiated Research Grant from the National Institute for Disability and Rehabilitation Research; a research initiative called for by the disability community to formulate the process of disability identity development within the cultural values of the disability community. As a member of a team of disabled researchers, I was asked to interview leaders of the disability community, because it was believed that my life with Ron had given me access to such leaders. The irony of being given this assignment is that one of the concerns raised at my proposal defense was that the sampling criteria seemed to be focused on interviewing only disabled people with

positive identities, perhaps because of concern that those who had achieved such an identity would have limited recall of earlier phases of their process. As will be seen in the profiles of each participant in this study, the memories of those retelling the stories of their identity development process remain clear and strong. Many commented that their conscious disability identity development did not occur in some dusty past, but rather, as mine did, at a later point in their lives compared to other people's identity development process. In conducting qualitative research, the importance of identifying the researcher as a primary element of the research process cannot be ignored or underestimated (Guba 1981), particularly those life experiences, beliefs, values, and assumptions that have been an integral part of a researcher's choice of topic and methodology used to explore that topic. For me, choosing to investigate disability identity development seemed as inevitable as other choices in my life – it was the only option grounded in both my heart and my head, as personal as it was political. The choice of methodology, again, was the only viable option given my research questions and the yawning gap in the identity development literature about disability identity development. Only foundation-building qualitative research could be used to investigate such an under-researched phenomenon as disability identity development (Akbar, 1991). Because my choice of topic came directly out of my own disability identity development process, I have chosen to tell the story of my disability identity development as a preamble to this Introduction, which outlines the cultural environments within which all disabled people must craft an identity. The story is presented in the same manner the stories of each person interviewed will be told later, including milestones and crises, relationships, attitudes of family and others, interaction with other disabled people, accomplishments, and activities that contributed to or hindered the development of my disability identity.

Researcher Identity Development Profile

Born the middle child of five, to missionary parents, I contracted polio at 10 months of age in San Jose, Costa Rica. Determined to get the best possible medical care for me, my parents returned to the United States and to teaching at a boarding high school for missionary children in the southeastern United States. It was a religious way of life that was unconcerned with popular American values and beliefs, a worldview that predisposed my parents' to construct their own response to my disability. They questioned traditional western medical approaches and pursued alternative means to strengthen and support my physical development, including the whole family in such efforts without focusing the process on me. They were aware of the stigma society placed on disabled people and deliberately set out to fortify me to deal with it positively. My father taught me, as early as five years old, how to use tools to make the world work for me. My mother's approach was that I "just had to make it with the rest of 'em!," which included chores and holding down summer jobs just like my siblings. My parents never limited my imagination to participate in life by any fear they may have had - letting me take risks and define my own physical limits. It was a childhood rich with activities, people from around the world and the freedom to run the mountain with the rest of the kids. Growing up in such an affirming, self-defined world laid the groundwork for an unapologetic sense of self, despite the fact I knew no other disabled people. It also was a world in which no one acknowledged that I had a disability, either.

All that changed at the age of ten when it was determined I needed surgery to halt the curvature of my spine. My parents took assistance from a Shriners' Hospital where I first encountered being treated as a "medical object." The next seven years were spent in and out of the hospital, encased in body braces and casts, enduring unnecessary leg surgeries. The experience of being reduced to defective body parts left me angry and numb, emotionally and psychologically disconnected from life, with no

language for my sense of violation and no one to validate those feelings.

Those years of medical control engendered in me a deep distrust of any form of institutionalized work or education. Eventually my self-defined hippie life led to fatigue induced depression that convinced me such a life-style was no longer viable. Pursuing a degree in Chinese Studies led to my first step toward a disability identity. An accident in my last year of undergraduate studies required I find a physical therapist able to work with my non-normal muscles. Our work together became a five year journey of integrating mind, body and spirit. He taught me to stop pushing my body to perform, to honor its signals of pain and fatigue and, ultimately, to accept that it was okay not to do everything. My body became my path to developing a spiritual life and integrating my whole self. Five years and two back surgeries later, that wholeness included new post-polio limitations; lifestyle changes made after my accident became the very ones needed to honor my body's new limits.

My final step to understanding myself as a disabled person came through an essay, "The Myth of the Perfect Body," written by a disabled psychotherapist, Roberta Galler, on disabled women's socialization. Her words explained why I had felt like an "alien" in my family - my divergent disability experience had shaped how I understood and viewed the world differently from my family. The essay explained my unconscious choice to be a "supercrip," the opposite of society's prescribed role of dependent, crippled woman. She explained that how disabled girls' "bodies were touched, talked about and handled by caregivers" shapes our sense of self and our sexuality as a disabled woman. I immediately understood my ambivalence towards white men -- the male doctors' conduct, in my youth, had taught me that what happened to my body had nothing to do with what I felt on the inside. It was healing to acknowledge the parallel between my experiences of being an object of male medical desire and society reducing women to seeing themselves objects of male sexual desire. I finally knew myself to be

whole – disabled body, mind, and spirit. In this one essay, I had found the final pieces of myself, my people and a home in a community I never knew I needed.

Without any personal connection to the disability community, my sense of belonging to the community was deepened by reading all that I could find about the disability experience written from the community's perspective. My perceptions and responses to the world were reflected back to me in words redefining disability as a socio-political phenomenon. A scholarship for a Master's in Public Administration became my path to further learning about disability law and policy. As an activist on campus I encountered younger disabled students who avoided us disability activists working to implement those laws on campus. Their avoidance of other disabled students puzzled me and helped me understand that anti-discrimination laws were not sufficient for young disabled people to identify positively with other disabled students.

A Ph.D. fellowship in Counselor Education gave me the opportunity to intellectually explore the disability identity development process I had been going through on my own and a research job on campus provided my first experiential knowledge of disability community. That job deepened my sense of belonging and being understood, as the Center for Universal Design was steeped in disability consciousness. I did not have to fight for the validity of disability rights or defend my positions on disability issues. I learned the power of working for social change from a position of strength, rather than anger, from a man, Ron Mace, who became my mentor and partner. Working and talking with him increasingly feel like a home place I had never fully experienced and we became partners in work and life. During our years together, I met many leaders of the disability community who became role models with lives and accomplishments that challenged and nurtured my own disability identity development. With his untimely death shattering my "home place," those disabled brothers and sisters encouraged me to continue my work, as he would have done. Grieving Ron's loss

become yet another step in my own disability identity development process of finding my own way to work for incremental cultural change. This dissertation is one of those incremental steps that, I hope, will contribute to cultural change within my community and in the larger society.

Summary

This chapter has introduced the researcher as a member of the community that will be the subject of this study. It has also described the cultural and social environments within which disabled people have constructed their disability identities. Chapter 2 will review theories of identity development and their applicability to the disability experience, as well as a review of disability research literature and constructs relating to disability identity development from multiple social science disciplines. It will also examine the very limited disability identity development research that has been done within the social model of disability. Chapter 3 will describe the qualitative research methodology employed in the study. Chapter 4 will discuss the Results – Individual Disability Identity Development Profiles of each participant in the study. Chapter 5 will discuss the Results – Disability Identity Development “Working Model” and Chapter 6 will discuss the conclusion from the research findings and the next steps that can be taken to further this line of research.

Chapter Two

When a child begins to feel that it is the color of his skin, the background of his parents, or the cost of his clothes, rather than his wish and his will which will decide his social worth, lasting harm may ensue for the sense of identity.

Eric Erikson

Literature Review

Community, as defined by Rappaport, is “a sub-group within society, which is perceived or perceived itself as distinct in some respects from the larger society” (1977, p.3). The disability community certainly fits the second part of that definition by its very proud claim of existence (Longmore, 1985), despite the fact that much of our society does not perceive that collective experience as positive grounds for such forming such a community. “Minority group” is a term used in recent history to describe “a group of people who, because of physical or cultural characteristics, are singled out from the others in society in which they live for differential and unequal treatment, and who therefore regard themselves as objects of collective discrimination” (Wirth, 1945, p. 347, cited in Atkinson, Morten, & Sue, 1989, p.8). The 1990 Americans with Disabilities Act established that disabled people, collectively and individually, “are singled out for differential treatment,” and as such are deserving of protections from that differential treatment. While the disability community does not fit the same profile as other culturally diverse communities with their multigenerational families that share the biological traits and cultural values and many question its actual existence, having a disability does qualify an individual for differential treatment from the rest of society. Furthermore, disabled people who identify collectively as members of the disability community articulate that the community functions as a place of belonging and common understanding, as well as the basis for collective action. The shared disability experience is increasingly the source of artistic and intellectual expression of unique

ways of being in the world.

For over 25 years, the disability community has been acting collectively to bring about change in how society views disabled people and how we view ourselves. The struggle for disability rights has led to the development of a strong collective identity that is now generating discussion within the community itself about the role of disability in collective and individual identity formation. Disability historian, Paul Longmore (1995), describes this discussion of disability identity, and its ensuing celebration of disability community culture, as the “second phase” of the disability rights movement. Disability studies scholars, at three consecutive annual meetings of the Society for Disability Studies, have increasingly articulated the need for the disability community itself to conceptualize our own disability identity development process. The consensus among scholars and activists alike is that such an identity must be grounded in the social model of disability and that positive in-group identification was an important element of a disability identity (Gilson, Tusler & Gill, 1997).

It is for this reason that the literature and theories of psychosocial identity development provide a useful framework for exploring disability identity development, particularly identity development in diverse cultural communities. Within identity development literature itself, few theorists have explicitly addressed the issue of disability (Morten, Atchinson, & Sue, 1988; Myers, Speight, Highlen, Cox, Adams & Hanley, 1991), yet the existing models provide fertile ground for exploring the theoretical similarities and differences between the disability experience and other diverse communities’ experiences. The identity theorists who have mentioned disability have done so within the context of disability as one of several identities (Morten, et.al., 1988; Myers, et al., 1991).

In contrast to identity development literature, an extensive body of rehabilitation literature exists, grounded in the medical view of disability, which has generating

research findings that support and reinforce that medicalized view of disability. Such a literature may provide an understanding of the context out of which a positive disability identity must develop, but is insufficient as a framework for exploring disability identity development itself. For this reason, this literature review will explore concepts relating to disability identity from a variety of social science disciplines that will be examined for cultural views of disability, as well as the validity of the findings from a disability community perspective.

The final group of research that will be examined is from the developing body of work on disability identity development from the disability community perspective itself.

Erik Erikson's Theory of Psychosocial Development

Erik Erikson's theory of psychosocial development is an epigenetic approach to ego development that he conceptualized as occurring over a lifetime (Mayer, 1998). While his theory is grounded in Freud's psychosexual theory of ego psychology, Erikson sought to demonstrate that psychosocial development is the result of the interplay between the individual psyche, the social/historical/cultural context, and the developing biological organism (Seligman & Shanock, 1998). In expanding the concept of ego development to include interaction with the social and cultural environment, Erikson reframed it as an individual identity development process. He describes his concept of identity as "the accrued confidence in the inner sameness and continuity of one's meaning for others, the inner experience of oneself" (Erikson, 1950, p. 235). His theory, then, is relational in its orientation and encompasses individual meaning-making, as it is constructed from the self-in-relation with others (Josselson, 1987).

Erikson theorized psychosocial development as "unfolding" in a succession of eight stages over a lifetime, with each stage presenting a new psychosocial "crisis" to be resolved that would result in the development of new ego qualities (Erikson, 1950). The resolution of these crises was seen to be a dialectical synthesis of opposite "attitudes

towards life” which led to a new “dynamic balance” of ego strength that is qualitatively different from, yet building on, previous ego qualities (Stevens, 1983). Erikson (1950, 1968) saw this dialectical process as interwoven with the unfolding needs and capacities of the biological organism as it matures throughout the lifespan. The resulting ego capacity achieved at each stage of development, then, is influenced by the social environment’s capacity to support that development (Stevens, 1983):

Stage 1: Basic trust versus mistrust ⇒ Hope

A dependent infant learns to trust or not trust that the world will supply its nurturance needs, resulting in an ego capacity to hope in the future.

Stage 2: Autonomy versus shame and doubt ⇒ Will

A child develops the ability for muscle control and independent action. The environment’s capacity to support and allow that development leads to the capacity to exercise his/her will in the world.

Stage 3: Initiative versus guilt ⇒ Purpose

A child begins to take risks in initiating actions that result in the capacity to act purposefully in the world...if controls and punishments do not lead to initiative crushing guilt.

Stage 4: Industry versus inferiority ⇒ Competence

A child begins to develop as sense of competence in demonstrating skills in the larger world of school when task accomplishment is valued over specific techniques.

Stage 5: Identity versus role confusion ⇒ Fidelity

An adolescent takes on the task of synthesizing his/her own identity by making choices about who he/she is and will be.

Stage 6: Intimacy versus isolation ⇒ Love

Young adults develops the capacity to love and have commitment to others because of an individual identity is strong enough to risk losing it in an intimate relationship with another.

Stage 7: Generativity versus stagnation ⇒ Care

An adult can develop the ego capacity to care for the next generation through raising offspring or producing creative work that requires the balancing of self-needs with those of others.

Stage 8: Integrity versus Despair and Disgust ⇒ Wisdom

In this final stage, an individual's capacity to face the end of one's life as a path consciously crafted is the wisdom of old age that balances knowing time is limited with having no regrets.

The psychosocial development Erikson (1959) conceptualized as a lifelong unfolding is a dynamic interplay between the body and the individual psyche, and between the individual within the culture at large. As an individual who is embedded in a culture resolves the developmental crises of each stage of development, new ego qualities are incorporated into the developing sense of self, resulting in an identity that continues to unfold in response to environmental demands and supports throughout the lifetime.

A Critique of Erikson's Theory of Psychosocial Development

Erikson's theory of psychosocial development (1959) grounds the concept of individual identity development within a physical and historical/cultural/social framework. The conceptualization that psychosocial development is the result of the interaction between the body, the individual psyche, and society remains Erikson's single most important contribution to the field of psychology (Seligman & Shanok, 1998). Erikson's emphasis on including the entire life cycle into his theory also provided a framework for viewing psychosocial development from a more wholistic and life-long perspective, underscoring the dynamic inter-relationship of the changing individual in a changing environment. In expanding the intra-psychic and sexual focus of Freud's theory to include meanings made from interactions with the larger culture, Erikson laid the groundwork for future multicultural identity work in developmental psychology. That is not to say, though, that Erikson's theory is neutral in the cultural values it represents or in the variety of human beings he imagines capable of such psychosocial development.

One of the major criticisms of Erikson's theory of psychosocial development is

that it primarily describes the development of European American males (Bennett, 1992; Gilligan, 1982; Josselson, 1988). Erikson's linear life-cycle model not only presumes European male cultural values as the norm, but also describes the development of a male whose "normally" functioning body progresses in an inferred uninterrupted and graceful manner into old age. While both Freud and Erikson grounded their theories in the body and linked their stages of development to a maturing physical organism, Minsky (1996) notes that the body virtually disappears in a focus on individual and cultural meaning-making, rendering "identity" virtually bodiless in its abstraction. Davis (1997) has stated that just as race "disappears" into its assumed Whiteness, so too does the body disappear into its assumed non-disabledness. Erikson, in fact, describes the psychosocial development process as a phenomenon that "unfolds by developing, not new organs, but a prescribed sequence of locomotor, sensory, and social capacities" (Erikson, 1950, p.58). Childhood disability, as well as the sudden or gradual onset of disability later in life, challenges this assumed "non-disabledness" as the inevitable linear trajectory of all human identity development. The linking of psychosocial development to mastery of the body and its functioning is problematic for disabled people who may never achieve the Physical mastery Erikson assumes in his theory, which limits the usefulness of Erikson's theory in studying the identity development of disabled people.

Even more problematic than the assumed non-disabledness of the body in Erikson's theory is the negative attitudes towards disability found in Erikson's work, negative attitudes that persists in our culture today. Coles (1973) relates that Erikson ascribed his own successful struggle for healthy psychological development, as an outsider in Germany, to his being "sturdy physically and balanced in a sensory way"; crediting his personal adjustment to his ability to move freely through the European countryside. Conversely, he ascribes maladjustment to children who do not have the opportunity for such free movement. Thomson (1997) points out that Freud, in his essay

“The Exceptions,” “conflates” deformities of character with having a disability when he describes disabled people as psychologically pathological, vestiges of the moral view of disabled people as morally deviant. Erikson (1963), too, conflates these when he equates the “negative identities” of Native American confined to a reservation to that of “helpless” hospitalized mental patients who have “given up” an “active life” (Erikson, 1964). Such conceptualizations infer that a specific level of virility (physical and sensory) and freedom of movement are necessary conditions for psychological “adjustment”; that a state of inner strength is essentially dependent on external physical activity for its development. Such a conclusion does not even consider that the systemic oppression in the external circumstances of Native Americans (Mphandre & Myers, 1993) and disabled people confined to state asylums (Rothman, 1990) may have had a bearing on the behaviors they exhibited.

The assumed non-disabledness of the body and negative conceptualizations of disability leaves Erikson’s theory open to the criticism of being “ableist” in its orientation. Linton (1998) defines “ableism” as the unconscious assumption that the non-disabled experience is the normative grounding for all experience, just as racism and sexism assumes the European American and male experience respectively are the normative grounding of all reality and theory. The very framing of the “crises” of each developmental stage reflects some of the limitations of such non-disabled assumptions and Eurocentric values. In Stage 1, the resolution of “hope” from having nurturance needs met can be problematic for disabled infants and newly disabled people when medical professionals and families confuse medical procedures intended to bring a person closer to society’s “normal” standards with interventions essential to supporting a disabled child or older person’s unique development from that point on. The pre-occupation of Western medicine with “normalization,” rather than supporting unique disability needs, has historically made meeting essential “nurturance needs” a secondary

concern.

In Stage 2, framing muscular control as an essential biological element of psychosocial development is problematic in the lives of disabled people who may never have or regain such a degree of muscular control. The concept of control, in this instance, connotes “domination of” the body, the capacity to will the body to follow commands that may not be possible or healthy for a disabled person to do. Living honorably with the limits of a disability requires collaboration with the body or psychiatric disability, necessitating a following of its lead in what is possible, rather than an imposition of standards of control that society may value. “Control over” the body is a Eurocentric value grounded in the belief that domination of nature is both possible and desirable; a belief which is only possible when humans are viewed as separate from and superior to nature. The framing of the developmental “crisis” of even this early stage as “autonomy versus shame and guilt” indicates that Erikson is grounded in the valuing of “separation from” others and “control over” nature (Meyers, 1988; Mphande & Myers, 1991). Such a conceptualization portends how problematic this theory is for disabled people whose lives will require a lifelong process of active collaboration and interdependency with other people in their social environments.

In grounding his stages of identity development in control, muscular or otherwise, Erikson (1959) fails to include disabled ways of being in constructing a viable identity. In Stage 3, the crisis of “initiative versus guilt” is grounded in the assumption of a child being “vigorous, active, and into everything,” requiring parents to introduce the proper measure of control to facilitate that child learning what he/she is realistically capable of doing (Stevens, 1983, p.47). “Control,” in the sense of limiting action, already exists in the disabling condition and calls for proactive, rather than reactive, responses from people in one’s social environment to enable that disabled person to develop a sense of who they can become. The psychosocial development of a disabled person requires not

control over, but rather an active exploration of less obvious abilities and collaborative facilitation of those possibilities. "Purposefulness," then, for disabled people is the result of actively supported, rather than parentally controlled, "initiative."

Again, in Stage 4, we find issues of control underlying the demonstration of skills as a child's world expands into the school setting. At this stage of development, Erikson (1959) defines "industry" as the mastery of culturally prescribed means of accomplishing goals in the larger world, i.e. reading, writing and arithmetic, etc. It is in such settings that negative cultural beliefs about disability begin to affect more fully the development of skills required for future roles in life. Traditionally, the task of developing a sense of "competency" for disabled people has been determined by rehabilitation medicine in its focus on eliminating the "functional limitations" of disability, the very aspect of a disabled person that cannot be changed (Gill, 1998). Within this therapeutic framework, efforts at "industry" are focused on recreating "normal" ways of doing things, rather than discovering alternative means of accomplishing larger social goals. If the focus of a disabled person's attempt at "industry" were focused on long-term goals of mobility and communication, rather than on the "normal" activities of walking and talking, a sense of competence could be developed through different means, i.e. power wheelchairs and voice synthesizers. Thus, any ensuing sense of "inferiority" arises not from a disabled person's lack of ability, but rather from an environment's lack of facilitating "different" ways to develop the competency of disabled people, while achieving the same social goals.

In Stage 5, Erikson conceptualizes the developmental task of the adolescent as synthesizing who they are with who they will be both vocationally and socially. Again, we find that society presents disabled people with a very different developmental "crisis." The cultural belief that disability renders one "unable," or even "sick" and "defective," has a very chilling effect on the kind of adult roles a disabled person is even thought capable

of fulfilling (Asch & Fine, 1988). When a disabled individual is dependent on those in their environment for opportunities to participate in all aspects of life, others' belief in one's potential ability is as essential for exploring role options, as believing in oneself. Research has found that special education and rehabilitation professionals, who control many of the vocational development opportunities for the majority of disabled people, routinely underestimate their client's abilities, thereby limiting the future roles disabled people are actually prepared to take on later in life (Nafziger, 1992). Conte (1983) found that such professionals viewed their disabled clients as primarily needing "pre-vocational services," rather than career development services, i.e. personal "adjustment" training, activities of daily living, and work orientation, etc. Even more indicative that Erikson's theorized activity of adolescence identity rarely happens for disabled young people is demonstrated by research that found the majority of disabled university students studied had had little or no work experience prior to coming to school (Weeber, 1996). The developmental task for disabled people in this "identity" stage would more likely be proving one's ability to do any kind of work - a qualitatively different task than freely trying on one work role after another to see which one fits! The developmental risk here is not that of "role diffusion," but one of "role deprivation"; while developing the capacity for "fidelity" is more likely to be loyalty to a belief in one's own potential, rather than to a particular career path.

In Stage 6, conceptualizing the developmental crisis as "intimacy versus isolation" is problematic for disabled people, as well as for members of other culturally diverse groups. Erikson's theorizing that the capacity for intimacy is a separate stage is a particularly European male view (Gilligan, 1982; Josselson, 1988). His definition of "intimacy" in this stage is primarily limited to genital intimacy, virtually ignoring the social or emotional intimacy so highly valued by women and people of other cultures (Bennett, 1992). His assumption that all human socialization is towards separation and

individuation is problematic for many reasons (Franz & White, 1985), but particularly because living with a disability requires a highly developed capacity for interdependent relationship skills throughout the entire lifespan, not just at a particular point. Evidence of how limited this very theoretical construct is can be found in the stories of disabled parents relating how their non-disabled infants and children respond with intuitive awareness of and accommodation to their physical limitations, as the parents care for the children (Blackford, 1990). Erikson's Eurocentric, non-disabled, male life may have limited his experiencing such intimate connection and caring earlier in his own life than he theorized it (Bloland, 1999), but a sample of one does not a representative population make.

In Stage 7, developing the capacity for "care" through "generativity" is, again, a developmental milestone society has not historically envisioned for disabled people, particularly the role of parenting (Finger, 1990). The historical cultural belief that disabled people are recipients of care, rather than caregivers, reaches into the lives of disabled adults today who, oftentimes, must defend their "right" to parent in social support networks and courts that do not acknowledge their abilities or right to care for their children (Asch & Fine, 1988; Johnson, 2000). This traditional generativity, and its alternative form of passing on knowledge and skills to the next generation for disabled people, may very well follow, rather than precede Erikson's theorized Stage 8.

Stevens characterizes the "wisdom" of Erikson's Stage 8 as "accepting the nature and inevitability of the pattern of one's life...while appreciating the richness of variability in the ways in which life can be lived" (1983, p. 53) is precisely the kind of wisdom that is generated much earlier in life by living with a disability in an ableist society. Disabled people who have developed such "wisdom" have had to learn to distinguish between the real limits in their lives due to their disability and the artificial barriers that society creates that limit their participation in life. The "wisdom" gained by

such a struggle actually creates the capacity to push through such prejudice to share the generativity/creativity of the disabled person with the rest of society.

While these observations have underscored some of the limitations of Erikson's model *vis a vis* disabled people, there are other aspects of the theory that have great saliency for the disability experience. Because Erikson's model of psychosocial development includes the interaction of the individual with historical/cultural time (Bennett, 1992; Seligman & Shanok, 1998), many theorists have found it useful as a starting point for developing culturally diverse identity development theories. There are many factors that can contribute to an individual not being able to successfully achieve a positive identity and the most salient one for disabled people is the social rejection of an aspect of oneself, e.g. racial group membership, sexual orientation, etc. (Marcia, 1987; Waterman, 1985).). Erikson (1950) saw that such a failure to construct a positive identity would lead to a diffuse sense of self subject to depression, anxiety, and lack of connection with others. While Erikson (1959) never articulated a model of identity development fully applicable to other cultural groups, in his later years he did acknowledge that it was essential to share a sense of community with others "like oneself," as well as observing the negative impact prejudice has on the identity development of African-Americans and Jews. He even alluded to a political element in a culturally diverse community's identity development which must be "won in action," as "one's personal or groups' identity may be relative to another's, and that the principal of gaining strong identity may signify an inner emancipation from a dominant group identity" (Erikson, 1968, p. 22). Erikson made this observation later in his career after watching a politicized Black consciousness unfold out of the black liberation movement.

William Cross' Racial Identity Development Theory

Cross (1971), in his prototypical stage model of the "Negro-to-Black Conversion Experience," predicated his individual racial identity development on a positive in-group

identification that came out of involvement in the Black liberation movement. The most fully developed model of Cross' (1991) theory outlines a developmental process towards active self-understanding in five stages:

(1) Pre-encounter – an individual is programmed to think passively of the world as non-black, anti-black, or the opposite of Black. Behavior and basic attitudes toward the self are determined by the dominant culture.

(2) Encounter – some experience manages to slip by and confront the individual's current feelings about himself/herself and the existing interpretation of the condition of Black people.

(3) Immersion/Emersion – the dominant culture is rejected and everything of value must be relevant to blackness.

(4) Internalization – a strong cultural/racial identity exists that is strong and secure.

(5) Internalization/Commitment – the security of a strong racial identity gives one the desire to work to eliminate racism for all oppressed peoples.

Parham and Helms (1985) have operationalized the first four stages of Cross' model by creating the Racial Identity Attitudes Scale (RIAS) which measures a subject's degree of agreement with statements typifying those four categories of racial identity: Pre-encounter, Encounter, Immersion/Emersion, and Internalization/Commitment.

A Critique of Cross' Theory of Racial Identity Theory

Cross' theory has been one of the most widely used theory of racial identity development model (Myers, et al., 1991; Parham, 1989). The major contribution of Cross' theory to the field of developmental psychology is in developing a model of positive identity development within an oppressive racist environment. The very framing of the identity development process within a racial and sociopolitical context greatly expanded the applicability of identity development theory to the real-life experiences of African Americans and other culturally diverse communities in this country. Because Cross' theory is grounded in liberation politics, the model lends itself to an intentional and strategic framework to further the development of a positive racial identity within the

African American community. It is this sociopolitical framework that makes Cross' theory particularly useful in modeling how the disability community can move beyond its own internalized oppression by raising the community's consciousness and developing a positive identity (Anspach, 1979; Hahn, 1982, Hillyer, 1992). In providing a framework for linking and supporting positive individual and in-group identity development makes this aspects of Cross' theory particularly salient for disability community organization and identity development research and work.

Several limitations have been pointed out as existing in Cross' theory. The first, and most global limitation, is that the theory is grounded in Eurocentric values of the positivist research tradition (Akbar, 1989; Nobles, 1989). Such critics assert that any theory or research about African Americans should be grounded in Afro-centric values and beliefs about the nature of life and being. These critics also see Cross' theory as positing a historically reactive racial identity which does not presuppose African-based identity antecedents independent of White oppression. Disabled researchers are also calling for a community-based research agenda that reflects the community's values and beliefs, as the traditional focus of disability research has generally not reflected the issues and concerns of the disability community (French, 1992; Gill, 1998; Zola, 1993b). Another limitation of Cross' model is that the linear stage-wise theory does not encompass the complexity of the racial identity development processes throughout the life-span (Myers, et al., 1991; Parham, 1989). The concern is that Cross' theory in its theorized sequential progression through the stages is too simplistic and does not truly reflect the daily and ongoing challenges of living in a racist society, as one ages, or as factors other than race have saliency in the identity development of an African American, such as gender, sexual orientation or disability. Such issues would also be a concern when applying such a model to the disability experience, as the ongoing realities of living with a disability can mean changes in one's condition or environmental supports that

make living with a disability and the identity development process quite fluid. In addition to the issues of aging with a disability, the complexity of having multiple facets of oneself intersecting with disability (i.e. gender, race, sexual orientation) cannot be addressed by a theory that encompasses only one oppressed aspect of the self (Myers, et al., 1991; Robinson, 1993).

These concerns and limitations notwithstanding, Cross' model has contributed greatly to the ongoing dialogue that is furthering the understanding of racial identity development in this country. The reactions to and inspirations from Cross' theory have generated greater understanding of the role of race in identity development for those both within and outside of the African American experience. However in relation to disability identity development, racial identity development theories arise out of commonly shared cultural heritage within a family and a community, a fact that is not true of the experience of the majority of disabled people. Only a Deaf person born into a Deaf family, which in turn is imbedded in the Deaf community, can share such a similar identity development process. For an understanding of an identity development process that requires an individual move away from one's family of origin and towards a socially devalued group, with its own culture, an examination of the homosexual identity development process is required.

Vivienne Cass' Theory of Homosexual Identity Development

Cass' theory of homosexual identity development has its grounding in the interactional emphasis of Erikson's (1959) theory of psychosocial development – the self in relation to others. It also builds on the foundation of racial identity development theory that emphasizes the process of identity development within a sub-culture context. The model outlines the homosexual identity development process in six stages:

- (1) **Identity Confusion** – awareness of homosexual feelings that cause internal turmoil, leading to a choice to deny or ask about the possibility of being gay.

(2) **Identity Comparison** – emotional turmoil lessens and there is greater congruence between self-perception and behavior, with increasing congruence with the dominant culture that can be supported by the presence of others were homosexual.

(3) **Identity Tolerance** – with greater acceptance comes comfortableness in acknowledging social, emotional, and sexual needs that may result in reaching out to other homosexuals for support.

(4) **Identity Acceptance** – results in a greater involvement in the gay and lesbian sub-culture that validates and normalizes one's homosexual identity.

(5) **Identity Pride** – pride develops to offset the anxiety arising from one's own acceptance of homosexuality and knowing of society's lack of acceptance. "Coming out" to more people and seeking increased support for the gay and lesbian community supports this.

(6) **Identity Synthesis** – support from heterosexuals, but at this point, leads to a synthesis of the private sexual self and the public self, with homosexuality being seen as an aspect of the whole self.

Cass' (1984) describes the movement of her model as being towards the integration of one's self-image of being homosexual with the view that all others in one's life hold of you. In providing a picture of the process of constructing both a personal and in-group identity that contrasts with the collective identity of one's family and community of origin, Cass has provided greater understanding of how that process can be supported within a community-of-choice context.

Critique of Cass' Theory of Homosexual Identity Development

One of contributions of Cass' theory of homosexual identity development, vis a vis the disability community, is that it provides a compelling description of a process of coming to identify openly and positively with an aspect of one's self that society has traditionally required that one hide (or attempted to eradicate). Unlike racial identity development theories, this theory of homosexual identity development charts a process of a movement towards a "built" community, rather than an identity developed within one's family or community of origin. Many disabled writers have noted a parallel between the experience of the gay and lesbian community and the disability community, even using

the language of “coming out” to describe their own process of identifying positively with the disability community and incorporating their disability into their sense of self (Brown, 1992; Corbett, 1994; Hillyer, 1992; Rousso, 1984; Zola, 1993a). As Bennett (1992) found among lesbians, all of these writers speak of the necessity of interaction with others like themselves in constructing their positive personal identities while acknowledging that the opportunity to experience such community outside of large urban centers is rare for both homosexuals and disabled people (Thompson, 1995; Zola, 1993a). Another contribution of Cass’ theory is that it charts the integration of a developing sense of self with others’ perceptions of that self, essentially by requiring others to come to terms with that part of one’s self that has traditionally been hidden or never verbally acknowledged. Such is the challenge of disabled people who must also construct a positive disability identity in the midst of familial and cultural environments that deny there is anything good that can be associated with disability, a person who may very well have been actively engaged in attempting to distance themselves from that disability.

Some of the limitations in Cass’ theory are reminiscent of other theoretical models in the European-American scientific tradition. The primary one being that a linear stage model does not truly reflect the complexities the identity development process can present homosexuals and that such a linear process can lead to perceiving the stages in a hierarchical and judgmental manner (Bennett, 1992). For Weinberg (1984), the theorized “uniformity” of the theorized process ignores the human capacity for fluidity throughout the lifetime. Others question whether the theorized “identity synthesis” stage is even possible given the violent realities of the current political climate, which has been underscored by recent fatal violence directed at gays in different parts of the country (Lee, 1977; Minton & McDonald, 1984). Cass’ theory is also seen to be limited as it primarily describes the “coming out” process, rather than the

lifelong process of managing a homosexual identity (Bennett, 1992; Walters & Simoni, 1993).

We can find similar issues of complexity and fluidity in the disability experience when self-identifying as disabled and as a member of the disability community made up of a broad range of kinds of disabilities and qualities inherent in people's disability experiences. From a radical feminist perspective, Kitzinger (1990) sees Cass' theory as limited because its "gay affirmative" approach "depoliticizes" the process of identifying as lesbian, emphasizing personal development over political change or seeing political consciousness as merely a stage one moves through (DeLois, 1993). Such identity tensions can also be found within the disability community, as radical liberation politics, disability culture, disability studies, etc. are all generating different approaches to challenging society's "ableist" beliefs about and responses to the disability experience.

Linda James-Myers Optimal Theory of Psychology

In the preceding discussion of theoretical approaches to identity development, we have seen many conceptual contributions to understanding the identity development process of particular groups within American society. In each theoretical approach, limitations arise primarily from the fact that the approach does not or cannot encompass the complexity of the human or group experience within its scope. Such limitations have all been ascribed to methodological problems, a dominant/non-dominant power differential, a political/personal dichotomy, individual/collective emphasis, single/multiple intersections, "zeitgeist"/lifetime timeframe, universal/in-group markers, etc. Myers (1988, 1991, 1998) and Myers, et al. (1991) see all of these limitations arising from the dichotomous, "either/or" Eurocentric worldview that is the underlying framework of all of these theories. The very oppositional thinking of the Eurocentric worldview is seen to be "sub-optimal" because it generates alienation, competition, exploitation, and the oppression of all peoples who ascribe to it (Myers, 1988, 1991, 1998; Myers, et al.,

1991). Within this “sub-optimal” worldview, individuals construct a sense of self that is dependent on external factors for validation; a sense of self that ultimately is self-alienating and fragmenting because it requires a constant proving of worth (Myers, et al., 1991)

Myers (1988) proposes a theory of “optimal” psychology grounded from an Afro-centric and indigenous people’s worldview that acknowledges the spiritual essence of all reality, unifying all forms of life and the spiritual/material dimensions. Within this optimal worldview, an individual’s worth is intrinsic, self-knowledge is the purpose of being, and individual identity is linked to the ancestors, future generations, the community, and nature (Myers, et al., 1991). In this worldview, relationships are marked by interdependence and cooperation (Myers, 1998), leading to “peace, joy, harmony, and the increased well-being of the whole” (Myers, et al., 1991). The six-phase model of Optimal Theory Applied to Identity Development (OTAID) describes a spiraling and expanding process of identity development within the optimal psychology theory vision (Myers, et al., 1991):

- (0) **Absence of Conscious Awareness** – person lacks awareness of distinctions between the self and their environment.
- (1) **Individuation** – person is only aware of a view of self-derived from the immediate surroundings; reinforcement from society can block awareness of other views of the self.
- (2) **Dissonance** – person begins to be aware of negative views of some aspect the self. Emotional re-evaluation of the self can lead to greater awareness of socially constructed dominant/devalued status or a denial such valuations exist/devalued aspect exists.
- (3) **Immersion** – person has increased identification and bonding with others who share common devalued status. Negative feelings may result in withdrawal from dominant group and its values and norms.
- (4) **Internalization** - person develops a secure sense of self, with all salient aspects of the self valued as an aspect of the whole self, with an increased tolerance of others.

(5) **Integration** – as self-knowledge grows and the true nature of oppression is understood, person experiences greater inner peace that extends to relationships with others. Sense of community with more people marks a shift in worldview.

(6) **Transformation** – the self is defined by its spiritual awareness of the interconnectedness and interdependence of all things, including the ancestors, the yet unborn, community and nature. One's culture and history are fully appreciated as part of the whole of humanity and all forms of life are valued. Even the negative consequences of "sub-optimal" systems can be seen as opportunities for growth in self-knowledge.

Myers, et al. (1991) outline a process of identity development that is characterized as an expanding of awareness of the self – from an initial lack of awareness of distinction from the whole of life, through a dawning awareness of and subsequent honoring of unique markers, to a conscious awareness of the unity of all life forms and things. It is a development process that echoes the spiritual wisdom of the *Tao Te Ching*, which speaks of the "ten thousand things" (distinct manifestations) arising from the universal oneness of the Tao and ultimately returning to that "childlike" state of cosmic oneness (Feng & English, 1972).

Critique of Myer's Theory of Optimal Psychology

The most powerful contribution of Myers (1988) Optimal Theory, and its application to the identity development process (Myers, et al., 1991), is that it provides an affirming and all-inclusive alternative to the European American worldview that has formed the foundation of the theories explored thus far in this chapter. In articulating an optimal worldview that is multidimensional, Myers (1988, 1991, 1993, 1998) challenges the one-dimensional Eurocentric scientific frame of reference that only acknowledges what is perceived by the five senses. This very worldview has lead to models of identity development that are based strictly on external markers that can only describe partial aspects of a developing self (Myers, 1998). By deliberately drawing on the shared beliefs and values of ancient African, Asian, Native American and other aboriginal

peoples, contemporary western physics, mystical Christianity, etc., optimal theory affirms that all peoples come from a common gene pool of ancient Africa (Myers, 1988; Myers, et al., 1991), thereby making the theory itself universal in its application to all peoples.

The most important contribution of the Optimal Theory Applied to Identity Development (OTAID), Myers', et al. (1991) is that it provides an approach to identity development that makes it possible to both honor and transcend the "diversity markers" that make us unique as individuals and as groups (Myers, 1998). Building on previous theoretical work, Myers, et al. (1991), extend the identity development process of "embracing" that part of oneself that is devalued (Baldwin, 1972) to acknowledging and embracing one's unity with all of humanity. This principle of unity is fundamentally a spiritual position that also extends this theory beyond the traditional scientific framework of psychosocial developmental and embraces spirituality as a part of all life (Haggins, 1995). This emphasis on the oneness of the human experience has given the OTAID model its capacity to encompass the realities of multiple identities and a theory that can reflect the real identity development process of a disabled African American lesbian. In acknowledging the unity of the spiritual/material realms, Myers (1988) provides an alternative to the medicalized Eurocentric view of disability that focuses on deviance from social/physical norms, resulting in the alienation of the disabled person from their body/condition and that individual from the rest of "normal" society. This unity principle also provides a means of disabled people healing the alienation from the body/condition, from other disabled people and from the larger society, laying the groundwork for wholistic disability identity development that extends beyond the current focus of the disability community primarily on the very material manifestation of rights.

Another important contribution of the OTAID is that the theory presents a resolution a powerful polarization found in the Eurocentric critique of the oppressor /oppressed duality, which holds that one cannot be both oppressed and oppressor.

Using Friere's insightful analysis that no oppressed person is oppressed without their own complicity, Myers posits that in accepting the oneness of all humanity, individuals must see themselves as capable of being both oppressor and oppressed. She points out that those who actually ascribe to oppressive ways of thinking are, themselves, oppressed by the "sub-optimal" system worldview, even if they are unaware of it (cited in Myers, 1998). This presents a particularly powerful challenge to disabled people who have been socialized on a bodily level, sometimes since infancy, to be passive recipients of medical/government /charity services, not as agents in constructing their own lives. Acknowledging that one is responsible for perpetuating a "passive recipient" sense of self also provides the means of crafting their own liberation, which does not require the external world to change before individuals and the community can begin to change themselves. It is an approach to self-liberation that ultimately believes the larger social dance of oppression can be changed by changing one's own personal steps in that dance (Lerner, 1985), an approach that can even be practiced by disabled individuals who may only have internet access to the disability community.

The sweeping scope of the Optimal Theory Applied to Identity Development (OTAID) is both its greatest strength and, at least for now, its greatest limitation. The OTAID model is grounded in abstract and metaphysical concepts that have not yet lent themselves to the development of a comprehensive measure of its phases, although various attempts have been made (Finley, 1998; Myers, et al., 1991; Sevig, 1994). This limited history of research has led to few opportunities to refine the OTAID model; though some work that is being done identifies some limitations that can be addressed. Finley (1998), in a qualitative study of women with multiple identities, found that the development of multiple identities was more complex than the OTAID theorized. The resulting identity pattern was one of various aspects of each women's identity developing independently in relation to different environmental factors. The

developmental process turned out to be one of multiple interweaving and overlapping spirals that only much later in the identity development process resulted in the theorized intersection of identities. In addition, she found that the influence of environmental factors presents another limitation of the OTAID model. Given the “sub-optimal” nature of the world in which we all live, she found it difficult to identify where the identity development process intersects with social change work needed to transform the “sub-optimal” world. This lack of theorized politicization is of particular importance, particularly in a community as embattled for its very physical survival as the disability community (Johnson, 2003).

The realities of disabled people lives that are isolated in medicalized and non-disabled familial environments oftentimes deny them access to alternative views of disability can make the process of disabled people nurturing each others' development extremely problematic, if not downright embattled. Yet, in a discussion of the Transformation phase of the OTAID model, Myers, et al. (1991) state that “harsher forms of victimization are unlikely to be brought into experience” in this phase (p.61). This perspective does not include the stark survival realities facing the minority communities in the “sub-optimal” world in which it must function, particularly the disability community. The “sub-optimal” view of disability has at its core a belief that life with a disability is not worth living (Gallagher, 1995), which leads to systematic denial of life-saving medical measures to disabled people, such as standing Do Not Resuscitate orders for ventilator users in the majority of US hospitals with no consultation of the user's desire to live, denial of transplant surgeries on the basis of disability, forced to live in institutions and nursing homes and denied developmental services to reach full human potential (NDY, 1999). These “harsh forms of victimization” are very much a part the lives of disabled people who may have achieved the place of “transformation,” yet still live in a world that views their life as not worth living. The urgency of the struggle against such

overwhelming hegemonic controls over disabled people's lives and the body makes it difficult to envision how this aspect of Myer's "transformation" will be achieved (Johnson, 2003).

The development of the Optimal Theory Applied to Identity Development (OTAID) has introduced into the field of multicultural work a profound tool for rethinking the various approaches to identity development human differences have generated and, in so doing, has provided a profound tool for evaluating worldviews that have unconsciously functioned within those historical approaches. Learning to honor differences while embracing the oneness of all of humanity is a profound path of healing in the personal, professional, and spiritual realm.

This examination of these multiple identity development models has identified various salient elements of the identity development process that intersect with what is currently known to be true of the disability experience. Erikson's emphasis on psychosocial development being a dynamic interactive process between the individual and their social/historical/cultural environment intersects with the disability community's definition of disability as an interaction between the disabled individual and their environment (Gill, 1987). From Cross' model of racial identity development, we find the emphasis on a positive in-group identity as an essential element of racial identity development mirrored in the current development of disability pride arising from the "identity politics" of the disability community (Anspach, 1979; Weeber, 1999). From Cass' model, the dual dynamics of developing a positive personal identity facilitated by an increasingly public positive identification with a community devalued by society can also be found in disabled people's movement towards identifying positively with the disability community (Corbett, 1994). In Myers' OTAID model, the emphasis on honoring one's uniqueness, as well as one's unity with all humanity, provides a framework for honoring one's place in the disability community while healing the alienation from

body/condition, society and between people with different disabilities. These theories and models will serve as an analytical framework for examining research about identity issues related to the disability identity development process.

Disability-Related Literature Review

Medical Model Research

Myers' (1988) concept of "worldview" provides a tool of analysis to employ when looking at the current body of disability research related to identity development. Akbar (1991) states that a worldview pre-determines the research questions asked, the methodology, and the answers that will even be considered acceptable. The Eurocentric worldview which has generated the majority of disability research that has segmented the disability experience into separate medical diagnoses based strictly in the material realm of bodily or behavioral anomalies, thereby limiting the scope and approach of research to that which can be measured, counted, and used to categorize disability status, and project future possibilities (Myers, et al., 1991). Gill (1987) describes the focus of this medical/rehabilitation research effort to be "disability as pathology" – functional/behavioral limitations and the methods necessary for the remediation of those limitations to ensure the possibility of some kind of future. This scientific view of disability-as-pathology employed statistical norms to generate the standards that humans were expected to conform to or face segregation from society on the basis of disability. Such a use of norms replaced the traditional cultural belief in "ideals" that all were expected to strive for, though not really expected to reach (Davis, 1995). The development of these "clinically defined norms" made it possible for medical professionals to measure a person's deviancy from those norms and devise corrective procedures to ensure the greatest degree of normalization (Gill, 1998).

Within this medicalized, Eurocentric worldview there is no place for the possibility

of anything positive being associated with disability, no positive grounds for a common collective experience and no acknowledgement that society had any responsibility for the many negative realities associated with disability. Identity-related issues within the field of rehabilitation psychology formulated the “problem” faced by disabled people as intra-psychic and social consequences that were believed to necessarily follow from the disabilities themselves (Goffman, 1963; Parsons, 1951). Goffman’s (1963) sociological treatise on disability and stigma characterized disabled people’s identities as “spoiled identities,” similar to Freud and Erikson’s “negative identities,” that required the development of defensive strategies to contain and manage society’s stigmatizing of disability (Anspach, 1979; Gill, 1998). Such identities presuppose that disabled people are only capable of “reactive” identities, which can theoretically have no conceivable positive, “indigenous” antecedent prior to reacting to the oppression of society (Akbar, 1989).

Such theoretical constructs have generated much research on non-disabled people’s perceptions of disabled people, the self-perception of disabled people, and the development of coping and “stigma management” strategies all within the context of disabled individuals struggling with their own deviance from the cultural “norm” (Gill, 2001). In the rehabilitation literature, identity issues have been framed as a solitary struggle of the disabled individual to “adjust” to being disabled. Livneh (1986), in a comprehensive meta-study of rehabilitation research, identified a composite five-stage model of psychological “adaptation” to disability:

1. Initial impact (accompanied by shock);
2. Defense mobilization (leading to bargaining and denial);
3. Initial realization (characterized by mourning);
4. Retaliation (characterized by externalized aggression);
5. Reintegration (involving acceptance and adjustment).

The final phase characterized the disability being accepted as a “containable obstacle to overcome...adjustment [is] the final positive outcome” (Livneh, 1986, p.12).

Hahn (1985, p. 310), in his exploration of disability and identity observes that such a context disabled people would have “difficulty in developing a sense of identity with an attribute that one has been taught to overcome.” This rehabilitation “adaptation” model bears a strong resemblance to Kubler-Ross’s (1968) stages of emotional acceptance of death, a clear indication of the negative context within which rehabilitation specialists envision this theoretical “positive” end point.

Although the model is presented as applying to the entire disability experience, its limited usefulness only applies to the initial process of coming to terms with a traumatic loss of functioning. It does not address longer-term identity issues of the newly disabled, nor does it address the identity development of those with lifelong disabilities. This rehabilitation “adaptation” process is always framed as a de-politicized, individual problem that neither acknowledges larger cultural issues, such as barriers caused by prejudice and discrimination nor the possibility of developing a positive identity independent of the medicalized standard of normal. Neither is there any consideration of the possibility that an individual personal rehabilitation struggle could expand into a positive collective identity with other disabled people (Gill, 2001; Goffman, 1963; Longmore, 1993). It is this Eurocentric medical/rehabilitation worldview that informs the remaining research we will consider in the rest of this paper, either as a worldview employed unconsciously in framing the research or as a falsely constructed reality that is refuted by findings of disabled researchers who are working within social model of disability. The final group of studies to be examined will demonstrate the kind of disability identity research currently being done within the values of the disability community.

Disability Related Identity Research

The first disability research we will examine are from multiple disciplines, such as sociology. Admi (1996), a sociologist, conducted a descriptive qualitative study to get an

insider's view of young people's experiences of growing up with cystic fibrosis (CF). Retrospective longitudinal life-history interviews were conducted to generate a grounded descriptive theory of that developmental process. The life-history approach explores the subjects' perceptions of their interactions with others in their social context, various roles experienced, and different life events over time. Multiple in-depth interviews (60) were conducted with 21 people (10 with CF and 11 family members without CF) over a period of 8 months in the subjects' homes or the hospital clinic where subjects were recruited. Medical records and personal documents were reviewed and all data was analyzed using constant comparative methodology. The initial sampling was non-probable and purposive to represent the typical population served by the clinic; theoretical sampling needs guided additional subject selection to address gaps. All subjects were White and middle class, between the ages of 16 and 25, with health conditions ranging from mild to very involved. Two subjects were married. Four of the subjects were identified as having CF before they were a year old, four between the ages of 3 and 7, and two as late as 10 and 14.

Admi characterized the pattern that emerged as an "ordinary lifestyle," in which CF did not have a central place in their sense of self. Admi found that these young people were involved in a balancing process to manage their own sense of their condition, other people's perception of them and environmental factors that influenced both. Admi found four areas of importance to these young people that she concluded as following a developmental "normative schedule" of interrelated psychosocial, cultural, social, and biological elements of human development:

- 1) Perceiving the self and the centrality of their disease over time
- 2) Constructing the view of others' perceptions of people with CF
- 3) Managing disease-related information
- 4) Managing medical regimes

The subjects defined themselves as ordinary, active children or young people

whose only sense of being different came out of the necessity of regular health management regimes. The young people had high ambitions and led their lives with vitality, refusing to allow their lives to be overly medicalized. The subjects identified as having “a health problem,” but refused to be referred to as “patients” outside a medical settings. Admi reported that the subjects understanding of their condition moved from an initial childhood disinterest in the larger “disease issues,” through an early adolescent preoccupation with its role and meaning in their lives and finally to a self-determined management of their own health. The subjects were very aware of others’ stigmatizing misconceptions of CF and developed complex and varied “telling” strategies to meet different situations and audiences.

The primary strength of Admi’s analysis was in contextualizing the discussion of her findings within the context of a minority experience in contrast to previous medicalized and psychopathology research. Acknowledging CF as a disability and that experience as similar to other minority experiences gave her a broader analytic framework within to work and hear what her subjects were saying. She found her subjects possessed a strength, self-efficacy, independence and competency never alluded to in the psychopathology-oriented literature. Contrary to accepted medical wisdom, Admi also found no evidence of a preoccupation with a shortened lifespan that was generally accepted in the literature as the inevitable byproduct of having CF. Admi noted that previously such instances of an expressed lack of preoccupation was typically “diagnosed” in the psychopathology literature as a defense mechanism of denial or avoidance of the long-term realities of having CF. The subjects did not view themselves as the deviant, sick, handicapped victims of the literature, nor did they consider their illness the “master status” of their lives. She found subjects to have highly flexible and sophisticated communication strategies based on realistic appraisals of people in their environment. And family relationships were reported to be much more supportive of the

subjects' self-directed strategies, which was in sharp contrast to the much-reported pathological patterns previously reported in medical and psychological literature.

While Admi's findings directly conflict with the generally accepted knowledge base of health-care professionals, the dissonance-producing affects of her findings are weakened by her lack of questioning the dominant role of medical professionals and their theories, in the lives of disabled people. The major limit of this study is that Admi continues to locate her discussion within a medicalized framework. Consistently characterizing CF as a "chronic illness" and "diagnosis," and equating that illness construct to disability are markers of such a worldview. While her analysis found an articulation of an "ordinary lifestyle," Admi did not explore possible explanations for such a self-presentation by her subjects. She also did not explore the subjects' knowledge of or involvement with the disability community or how that may or may not have influenced the subjects' sense of self. Researchers within a disability community consciousness would have known numerous possible motivations for such a normalized self-presentation and inquired about them, as well as understanding the critical role of the disability community in developing a sense of self. Such researchers would not use illness language or let the assumed rightness of the dominant role of medical personnel to go unaddressed, however subtle the challenge or whomever the audience.

Two related studies by sociologist Charmaz (1994, 1995) also examine issues of identity and "chronic illness." They are included here because the majority of the health conditions she categorized as "chronic illnesses" are, in fact, "disabilities" as defined by the Americans with Disabilities Act (i.e. heart condition, post-polio syndrome, arthritis, multiple sclerosis, diabetes, stroke, etc.). The two studies will be analyzed together because the researcher's worldview influences the content and analysis of each study in similar ways. In the first study, Charmaz (1994) explored the identity issues of men who had chronic health conditions that seriously affected their daily lives. Data collection

consisted of forty formal in-depth interviews with twenty men, as well as a number of informal interviews. Personal accounts by authors with disabilities and previously collected interviews with women who had chronic health conditions were utilized to identify gender differences. Grounded theory methods were used to analyze the data and refine data gathering. As an analytical construct, Charmaz utilizes a symbolic interactionist definition of dual identity consisting of a “social identity,” conferred by others who share cultural meanings and community memberships, and a “personal identity,” constructed by the individual that differentiates themselves from others.

The men in the study spoke of identity issues Charmaz characterized as “identity dilemmas” arising from the conflict between dealing effectively with the real loss of some ability, while preserving or reclaiming some valued aspect of themselves. For the men interviewed, their sudden change of health status (i.e. heart attack, late stage cancer, stroke, diabetic coma, etc.) was their first “identity dilemma” of encountering their vulnerabilities and mortality which resulted in a future they had not imagined. With the loss of their various abilities, these men lost their stable identities requiring they deliberately reconstruct their identities through finding personal and social validation. Their second “identity dilemma” was how to realistically accommodate their uncertain future, which required they acknowledge their permanently changed circumstances and ultimately led to a reappraisal and reworking of their lives, priorities and relationships. Charmaz noted that for some of the younger men, they found the changes in their circumstances and perceptions to be paths of self-discovery that shaped the foundation of their adult male identities. The third dilemma Charmaz identified was how these men variously defined their health conditions as an enemy, ally, intrusive presence, or opportunity depending on the circumstances and how those circumstances influenced their sense of self at any given time.

While most subjects developed an appreciation of lessons learned through their

diminished “health conditions,” they struggled to preserve valued aspects of their old self. These men tried to limit the ways their disability encroached on their lives by increasing control over some aspects of life using old identity patterns, i.e. reducing the visibility of their disability in public, while privately struggling to maintain some semblance of their traditional male power roles their loss of ability had radically changed. Charmaz noted that traditional male socialization in this culture provides an “action” impetus for recreating a life after illness or injury, but also impedes that process by only allowing male very limited options for a viable male identity. The subjects’ willingness to learn new ways of being male determined the extent to which their physical changes either strengthened or diminished their identities. Being able to imagine future possibilities preserved the subjects’ sense of self as they made progress towards them, though an inability to make progress led to depression.

In the second study, Charmaz explored the role of the body in identity issues as individuals adapt to the impairments of their “chronic illness,” a process she characterized as the new identities people construct from meanings derived by acting in the world with their “problematic bodies.” First analyzing 115 previously conducted interviews on chronic illness for references to the “body in illness,” Charmaz then conducted twenty-five in-depth interviews specifically focusing on the topic with people who had various chronic health conditions. She also used autobiographical accounts from other disabled people for checking her developing concepts. Her analysis presented stages of “adapting to impairments” as a means of discovering and understanding the experience of illness:

- (1) “Experiencing an altered body,” subjects experienced guilt and shame, because they felt betrayed by and alienated from their bodies. In anticipation of full recovery, their initial distancing from their body gradually became an attentive listening to it and support the permanent bodily changes.
- (2) “Coping with changes in bodily appearances” subjects found that

reducing the visibility of their illness/disability limited its effect on their lives and relationships with others, though the less visible the limitations led to people not validating their true limitations due to the lack of any visual markers.

- (3) “Changing identity goals” in which subjects found that the greater visibility of an illness/disability influenced their own choice of new identities, as much for emotional and social relationship reasons, as the bodily changes themselves. Subjects’ felt their identity goals had to be “lowered” when their bodily needs conflicted with their need to balance relational and work roles.
- (4) “Identity trade-offs” were seen as conscious choices to give up some valued aspect of their identity to maintain others that were strengthened by validation from others in the subjects’ social environment.
- (5) “Surrendering to the sick body” in which subjects actively chose to cease pushing bodily limits, seeking victory or control over their condition and flowing with its realities instead. This choice became a point of (re)integration with the body and, thereby, an opportunity to transform the sense of self.

Charmaz concluded that for her subjects, illness presented an opportunity to construct a conscious unity of body and self by learning more fully who one is through struggling to live consciously with the body.

The findings that Charmaz presents as direct reporting of the perspectives and identity struggles related by her subjects are very powerful and rich, with the emotional struggles presented in a vivid manner that communicates the intensity of that experience. Her summary remarks indicate that she has listened well to her subjects, as they convey a clear composite picture of her subjects’ meanings. The problems with her work, again, in the medicalized framework and worldview within which she categorizes and interprets what she hears, her use of illness language to describe the long-term effects of disabling health conditions. She introduces both studies describing the chronic health conditions of her subjects as “assault and catastrophe” and labels themes and categories with language that equates disability with sickness, even when the words used by her subjects do not reflect her choice of labels. For example, one theme

“surrendering to the sick body” actually deals with subjects’ positively experiencing liberation and wholeness by honoring their bodies’ limitations, rather than experiencing their body as “sick.”

Charmaz seems to have predetermined her framework of equating disability with illness, as evidenced by her exclusive use of chronic illness literature as her filter for information. Just as in the medical/rehabilitation literature on disability, Charmaz’s sociological study frames her identity struggles as a depoliticized individual struggle, within a completely non-disabled world. She does not refer to the existence of the disability community’s nor does she demonstrate that a critical disability consciousness informed any part of her analysis. Even the autobiographical personal written accounts she chose to illustrate and validate her theoretical construct, included only one account that reflected a critical disability consciousness. Nobles (1989) very poignantly points out that such use of autobiographical excerpts is questionable at best, as such excerpts can be open to multiple interpretations and are more than likely influenced by unknown historical press.

In her analysis of both studies, Charmaz uses a symbolic interactionist construct of identity development that ultimately proves limiting and problematic. Her use of this theoretical construct does not seem to allow for the existence of a context beyond the immediate environment in which her disabled subjects constructed an alternative individual or social identity other than that conferred on them by their interactions with non-disabled people. She does not explain her rationale for the use of this identity construct, leaving one to questions whether it was adopted because she believed it to be a universal identity construct or whether she chose it *post facto* to describe the isolated identity struggles of her subjects who seemed not to have ever encountered the disability community. Whatever the reason, its use leads to a rather fragmenting symbolic interactionist construct does not include the possibility of a collective disability

identity based on common experiences with other disabled people that can be constructed independent of validation from non-disabled people.

Becker (1981) conducted a qualitative study of deaf adults' self-perceptions and stigma management strategies using participant-observation and interviews. Initially, 200 participants over 60, who had used American Sign Language (ASL) since childhood, were observed in settings where they naturally gathered. Sixty of those participants were then selected for in-depth interviews over a one-year period using ASL. Of those interviewed, ninety-two percent came from hearing families who had communicated negative attitudes towards deafness and the use of ASL. The remaining participants had grown up in deaf families and viewed themselves as carrying on Deaf cultural tradition. Among the subjects from hearing families, Becker found that the use of ASL was a symbolic marker of having a Deaf identity, which he interpreted as a dualistic and devalued perspective on deafness learned from the hearing world of childhood. He seemed unable to grasp that there could be a positive way to identify as disabled.

Becker based his interpretations in the mono-cultural, psychopathology framework of "stigma management" and "adapt to their disability" that made it impossible to view his subjects' increasing identity with the deaf community as a sustaining sense of community with other Deaf people learned in residential schools of childhood. Such a framework continues to centralize the "non-disabled" experience as the grounding of all theory and truth (Linton, 1989) and eliminates a legitimate desire to be able to relax and enjoy the company of those with whom one shares a common language and culture (Dolnick, 1993). He interpreted the problematic nature of communicating with hearing people as creating intra-psychic conflicts, rather than a communication breakdown between members of different different language and culture groups. Such an analytical framework presupposes that members of devalued cultural groups can only be passive recipients of negative messages from the dominant culture, essentially leading to

reactive identities (Bat-Chava, 1994). As Akbar (1991) observes, such an interpretation cannot conceive of a Deaf identity constructed independently of the opinions of hearing people.

Additionally, Becker used traditional measures to quantitatively examine the relationship between the group identification and self-esteem of the Deaf adults observed at the Deaf Club. He found that deaf people were, in fact, active agents in constructing a wide range of dynamic responses to the hearing world that were far more complex than his social identity theory presupposed. His call to rework theories to reflect the complexities of real world Deaf identity processes echoes the disability community's call to rework the limited disability identity constructs of the medical and psychopathology literature. It is noteworthy that in a later study on the service needs of deaf women Becker conducted with a Deaf community educator (Becker & Jauregui, 1985), the tone of the entire study was different. Deaf consciousness and culture was an integral element of the design, as evidenced the use of deaf-affirming language previously missing in Becker's work. The findings of the study were also presented in a manner that reflected the true discriminatory nature of society's interactions with Deaf women, rather than presenting these women as reactive recipients of stigmatizing attitudes. Fundamental changes in design and reporting only occurred because of a cross-cultural collaboration between a Deaf and non-deaf researcher, demonstrating the essential importance of researchers who identify with a culture being involved in the design and analysis of studies to ensure a knowledge base that truly reflects the true lived experience of disabled people (Akbar, 1989).

Yoshido (1993) conducted a qualitative study initially designed to explore how people with traumatic spinal cord injuries reconstructed their lives after their injury. Yoshido used semi-structured interviews designed initially to explore the role of work, community living, and socio-economic status in the process of reconstructing lives.

Early interviews revealed that issues of identity were a primary concern to participants and the theme was explicitly included in the remainder of the interviews. The 35 participants ranging in age of 16 to 52 years of age, were predominantly male, employed and in relationships. Participants' years of living with their spinal cord injuries ranged from 1 to 22 years. Yoshido used symbolic interactionist theoretical approach in analysis of the data and grounded theory methodology to elicit and organize the data into the theoretical model that emerged. Her model of the identity reconstruction process resembled that of a pendulum, with identity constantly moving between five different orientations: 1) the former non-disabled self; 2) the disabled identity as the total self; 3) the super-normal self; 4) the disabled identity as an aspect of self; 5) the middle self. Yoshido focused on reconstructing the insiders' first person perspective of her subjects, yet took her analytical framework from the "disability as chronic illness" literature. She reported her findings as an identity transformation process as a "struggle-among-the-normals" framework, but was unprepared to fully hear her subjects' positive experiences with other disabled people and failed to follow up on them or explore literature from the disability community perspective for more information about the phenomenon. Yoshido was able to perceive that the identity reconstruction process she heard from her subjects was, in fact, a constantly shifting, dual-directional process of transformation which did not reflect the linear rehabilitation constructs of "adjusting" or "adapting." Neither did it reflect the cultural belief that disability is an inherently bad thing, as participants related positive personal outcomes from their disability experience. But without the guiding framework of disability consciousness and an ongoing self-examination of her own unconscious assumptions about disability, Yoshido's findings missed a significant part of the picture and perpetuated the medical model of disability in her summary.

A longitudinal phenomenological case study, conducted by Frank (1988), with a

young lady, Diane DeVries, born without arms or legs which gives keen insight into how a disabled woman constructed her own “resistant” sense of self within a culture that viewed her as an orthopedic defect and “freak.” Frank’s study is framed as a refutation of the rehabilitation psychopathology view of Diane’s “maladjustment” to her disability due to an inner conflict about her body not conforming to “normal” standards of appearance. Diane’s “different body” did not interfere with her having a social “storyline” equal to that of other young women her age and socioeconomic background and the language she used to speak of her own body revealed an inner sense of “intactness.” She considered the body a natural way to be and expressed a strong positive identification with the Venus de Milo. What emerged in Frank’s data analysis was that the real conflict in this Diane’s life was between how she experienced her body and how rehabilitation professionals viewed her body.

Frank describe Diane’s “embodiment” as an approach to life that was guided by two overriding values – mobility and independence of self-care. She would adopt any strategy or device that would enable her to get through life on her own terms. Her childhood experiences had been that of having her body colonized by prosthetic experts who weighted her body down with cumbersome and painful equipment which forced her into a role of dependency to even put them on. Diane found that the artificial limbs served no functional purpose but to allay the “aesthetic fear” of her physical difference in the non-disabled rehabilitation professionals around her (Hahn, 1988). She responded by rejecting any prostheses as an adult, got married, used a power wheelchair and dressed flamboyantly in clothes that accentuated her breasts, which she considered her “best feature.” Labeled an exhibitionist by rehabilitation professionals, Diane persisted in her own strategies of resistance for liberation by constructing her own together look that did not require she hide her stumps under clothes or prostheses (Robinson & Ward, 1991). Documenting Diane’s pre-existing sense of intactness further

supports other findings that many people disabled since childhood view – it's the only bodily experience they have ever known and it is not experienced as defective (Rouso, 1984; Weeber, 1991).

Frank frames this very personal story within a critique of the culture values and beliefs that shaped the medical profession and rehabilitation practices that violate the bodily integrity of disabled people. In revealing how this study also had become her own personal journey of facing deep-seated fears of loss, helplessness, and immobility, Frank demonstrates how a non-disabled researcher and their work can be transformed through a willingness to explore unconsciously held beliefs, values and assumptions about the disability experience. In so doing, they contribute to a body of knowledge that challenges the accepted wisdom of society embodied in traditional research literature.

Disability Identity Development Related Research

Phillips (1985), a disabled folklorist, collected oral narratives on the experience of disability in American culture from 33 disabled adults over the course of eighteen months. The majority of her participants were European Americans disabled since childhood. All were highly educated, though their socioeconomic status did not reflect the typical benefits of advanced degrees. Her research was not initially directed at exploring identity issues *per se*, it became one of the many facets of the picture that emerged in her analysis (Phillips, 1990, 1993). Participants' reported a problematic relationship to the normalization standard imposed on their lives by rehabilitation professionals. Using language that Phillips described as the "deification of normality," participants characterized it as a one-way street with them making all the adjustments to society. The interviews traced an ideological shift in the participants' perception of their disability and society's requirement for normalization over time, from a complete embrace of the rehabilitation agenda to that of viewing disability as a cultural minority experience. Phillips described a dynamic process of personal transformation that

ultimately led to a self-defined “individualism” characterized as “assimilation *sans* denial” and also without an apology for their difference. Participants related complex strategies for constructing their own versions of independence that included assistive devices, personal assistants and medical practices they chose for personal, not medical, reasons. Participants also reported becoming involved politically in demanding that society change.

Employing the disability community perspective in analyzing the data gave Phillips a much broader lens through which to interpret the data gathered in her interviews. Her knowledge of both perspectives enabled her to understand that some of her subjects’ success-oriented strategies could appear to be normalization processes, yet were, in fact, motivated by personal self-defined goals. As a disabled woman, she knew that self-presentation can be a powerful and subtle form of resistance that proudly challenges normalization standards by “inverting” her difference it into a celebration that difference. Phillips concludes with an explicit discussion of the implication of her findings in the field of rehabilitation and how the field itself must change in response to the real developmental needs of disabled people, a conclusion that can only come from research that is conducted to further the needs of the disability community (Akbar, 1991; Oliver, 1990).

Gerschick & Miller (1994) qualitatively examined the intersection of the social construct of masculinity and how disabled men created or maintained their gender identities. Ten disabled men with mobility impairments, primarily men with para- and quadriplegia, were interviewed. Eight participants were European Americans and two African Americans. While the majority of the participants were under-employed, there were class and racial differences in resources available to them. The semi-structured interviews were conducted by the disabled researcher, with follow up conversations to check the accuracy of the reported findings. In addition, participants rated a list of

traditional masculine characteristics for importance to their sense of self, with all data analyzed using an analytic induction approach to see the relationships.

Gerschick & Miller identified three distinct responses to their subjects' "double bind" of traditional cultural expectation of masculinity and cultural implications of being disabled men: 1) "reliance" on traditional masculine patterns of control, independence, strength and concern for appearance; 2) "reformulation" of new ways to meet traditional standards of masculinity; 3) "rejection" of traditional masculinity and intentional reconstruction of social definitions of both masculinity *and* disability. Gerlisck & Miller reported that every participant used each response at one time or another in their lives and that there was a distinct pattern of using different responses in different areas of their lives, in different context.

This study was conducted collaboratively by a disabled and non-disabled researcher, utilizing a larger analytical framework that included a critique of cultural values and beliefs of masculinity and disability. The disabled researcher conducted all the interviews, specifically because of his shared cultural experience with study participants. Other studies have indicated that data gathered by disabled researchers is qualitatively different from data collected by non-disabled researchers both in questions asked and answers given (Weeber, 1999). Such findings contribute, not only to a useful new body of knowledge, but also present a critique of the larger dominant culture's worldview. The identity processes identified in this study underscore that disabled people's identity is an interactive process of constructing both a collective and personal identity, an critical approach to constructing identity that can ultimately challenge and reconstruct society cultural patterns in general.

Priestley, Coker & Watson (1999) conducted a two-year study of the lives of children between the ages of 11 and 16 who had a wide range of disabilities. Data was gathered through participant observation in schools, social settings, interviews,

ethnographic field notes, group discussions and the children's creative writing projects. Some of the disabled children were in segregated schools, while others were mainstreamed and/or in resource rooms in "regular" schools. The findings reported focused on the stories the children told about how they identified themselves in relation to their disability and how other people viewed them. Some children had positive collective disability identities as found disabled adults involved in the disability rights movement, while others rejected such an identity. The majority moved fluidly between the two perspectives, presenting themselves in different settings with different language, depending on how important their disability was to them in a particular social situation. Some of the children identified "being disabled" as only having visible impairments or using assistive devices. Others with less visible disabilities tended to distancing themselves from children who had "worse" disabilities, while others had no problem claiming their "impairment" as a disability. All these children viewed having a disability as a generally negative thing. Some of the children saw disability as an ordinary human variation and believed they shared the experience of discrimination with all other disabled children. These children were focused on changing their environments and others' attitudes.

The researchers located their study within the social model of disability and found their balance of ethnographic methodology in natural settings and interviews led to very different conclusions than traditional "positivist" medical research had previously reported. The social model of disability presupposes a disability identity exists in disabled people prior to its conscious articulation and that observing the language used by disabled people marks that identity. What the researchers found was that disability as a social issue existed in the background of these children's worldview and that any inquiries about disability had to be made within the context of the children's' whole world. These young people did not focus on their own disabilities, but on others' disabilities

through comparison, on discrimination they experienced in their environments or on others' lack of acceptance of them and their disabilities.

One final phenomenological study cannot be excluded, though modesty might suggest otherwise. Weeber (1999) conducted a pilot study on disability identity development, within the social model of disability, which explored relationships and communication patterns with disabled and non-disabled people. The semi-structured interviews were conducted with seven disabled adults between the ages of 40 and 53 and all participants were college educated and in professional roles. Six were White and one African-American; five were male and all were heterosexual. All participants had mobility impairments and one had additional chronic health conditions. The participants were selected by a purposive sampling of those who identified with the disability community and had been disabled long enough to adjust to any later-in-life onset of disability. A follow-up contact was made with participants for personal reflections on the interview content and any additional thoughts to be added.

The participants related a sense of aloneness in their lives prior to encountering the disability community, whether they had had their disability all their lives or acquired it later in life. Participants recounted that their families and social circles focused only on the mechanical aspects of disability and silent about the emotional and psychological aspects. Participants reported hiding the full extent of their limitations from others and received no social support for choosing to use assistive devices when physical limitations increased. Participants related negative public reactions to their disability and private concerns about how such negative views might affect their attractiveness or opportunity to be sexual. The inaccessibility of environments exacerbated their experience of isolation, but also served as the impetus for their developing a more activist stance later in life.

None of the participants sought out the disability community or even knew one

existed, but “felt” the connection of shared experiences and common understanding when first “accidentally” encountering it. Reframing disability as a civil rights issue enabled all the participants to transform their prior aversion to other disabled people into a sense of community and belonging. In experiencing such community, the participants became more open about their true limitations and believed more in their real abilities. Participants spoke of an emotional comfort found in the disability community that, for some, led to a spiritual sense of body/spirit unity.

Participants expressed a sense of comfort and safety in working with a disabled researcher and acknowledged in the interview process and follow-up conversations that it influenced the quality of information given (Weeber, 1999). The design of this study was guided by participatory action research values, as well as a “deliberate psychological intervention model” that seeks to promote psychosocial development by making the interview process itself an opportunity for personal growth and reflection, in addition to contributing to the development of a knowledge base necessary to meet the disability community’s needs. Each participant expressed some personal benefit from the interview process that confirmed the intended reciprocity of the process. Because of the hegemony of the medical model of disability, such personal benefits for study participants can only be realized when research is designed and guided by researchers working within the social model of disability who are committed to addressing disability community needs and pushing the envelope of the scope of traditional research paradigms.

This review of the limited research literature associated with disability identity development reveals both the need for such research and the fact that this nascent body of knowledge is generating very different information from that promulgated by medical model of disability. We find another picture emerging of a dynamic interactive disability identity development process that reflects the interactive nature of Erikson’s

psychosocial identity development process, though not the presumed “negative identities” he envisioned for disabled people. We also find emerging a clear picture that an awareness of or embracing disability identity politics plays a large role in the initial steps towards developing a positive disability identity. This beginning point of disability identity development looks similar to the “internalization” phase of Cross’ (1991) racial identity development model in that it acknowledges a common experience across diverse groups. Reframing the disability experience as a civil rights struggle equal to that of other culturally diverse group enables disabled people to begin to think collectively and develop a critical consciousness that will shape their own identity. The political elements of disability identity development is an ongoing process as so few disabled people are exposed to it in their lives.

The combined process of constructing a personal identity while moving towards a more open, public identification with a devalued group is another facet of disability identity development found in this literature review, just as it was in the research on homosexual identity. It is about integrating one’s whole self into an identity that is grounded in a community different than one’s family and community of origin (Gill, 1998). The common bond of understanding and a sense of belonging experienced within the disability community in the reviewed research are in sharp contrast to the lack of understanding and sense of alienation reported within families and communities of origin. This social disconnection is also found in the reported resistance of family and friends to the use of equipment that makes life easier; demonstrating the centralizing and supremacy of the normalization agenda in disabled people’s social environments. The invisibility of the disability community also contributes to the isolation of disabled people from each other and underscores the challenge to the development of the disability community itself.

The dangers associated with having a disability, or “coming out” as disabled, may

not seem as hostile as the murders of known homosexuals, but they are real threats nonetheless. The number of parents who murder or abandon their disabled children is on the rise, the refusal of health care to people with involved disabilities goes largely unquestioned, and genetic testing and engineering for birth defects are seen as medical miracles. The current push to legalize physician-induced-death in many states is evidence of a cultural climate ruled by the medical profession's endemic belief that life with a disability is not worth living (Gallagher, 1995). The press did not tell the whole story that 75% of the people Jack Kevorkian assisted in killing themselves were disabled people with chronic health conditions, not people with "terminal illnesses." The challenge of finding one's way to a community so devalued and embattled is an act of courage which speaks of the fundamental human need to be with others who can appreciate and understand the totality of one's self.

A final element of disabled people's journey towards wholeness explored in this literature review is the expressed need to be valued and accepted as a human variation, one of a myriad of possible diverse human forms, not as a defective human. Understanding the worldview that hierarchically categorizes diverse human forms provides a tool for reconstructing a devaluing worldview and claiming a personal/collective identity that demands an equal place at the human table. The work that must be done now is to develop a knowledge base that truly reflects the disability identity development process. Without the knowledge of how that process actually unfolds, effective strategies cannot be developed to nurture that development.

Guiding Assumptions

Because this research project is being conducted within the social model of disability, it has been framed within the context of several underlying assumptions. The first being, disabled people who express a positive identity will describe a trajectory through phases or categories similar to those delineated for members of other culturally

diverse communities. Second, that a period of association with other disabled people will be critical in supporting the positive identity development of the participants. And lastly, that a person's disability status will interact with their other diverse statuses, such as race, gender, sexual orientation, etc., leading to markedly different patterns of disability identity development (Gill, 1998).

Summary

This chapter reviewed theories of identity development for their applicability to exploring the disability identity development process. The chapter also discussed the inadequacy of traditional disability research, with its medical and psychopathology orientation, to explore issues related to disability identity development with a positive and collective framework. Finally the chapter examined the limited research that has been done about identity development within the social model of disability. Chapter 3 will discuss the research methodology for this study.

Chapter Three

By seeking to understand the values of such groups in their own terms and not in the terms supplied by the dominant culture, studies of women and minorities articulate the previously submerged power relations. And bringing these relations into broad social consciousness is a vital step in the process of changing them.

N. Aisenburg & M. Harrington

Method

My initial approach to investigating disability identity development was to use a modified version of Helms' existing RAIS instrument (Helms and Parham, 1985), as other researchers had done with homosexual identity development (Cass, 1984), womanist identity development (Ossana, et al., 1991), etc. Over time, this strategy began to feel premature, and just a little bit intellectually dishonest, since using such an instrument could infer that existing research had established that disability identity development mirrored that of racial identity development. As the literature review in Chapter 2 demonstrated, there has been no significant cross-disability research investigating disability identity development within a social and community model of disability, much less a body of literature that supported the possible use of any existing identity development measure. While grappling with these issues, I was encouraged to investigate qualitative research methodology because my "research questions call for qualitative methodology." A qualitative methodology class project investigating disability identity development (Weeber, 1999) confirmed this direction for my dissertation research and that project became a pilot study for my search for dissertation funding.

My search for funding led to an invitation to join a team of disabled researchers at the University of Illinois - Chicago, led by Dr. Carol Gill, writing a proposal for a 3-year field-initiated grant to investigate disability identity development, defined in this project as "a strong self in harmony with the experience of disability" (Gill, 1998, p. 5). It was to be the first national study conducted to generate a theoretical model of disability identity

development comparable to identity development models developed for other culturally diverse populations (Gill, 1998). My contribution to the proposal and the project was the theoretical training in culturally diverse populations' identity development from the NCSU Counselor Education Department. The 3-year study, "Re-defining Wholeness: Formulating a Minority Group Model of Disability Identity Development," was eventually funded by the National Institute of Disability and Rehabilitation Research (Gill, 1998). The over-all project employed both qualitative and quantitative methodologies, though the first year used only qualitative to gather the data that would generate a model of disability identity development. The task of year two was to operationalize that model into a measure to be tested and validated with large groups of disabled people around the country and the third year task was to investigate, in-depth, the intersection of race/ethnicity, gender, class, sexual orientation with participants identified in the first year activities.

The team's choice of qualitative research methodology for the first year's activities mirrored the recommendation of Akbar (1991) in the research agenda he outlined for African American psychologists. He described "ethnographic research" as the "only authentic form of empirical research that is appropriate for this [beginning] point of our development" (Akbar, 1991, p. 720). He identified qualitative research as the foundation of an emerging body of research that would reflect the true needs and values of the African American community. Such qualitative research, he believed, would help develop culturally appropriate theoretical questions for further quantitative research, as well as provide a means for researchers to identify practices and patterns of strength that have defined and sustained the African American community throughout its history (Akbar, 1991). Just such a research agenda has also been called for by disability studies scholars in researching within the disability community (Davis, 1997; Gilson, Tusler and Gill, 1997; Gill, 1998; Linton, 1997; Morris, 1992; Oliver, 1990; Zola, 1993b).

For the first year's task, the team used a subjective, phenomenological approach to explore the phenomenon of disability identity development. Such an approach "assumes that the person is best suited and understood from his or her own perspective" (Neimeyer & Resnikoff, 1982, p.79). Since Bronfenbrenner (1979, p.4) had identified that "...what matters for behavior and development is the environment, as it is *perceived*, rather than as it may exist in 'objective' reality," this study is concerned with investigating the "insider gaze" of Bronfenbrenner's innermost doll - the "meanings" disabled people have constructed in their lives while embedded in the social environments around them. Glaser & Strauss (1967) consider this approach optimal because its focus is to better understand human behavior, as well as its capacity to facilitate the development of new theory. The semi-structured, in-depth interview protocol of the first year's activity are also recommended by Denzin (1970) and Bogdan and Taylor (1975) for researching psychosocial phenomena such as identity development, as they are especially effective in eliciting subjective experiences and meanings of the participants.

Participant Sampling

Being the first national effort to investigate disability identity development within the social model of disability, this study is targeting all disabled people, particularly those seeking to understand their sense of self and their disabilities and how society influences both. Cross (1971), Cass (1984) have identified positive "in-group" identification as an essential element of positive individual identity, so this project is also particularly interested in those disabled people who have positive identification with the disability community. While the definitions of disability found in the ADA were guiding factors for recruitment of participants, the team also asserted that each disabled person was competent to identify or not identify as members of the disability community. For example, a Deaf man I interviewed claimed membership in the Deaf community, as well as the disability community, though many other Deaf people would not consider

themselves members of the disability community. Similarly, many people who have chronic health conditions, such as diabetes, heart disease, chronic fatigue syndrome or multiple chemical sensitivities may also not consider themselves members of the disability community, although under the ADA they certainly are defined as having a one.

Because the disability community identifies itself as cross-disability in nature, “diversity” within the context of disability studies scholarship, such as this study, must also include the diversity of types of disabilities, historical time and age of onset and degree of disability, as well as gender, race/ethnicity and sexual orientation. Disabilities in this all-encompassing definition of the disability community include psychiatric disabilities, physical disabilities, cognitive disabilities, communication disabilities, learning disabilities, hearing and vision disabilities, and people with chronic health conditions, such as chronic fatigue syndrome, multiple chemical sensitivities or diabetes. Recruitment for the over-all project, including the leaders, specifically targeted diverse racial and ethnic groups within the disability community, as such groups do not figure prominently in more mainstream disability organizations or in their leadership due for the same reasons that racism exists in the larger culture. Those recruitment efforts included working closely with community-based advocacy groups and independent living centers that primarily served culturally diverse populations, churches, as well as such groups as the Minority Concerns Committee of the National Council on Independent Living that represented the concerns of Native Americans, African Americans, Hispanic Americans, Pacific Islanders, etc. All participants in the study were also required to be 21 years of age or older.

My contribution to the in-depth interview phase of the project – the subject of this dissertation - was to interview leaders of the disability community about their disability identity development. Dr. Gill, Principle Investigator, thought that I would have greater access to leaders, as I had come to know and be known by many of them in my life and

work with Ron. While it did prove useful to have personal *entre* into the very busy schedules of these leaders, the leaders who participated understood, to a person, the importance of this project for the disability community and were eager to participate on the study's own merits! It was ironic to be asked to interview this particular group of people for the project, as concerns were raised during the defense of my research proposal about the focus of the over-all project to interview only those people who had positive disability identities. My sample, made up solely of leaders who have a positive disability identity, may appear on the surface to be a sample of participants with "minimum differences," (Glaser & Strauss, 1967). But from the perspective of diversity within the disability community, this sample can also be seen as a "maximum variation sampling" (Patton, 1990) due to the diversity of the disabilities included, the point in history disabilities were acquired and the age of onset, as well as racial, ethnic, gender, sexual orientation differences. Glaser & Strauss (1967) point out that such a sample can be useful for theory building by identifying the broadest range of similarities and variations within one's working hypotheses and the themes that emerge. What I found emerging from the interview data were the "dense categories" predicted from such a sample, as the similarity of themes found in individual interview themes and their descriptions eventually collapsed into fewer, but stronger categories that generated my "working" theory of disability identity development (Glaser & Strauss, 1967).

A list of potential disability community leaders to interview was initially generated by the research team on the basis of current or past leadership positions in national disability organizations, current or past roles in government agencies dealing with disability, leadership in grassroots disability organizations, directors of major independent living centers, contributions to disability studies scholarship, etc. In an effort to ensure triangulation in identifying leaders to interview, I posted an internet query (see Appendix A) that was widely circulated by community members through disability

organization listservs, disability websites, personal email lists, etc. asking members of the disability community to identify those individuals considered to be leaders of the community. The wide circulation my simple request received demonstrated the remarkable role the internet plays in facilitating communication among members of the disability community who can be quite physically or geographically isolated from each other. Along with a few responses suspicious of my credibility, motives and intentions, hundreds of names were submitted, with a sufficient duplication of names on the team's list to assure me that the group of leaders we had identified, indeed, reflected the people members of the community considered their leaders. In addition, I utilized the snowball sampling technique, asking leaders I had already interviewed to suggest other people I should try to interview, particularly in identifying leaders of diverse cultural backgrounds to contact.

Disability Community Leaders Demographics

The demographics of the interview participants are as follows (See Appendix B), with profiles chronologically describing the disability identity development of each participant to be discussed in-depth in Chapter 4:

Current Ages: 35 to 72

Gender: 9 women and 9 men

Race/Ethnicity:

- 1 Latina/Native American
- 4 African Americans
- 13 European Americans

Ages of onset

- 11 participants had congenital/early childhood onset
- 7 had later-in-life onset, between the ages of 14-24.

Other “minority” status claimed (in addition to disability):

- gay
- Latina/Native American
- African American

Disabilities:

- 1 blindness
- 1 Deaf
- 1 muscular dystrophy
- 1 cognitive disability
- 1 cerebral palsy
- 1 spina bifida
- 1 myesenia gravis
- 2 spinal cord injury
- 2 psychiatric disability
- 2 congenital and later-in-life amputee
- 5 polio/post-polio

Professional roles/positions:

- Attorney, national disability rights organization
- Director, regional disability rights training center
- Officials, federal agency
- Congressional aide
- Media professional,
- Director, independent living center
- Disability Studies professors
- Social work/counseling professional
- President, regional disability rights organization
- International disability rights organizer,
- Magistrate/disability rights trainer
- Disability lobbyist/consultant,
- Member, National Council on Disability
- CEO, national disability membership organization
- Historian/writer.

The final number of interviews included in this study is less than the stated optimal number requested by my committee, but I concluded theoretical saturation had been reached when, after interviewing eighteen leaders, only one participant described an identity development process that differed significantly from those described by the other eighteen participants. He was the only participant raised in an extended family that shared his disability. He born deaf and grew up embedded in a Deaf community and culture that affirmed each person, which created a sense of self in him that was never included a sense of shame expressed by all but one other participants.

Ethical Treatment of Participants

This study was approved by the North Carolina State University Institutional Review Board on Research Involving Human Subjects and those guidelines were followed throughout the project. Potential participants were contacted either by phone or in person to inquire if they would be willing to participate in the study. Participants were informed the interview would be audio-taped and a transcription made for their review. Upon agreeing, participants were all given the Informed Consent Form (See Appendix C) to read and sign before the interview, which assured them of the confidentiality and anonymity of the interview contents. Each participant was also informed they would be paid \$40 for their participation in the project and that they could withdraw from the study at any point without penalty. It was considered an act of respect to pay participants in the project, as our team of disabled researchers are well aware of the academic exploitation that has occurred among disabled people in the course of non-disabled people doing research “on.” Each participant was sent their interview transcript in electronic format with a request to review for accuracy and anonymity (Appendix D). There were no responses to this emailed request for feedback, for reasons I can only speculate on. Either, there were no glaring misrepresentations in the transcripts and, given the business of participants’ schedules, participants felt no need to respond or they simply did not read them, perhaps from lack of concern or reasons of trust that had been established.

As my analysis of the interview content progressed, each person was sent a Participant Profile of their disability identity development process as related in our interview, with a request to review the profile for accuracy of chronological flow, content and emphasis, as well as authenticity of “voice” (See Appendix E). The profile was constructed by “cutting and pasting” interview content into a chronological narrative of each participants’ disability identity development, giving attention to milestones noted,

significant people, events, attitudes, choices, etc. described in the interview. Three of the participants asked that their real names be used as everyone would know who they were anyway and six others stated those who knew them could probably identify them, but were unconcerned about it.

Sadly, three of the leaders included in this study died before this dissertation could be completed. One died, while two became seriously ill and hospitalized, before I was ready to do member-check follow up with them. I must trust that I was as diligent in telling their stories, in their voices, as I was with the others' who responded that their profiles most accurately reflected their lives. I had nine written responses to the Member Check communications that were positive, with one requesting correction of a chronological error that masked the true, another asked to correct an over emphasis of a family members' attitude. Another asked to change their pseudonym and another clarifying the degree of influence a person or an event had on their identity development. A couple review comments reflected on how the interview process itself had sparked additional insight into their own understanding of themselves or their life course. It had been an opportunity to revisit memories that had not been examined from such a perspective – the kind of feedback every developmental psychology researcher likes to hear!

Trustworthiness of Findings

Credibility

Within qualitative research methodology the task of establishing “internal validity” is viewed more as the task of establishing the “credibility” of the researcher’s data collection and conclusions by determining how closely the findings resemble the stories participants related about their lives. I used several strategies to ensure the accuracy of my representations of the information shared with me by those I interviewed: peer debriefing, discrepant or negative cases and member checks.

Peer debriefing: I used peer debriefing during this research process to clarify my own process and thinking by helping me test hypotheses; get guidance on possible and best methodological approaches and as well as serving as a means to get confidential, yet professional, psychological support while struggling with the isolating research process (Lincoln & Guba, 1989).

I met weekly with my research advisor (45 hours approx.) primarily during the analysis phase. Because the data collection methodology had been worked through with the research team in Chicago, my greatest need was for local, on-going support while analyzing the data I had collected for my own dissertation. These meetings contributed greatly to the following choices in my data analysis (a) streamlining the coding procedure; (b) identifying emerging model positions; (c) contrasting realities between diverse populations and existing models; (d) creation of individual profiles and inclusion of those in “Results” chapter; (e) member checking procedures; and (f) using peer auditor to compare model phases. The collegial discussion and much laughter during these meetings certainly relieved me of some of the stress of my solitary pursuit, as well getting the support and guidance I needed from someone more seasoned in the research process.

I also “met” by phone with the Principle Investigator (6 hours) of the overall project to discuss the parameters of my analysis of the sub-set of interviews I had conducted for the project and for my own dissertation. The discussions focused on the scope and level of my analysis, as discrete from the larger team analysis of all the interview data that was also underway. These conversations helped clarify (a) the relationship between my dissertation analysis and the larger project; (b) the usefulness of the level of my analysis; (c) the categories and themes emerging from the data; (d) disability characteristics that influence disability identity development. The conversations also helped relieve some of my own stress about not know how to juggle

reporting my own research within the context of the larger project, as well as reassuring me that I was on the right track.

Discrepant evidence or negative cases are indicated by the indention of the entire discussion of the discrepancy. Maxwell (1996) describes identifying discrepant evidence or negative cases as a means of testing conclusions drawn from the data. He recommends closely examining such “disconfirming” data, as well as the supporting data, to give a researcher the opportunity to evaluate the viability of their conclusions and modify them as they go along. I had hypothesized that some modicum of positive family support would be a significant factor in disability identity development, yet found one participant, disabled as a older teenager, who did not even have marginally positive family support and another participant, diagnosed with a psychiatric disability as a young adult, who also did not have family support his identifying as a disabled person. Another hypothesis was that all disabled people go through a time of feeling negatively about themselves as disabled people, yet one participant who was born deaf into a Deaf family described never having such negative views of himself.

Member Checks. The original raw data was supplied by participants, who also contributed to the credibility of my representations of that data by responding to my member check requests. Lincoln & Guba (1989) consider this kind of feedback a “crucial” element in establishing the credibility of how the data is presented and the interpretations drawn from that data. Through the member check process, participants were given the opportunity to verify the veracity of the interview contents – though none did in this case, for unknown reasons (See Appendix D). More importantly, participants had the chance to review the chronological disability identity development profile I had constructed from the contents of their interview. I asked for feedback about the

accuracy of details and “voice” of the chronological description, as well as the level of anonymity the profile afforded them (See Appendix E). Six people responded in writing to my email request, while 9 others responded verbally when contacted by telephone. The follow-up phone conversations usually began with a rueful acknowledgement of “owing” me something, indicating that my original request had some significance to them, even if their busy professional work had eclipsed its urgency. Sadly, one participant died in the year following our interview and two others developed severe health problems, making it impossible to reach them to get feedback. I am relying on the consistently positive feedback from the other participants to reassure me that I also told the stories of these three participants with the same accuracy I have been told I achieved in the other profiles.

Transferability

In qualitative research, the task of establishing “transferability” of one’s findings is generally seen as an alternative to “generalizability” or “external validity” in quantitative research. “Transferability” is intended to determine if hypotheses can apply to one or more settings or contexts due to the similarity of the settings (Guba & Lincoln, 1989). Donmoyer finds the concept of “transferability” problematic because of its emphasis on similar conditions in different settings, stating that “the propositional language of hypotheses – is too gross a tool to encompass all that we learn from experience” (1990, p. 187). He sees “transferability” as insufficient to explain how similar experiential knowledge can emerge from multiple personal experiences in different settings or how similar processes, such as disability identity development, can emerge in multiple disabled people who have different disabilities and come from dissimilar settings. In the same vein, Becker questions employing the a variation of the concept of “generalizability” when one is not really looking for all settings to be similar, but rather “about a process, the same no matter where it occurs, in which variations in conditions

create variations in results...[a] classier form of generalization anyway" (1990, p. 240).

Given that this study is intended to develop a theory of the process of disability identity development from the data related by disability community leaders, it is possible to conjecture that the findings of this study may be extended to the disability identity development of other disabled people. It is also conceivable that, given different contexts or resources, disabled people will achieve similar identity positions that were articulated by the leaders, though the leaders themselves may have grown to other positions at the time they were interviewed. Such an approach resembles what Maxwell refers to as "face generalizability" in evaluating qualitative research results, in which "there is no reason *not* to believe that the results apply more generally" (Maxwell, 1996, p. 97).

Thick description. Employing "thick description" to establish a process "transferability" from one group of disabled people to another requires describing in great detail the factors I consider relevant to my working hypotheses, such as place, gender, time, etc. I used Donmoyer's (1990) adaptation of "schema theory" as an alternative means of establishing "transferability" between participants' emerging identity processes, much as he used it to discovering similar processes in case studies that were done in dissimilar settings. Using Donmeyer's (1990) liberal interpretations of Piaget's cognitive processes - assimilation, accommodation, integration and differentiation participants enabled me to identify similarities and differences in the identity development processes between individual participants that transcended the context "dissimilarities" of their disabilities, geographical settings, ages of onset, gender, racial/ethnic, sexual orientation, etc. Contextual notes and my observations about the interview precede each individual profile. In the theoretical notes that follow the profiles, I use my own liberal interpretation of schema theory that involved far more than cognitive structures, to analyze the processes of identity development participants described.

Dependability. The qualitative research equivalent of establishing the “reliability” of one’s findings is generally viewed as the task of establishing “dependability,” though qualitative research is a far more flexible process, than the lock step design plan of quantitative research (Lincoln & Guba, 1985). Establishing dependability can be accomplished by thoroughly documenting how the study design was carried out, as has been done throughout this chapter, describing how decisions about methodology and research processes came out of my consulting with peers and in response to new situations during the research and analysis processes.

Field Notes. Information from field notes about process issues have also been incorporated into the notes preceding and following the participant profiles,

Confirmability

As a member of the community who has been constructing my own disability identity, the prospect of approaching the issue of “confirmability”, or “objectivity,” presents me with some problematic issues not fully acknowledged in either of these traditional approaches. Glaser and Strauss (1967), in their discussion of establishing “confirmability” in grounded theory, enjoin ethnographic researchers to conduct themselves without pre-existing theoretical knowledge or culturally-derived assumptions in their gathering of and analyzing data and demonstrate that by describing their process of analysis. Yet, as was demonstrated in the literature review (See Chapter 2), such an erasure of pre-conceived notions about disability in several grounded theory studies was not achieved which were conducted by a well known “grounded theory” researcher in which the theory she constructed, claiming it to be “grounded” in the data, was, in fact, grounded in traditional views of disability. Given such demonstrated difficulty in achieving “objectivity,” Guba and Lincoln choose to focus on demonstrating the “confirmability” of one’s analysis as “rooted in contexts and persons apart from the evaluator” (1989, p. 243), by providing enough thick description of the analysis process

for others to be able to follow the process. The on-going documentation in my notes of how my analysis was conducted within each interview, and between all of the interviews, serves to address this issue of “confirmability.”

As a disabled person working for social change, my sense of accountability and responsibility lies first and foremost with my community. As a disabled researcher, I do not strive to be the “distant and neutral” researcher Roman and Apple (1990) doubt can even exist. Rather, I seek to conduct myself by the principles of “feminist materialist” qualitative research they articulate: that the research I conduct resonates with disabled people’s needs and lived experiences; that it contributes to their own understanding of the power structures that have existed in disabled lives; that participating in the research process itself benefits the individuals involved; and that presentation of the work is in language that is accessible to members of my community (Roman & Apple, 1990).

While “feminist materialist ethnographic” requires I acknowledge the role of my subjective experiences and political commitment to disrupt traditional power relationships in my research, it also requires documenting how my personal and theoretical assumptions were changed because of participants’ self-knowledge and greater knowledge of the cross-disability community experience (Roman & Apple, 1990). In this spirit, such reflexivity is included in my theoretical notes following each disability identity development profile.

External Auditor. I collaborated with an external auditor with the purpose to further establish that my conclusions are not the products of my own imagination. Through my advisor, I found a colleague quite willing to participate, who had recently completed his dissertation on homosexual identity development and was currently practicing in the community. His primary motivation was a sense of scholarly reciprocity, a sort of “paying it forward” in supporting a colleague coming along, as he himself had been supported. As a counselor, he also wanted to learn about the disability identity

development process for working with those disabled clients he would encounter in his practice. We met six times (9 hours) over a two-month period, first to discuss the goal of the research and the goal of the auditing process. The focus of the auditing process was strictly to “discover” a theoretical model of disability identity development within the social model of disability. As participants articulated different perceptions of disability, disabled people, society, etc., i.e. “positions,” the auditor was to code it with a number (1, 2, etc.) reflecting their relationship to previously number statements. The numbered identity “positions” were then linked to verbatim quotes that contained the new perceptions. Initially, I did not share my own developing theory of identity “positions” or their characteristics with the auditor, wanting him to approach the interviews without my influencing his perceptions. The final coding step was to “collate” the chronological positions and quotes from each interview to develop an emerging model of disability identity development process, as the auditor understood it.

Our discussions focused around comparing our coding of the chronological identity “positions” in each participants interview and the influences associated with those positions, i.e. parents, teachers, other disabled people, etc. They also involved (a) discussing, in depth, disability as a social construct and cultural beliefs that influenced the reading and interpreting of the raw data itself; (b) the similarities and differences between the disability and gay community identity development process; (b) the methodological differences between working from an existing theoretical model and “discovering” a model as it emerges from raw data; (c) comparing the various kinds of influences present in the disability and the homosexual identity development process.

I grappled with the issue of finding a local peer auditor to collaborate with on this project, as I knew of no other scholars in the area who were intellectually prepared to engage with the data from the perspective of the social model of disability. This is not to say counselor education scholars are not constitutionally able to understand the social

model of disability, but rather that there is little or no training in the profession that prepares them to engage critically in disability studies scholarship along these lines. My plight underscored Roman and Apple's concern about the assumed neutrality implicit in the traditional standard of "confirmability," in which they posit that without engaging honestly with unequal power relationships, both in one's own identity development and in the over-all disability experience, attempting to analyze such data can amount to mere "intellectual tourism and voyeurism of researchers" (1990, p.64). The dialogue process of working with an auditor with no training in disability as a social construct during his academic career, proved to be as much an exploration of unexamined beliefs and assumptions about the disability experience and disabled people, as it was a process of confirming or disconfirming my own developing theory. Yet, I found the "dialogic" nature of our discussions quite valuable, as it enabled me to further clarify in my own mind the progression and content of the identity development "positions" in my emerging model, as well as exploring how a lack of knowledge of unequal power relationships in the disability experience influences others' understanding of such data. While this may not qualify as traditionally defined "confirmability," our discussions were conducted in the spirit of feminist materialistic ethnography "emancipatory praxis" (Roman & Apple, 1990, p.61), as I was forced to be self-critical of my own assumptions and conclusions while examining and discussing the differences between our viewpoints.

Data Collection

Investigator

My salient background information has already been discussed in my own disability identity development profile in Chapter 1, which profoundly influenced my data collection and analysis. The very choice of my dissertation topic grew out of my own life experience as a disabled woman, which had given me insight into how a member of any devalued community can deny or devalue aspects of ourselves because of social

devaluation. My professional interest and training in multicultural approaches to public administration and counselor education peaked my interest in how institutionalized discrimination impacts the identity development of devalued peoples. I realize that my perspective of the disability experience is limited by my relatively mild impairments and the social “acceptability” of my polio, which allowed me to enjoy the privileges of walking mobility and thinking I was “passing” as non-disabled. I have also had limited experiential knowledge of the more desperate realities many disabled people live, though I have lived in Section 8 housing, and on food stamps, SSDI, and Medicare for a time. The leaders I interviewed were also privileged as I had been, having access to the same excellent education and middle class sense of options that benefited from, though none of us are strangers to the inner experience of what it is to be “dealt out of the game” institutionally, culturally and professionally on a daily basis. Throughout my data collection and analysis, I was privileged to bear witness to the strength and creativity each person revealed in their interviews; how each found the strength and wisdom to claim their whole selves while living in the midst of almost overwhelming negative cultural press and how they transformed their knowledge into meaningful work to change society.

Establishing trust with research participants can be a challenge for researchers working as “outsiders” with strangers or members of cultures or communities different from their own and in settings that are unfamiliar (Glesne & Peshkin, 1992). For those of us doing research within our own communities, trust is a far less daunting task to achieve, particularly when one is already known as a colleague who shares similar values and beliefs. I anticipated this from previous research done within the disability community, as I was told on multiple occasions that, as a disabled researcher, I was given qualitatively different information than a non-disabled researcher would have been given. Disabled people described it as “feeling safe” to be interviewed by a member of

the disability community, because they knew they would not be subjected to “stupid questions” (Weeber, 1999). Communicating our shared identity as members of the same community also enabled me to establish trust more quickly with those participants who did not already know of me (Merchant, 2001). Given the semi-structured nature of the interview process itself, my counselor training enabled me to ask appropriate and thoughtful follow-up questions that led to fuller accounts of the identity development of each participant.

Settings

I conducted eighteen interviews of people designated as “leaders” by the community, with eighteen discussed in this dissertation. The one interview not discussed here was with a twenty-seven year old, African American/Native American woman, who had just been awarded a national youth leadership award from a national disability organization. Throughout the course of the interview, I sensed this young lady was still struggling with her own identity *vis a vis* her family, the African American community and the disability community itself, either because of age and/or because of the invisible/episodic nature of her disability. Further analysis of her interview, in comparison with other national leader’s interviews, confirmed that sense for me. Consulting with my peers, I concluded her interview would be better included with the larger national pool of interview participants, rather than a focused group of national leaders. While not yet the voice of a seasoned national leader, hers is an important voice to be heard within the larger project, because of what she had to say about the management of the intersection of race, gender and disability, as well as intra-disability community dynamics of visible and invisible disabilities.

Ten interviews took place face-to-face in people’s apartments, offices, or hotel rooms. One interview even took place in a quiet corner of the Barnes & Noble Bookstore on the ground floor of the World Trade Center – the only wheelchair

accessible spot we could find in downtown New York City after an outdoor disability rights demonstration! All read, discussed and signed the Informed Consent Form prior to the interview (See Appendix C). The other seven interviews took place by phone, with informed consent forms faxed beforehand, returned signed and discussed before the interview. The majority of the interviews were 1½ to 2 hours in length, though one lasted approximately 2½ hours. The interviews were all conducted in an atmosphere of relaxed congenial sharing, as the participants all expressed a belief in the importance the study had to the disability community.

Interview Protocol

The interview guide (See Appendix F), used in the in-depth individual interviews, was developed by the research team from a number of sources. Those sources included research questions from previous disability identity development research done by team members (Weeber, 1999; Gilson, Tusler and Gill, 1997; Gill, 1997); from statements made by participants in five focus groups the research team conducted to generate discussion of issues related to identity development; modified questions from existing research about racial, ethnic, gay and women's identity development (see Literature Review); as well as from insights gained from an increasingly published body of autobiographical accounts of disabled people regarding their own identity issues (Murphy, 1990; Zola, 1982; Klein, 1997; Fries, 1997; Claire, 1998; Mairs, 1996). The first seven questions of the interview guide focused on the disabled person's view of their disability, the centrality of their disability to their sense of self, what had made it difficult/easier to be a disabled person and how their views of their disability had changed over time. The next three questions explored the similarity/differences of their view of disability with significant others' views of them, their contact with other disabled people and the intersection of their disability with other aspects of themselves described in their answer to the opening question. A final, very open-ended question sought to

capture any aspect participants thought important to their identity development process that had not yet been raised in the course of the interview.

The interviews were designed to be semi-structured, with open-ended questions that ultimately proved to be more of a guide for the flow of information, rather than a lock step series of questions. Such flexibility enabled me to ask follow-up questions not included in the interview guide that related to the large goal of the interview and also to note questions that were answered naturally in the course of a participant's narrative response to another question, without actually posing the questions themselves. Guba (1978) speaks of this form of interview as a "discovery mode" that is appropriate for exploratory research into such understudied phenomenon as disability identity development. Field notes recorded after the interviews, in the transcription process, and in the member checking communication reflected on the frankness of participants' answers and how that frankness seemed to come from the participants' commitment to the adage that "the personal is political"; that in telling their personal stories other disabled people would benefit, as well as contributing to greater understanding of our true lived experience in the larger society.

Data Management and Analyses

Data Management

Conducting qualitative research generates a large volume of narrative data over the duration of the process. Glesne and Peskin (1992) view the ongoing analysis of that data as the process that shapes and focuses the study. I recorded twenty-six hours of audiotape that translated into two hundred forty eight pages of printed interview transcripts.

Transcription. Each interview was transcribed either by myself, or a private transcription service, with me transcribing one-third of the interviews and the transcriptionist transcribing the other two-thirds. I carefully reviewed each transcript for

accuracy, as the transcriptionist was blind and could not review the typed transcript, paying close attention to those parts of the tape she noted were difficult to understand. While reviewing each tape, I also made notations of paralinguistics, such as laughter, emphasis, pauses, etc. in the body of the transcript to ensure an accurate representation of the participants "voice" in re-telling their story. Despite careful, and sometimes multiple, reviews of sections of audiotape in several transcripts, I was unable to decipher what was being said, though member check comments would lead me to conclude that those spots did not interfere with the accuracy of the profiles constructed. While reviewing the transcripts, I also "cleaned" them of obviously identifying information to ensure as much anonymity as possible before sending to the participants for review (Finley, 1997). Such identifying information consisted of names of the specifics of their disability, cities, schools, places of employment, organizational affiliations, etc.

Data Analysis

The purpose of this study being to "discover" a theoretical model of disability identity development, I used Glaser & Strauss' (1967) four-stage constant comparative method Guba that builds on itself throughout the process of data analysis: (1) comparing themes between interviews; (2) distilling themes into categories and outlining their properties; (3) set the limits of the emerging theory; (4) drafting the theory in written form. During the first two stages, I did all the coding on hard copies of the transcripts, which I then transferred to *Atlas.ti*, a qualitative data analysis program, chosen by the research team to manage data and aid in its analysis.

I first began reading the interview transcripts, first, to identify general themes based on the research questions, as well as elements of Bronfenbrenner's (1979) ecological model of human development, such as others' perceptions of their disability, positive/negative environmental factors, other disabled people, etc. General themes that emerged directly from the interview questions included (a) others' attitudes, beliefs and

assumptions; (b) positive/negative environmental influences; (c) self-perceptions; (d) multiple identities; (e) self-perceptions; etc. Also at this stage, I was looking for themes that may prove significant, if articulated in subsequent interviews, identifying them as “emerging themes” when other participants articulated similar issues. For instance, Phyllis described her sexual identity developing in her early twenties, concurrent with her encounter with a new definition of disability (“sexuality”), so I began looking for similar themes in other interviews. After several participants referred to their sexuality in the same manner, I determined it was an “emerging theme” (See Appendix G). The intermediate step of transferring the data and codes to the *Atlas.ti* program gave me another pass at distilling the themes from all the interviews into stronger categories.

The third “delimiting” stage of this constant comparative method took the form of my writing the individual disability identity development profiles of each of the participants. The process of writing a chronological narrative enabled me to begin “delimiting” the model of disability identity development by identifying which themes were present in the different “positions” participants described as their identity development unfolded. The narrative profiles were constructed using a “chronology technique” recommended by Glesne & Peskin (1992) to describe a process that develops over time (See Chapter 4). In writing the profiles, I “cut and pasted” direct quotes of phrases and words of participants to describe issues salient to the timeline of their identity development, as well as distilling lengthy descriptions of salient, complex situations or patterns participants’ stated influenced their identity development. The profiles when participants were either born with, acquired or identified as having a disability, with no theoretical timeframe considered other than the unfolding of each individual story. The written style of the profile narrative is in descriptive everyday language, because I wanted to match the tone and “voice” participants used in the telling their stories and to ensure that the language of the dissertation itself will be accessible to all members of the

disability community (Glesne & Peskin, 1992; Roman & Apple, 1990).

The final stage of this theory “discovery” process entailed putting the full description of theory of disability identity development into writing, as it emerged from integrating the themes and identity “positions” from all of the participants in the delimiting stage (See Chapter 5). Notes and memos written during the coding and delimiting stages helped me articulate the subtleties of properties of the different “positions.”

Summary

As described in this chapter, the process I followed in conducting this qualitative study was an active process of communication and reflections with the data, members of my research team, the leaders I interviewed and my colleagues locally. The complexity of the research process itself mirrored the complexity of the disability identity development process that emerged from the data, with neither developmental process unfolding in isolation from supportive people and environments. Chapter 4, Results – Individual Disability Identity Development Profiles - will discuss in-depth my investigation of the identity development of each participant and how its process reflected the emerging themes, as well as my theoretical musings about their disability identity development.

Chapter Four

Thus gradually the lesson was learned that no one, including myself, really wanted to hear the mundane details of being sick or handicapped, neither the triumphs nor the hardships.

I.K. Zola

I remember that first day, being in a room with 500 people with disabilities who were talking empowerment and politics and a lot of things. And I said, "Okay, these are the people I've been looking for!"

Karla

Being without a sense of self, without confidence in that self, is more crippling than being crippled. Without faith in oneself, the really difficult problems cannot be solved.

Y. Duffy

Results – Individual Disability Identity Development Profiles

In this chapter I present individual profiles of the disability identity development process of each of the eighteen leaders I interviewed. The leaders' profiles represent diverse disabilities, ages of onset, progressive and stable, cultural, racial, ethnic and sexual orientation backgrounds. The profiles have been constructed using the theoretical lens of Bronfenbrenners' (1979) ecological model of human development to identify how each person's disability identity development was influenced by interpersonal relationships, the response to their disability in community settings, family or personal responses to laws and policies directed at disabled people, and the beliefs, values and assumptions about their disability that were communicated to the participants, significant events and other influences in their life experiences that they related to their sense of self as a disabled person.

Each participants' interview data are presented in as a chronological process that summarizes the important events and influences on their disability identity development. I used verbatim quotes, of varying length, to present the participants' own story in their own words, with paraphrasing summaries of broader strokes of information the

participants related to tie the quotes together. Before each profile, I described the context of the interview, the reason the participant's inclusion in the study and how they described themselves at the beginning of the interview. After each interview, I report my theoretical notes recorded during my analysis of the interview data. Finally, I document the credibility of the profiles by reporting participants' responses to my member check requests, as well as any peer debriefing I may have felt the need of discussing with colleagues.

Phyllis

Contextual Field Notes Phyllis asked to do her interview in the hotel room of a visiting friend, so she could lie down during the interview. It was clear before the interview began that there was much trust between these friends, as evidenced by the fact that the friend stayed in her room resting during the interview. It became clear, also, that issues of identity had been a topic of conversation between the two, as the dynamic between them was that of sisters who share a common worldview and had no need of secrets. I had met Phyllis on many occasions during the past five years, as she was a long time friend of my partner and someone who had been supportive of me after he died. Her most immediate professional position in a federal agency pivotally responsible for national disability policy was the team's reason for including her in the list to be interviewed. And after an initial failure of the first tape to record, the interview lasted the full hour of a second tape. There was much laughter and joking during the interview, as had been the case at times that we had discussed such issues in a group of disabled women hanging out, "gimp girls" as Phyllis call us. Phyllis's answers indicated that she had thought much about the topic of her own identity development, as well as thought about it in the terms of traditional psychology theories of identity. The majority of the interview proceeded in the usual one-on-one format, though near the end Phyllis' friend humorously challenged her interpretation of a workplace dynamic *vis a vis* Phyllis'

disability. It was a difference of interpretation that could very well have arisen from the highly visible nature of Phyllis' disability that had generated much under estimation of her abilities throughout her professional life, and her friend's disability, which had been virtually invisible throughout much of her career that has been focused primarily in the disability community.

Demographic Description

Phyllis identified herself as a middle-aged, "pasty" white, professional American woman, with a family and a husband who has worked all of her professional career in academia or government.

Chronological Identity Development Profile

Phyllis, the youngest daughter of a large Irish family, became disabled in infancy from polio. She described her family as being very matter of fact about the "practical stuff" of her disability - "it was a major characteristic of our family...we talked about it a lot 'cause it was goin' on." There were many hospitalizations and daily physical therapy until she was sixteen years of age, but "not much philosophizing about it" or discussion of its emotional impact on the family or their resources. She also spent some unspecified period of time at the same residential rehab center that Garth was in for rehabilitation after contracting polio. Ironically, the practical the talk and willingness to help never extended to making their house accessible – "...still! I grew up in a totally inaccessible house – now it's a mixture of beautiful accessibility and inaccessibility." Phyllis can only speculate on how her siblings felt about or reacted to the amount of attention her disability required from her parents, as it has not been discussed among them. Neither was she, initially, aware that her mother had to struggle with school officials for her to attend the neighborhood school with her siblings and age-peers. What she does know is that was an accomplishment that she knows enhanced her sense of not being that much different from the other children around her, despite her obvious

disability. In third grade, she learned of school officials' negative attitudes about her attending their school, but was not included in conversations about such things until she was in high school, when the principle tried to block her attending his school, claiming she "couldn't possibly do what she was already doing - go[ing] to that school!"

Childhood friends shared Phyllis' family's practical approach to her disability; they were "age and interest mates" concerned with doing things or getting to places together. Phyllis viewed her disability as "an isolated aspect of my life," encountering disabled people only in medical settings and did not "have any identity with them." In high school, she identified herself as "definitely the egghead kind of girl - head of the debate team, the trigonometry club-type." She knew her disability limited her opportunity to date and "work out all that adolescent stuff," so she deliberately dealt with it by being the "smartest girl around - I chose to excel where I thought I could win...disability requires a reaction, you can't have a disability and not react to it and my reaction to it was to be better and to strive better." She sees this drive to win as her "basic temperament" – imagining that without disability she "might have been a Type A stock broker...or a tennis champion," rather than an "aggressive intellectual person." While Phyllis' family had always "verbalized" their expectations were that Phyllis would fully participate in life, she learned much later in life that her mother had always thought she would live with her. Neither did she tell Phyllis of her own terror when Phyllis went off to college - "she didn't share any of that terror with me...she didn't play out her fears in my life...I was totally oblivious to it!" Even now, her mother does not volunteer such information unless Phyllis asks about it.

Phyllis had grown up viewing her disability as "her personal problem" and how "I got around college was my problem, and my family's problem, not anybody else's problem." Yet, in graduate school she "serendipitously" encountered a "new paradigm of disability" that "radicalized" her. A teaching assistantship in rehabilitation counseling

introduced her to the literature of the disability rights and independent living movements and young disabled professionals she met at conferences who were articulating that they did not see themselves as having “personal failings or as defective models of human beings.” Understanding her disability as a “marginalized” experience gave Phyllis a political identity, a uniting political characteristic with other people with disabilities.” During those years, Phyllis lived “wildly” and sought out “a lot of psychological help to deal with the real downs... loneliness and isolation, [I] had no language to express it. I was doing what 18 year olds do at 26...doing the high level identity development later than my peers.” She spoke of it as a long struggle to know who she was and claim her own value in a world that gave her “so much negative input.” Phyllis always had to counter others’ under estimation of her abilities, a fact she believes limited her career opportunities tremendously – “I always said I had to be the smartest person in the room or else nobody would listen to me!” She knows she has had “fabulous” opportunities, “had incredible luck in people, I’ve met fabulous people, gotten to know great people and they’ve helped me in my career.” She believes if she had been a non-disabled man with her characteristics, she “would have gone farther and faster, if he did exactly what I did – over-prepare, put out more energy, focus.” Even in positions of authority in academia and government, Phyllis has always had to address people’s pre-occupation with her disability – “I had to do the crip-crap first,” before getting on with the business at hand – holding a staff meeting, buying a house, interviewing a faculty candidate, etc. - “I had to handle the audiences’ difficulty with my disability, before I could give the lecture.”

Over time, she has become less sensitive to such reactions, as “it has become less important,” while her disability itself has become a “more interesting aspect” of herself that she now shares with a growing number of disabled friends - “a very special bond of talk about the practical, emotional, sociological and political aspects” of the

disability experience. Her appreciation for the creativity, skills and shared humor of disabled people has grown in these later years, yet she does not see her disability as “the center of my life. It’s not what I’m living for.” Her world is populated with disabled and non-disabled friends alike and her interests range widely. Phyllis sees the place of disability in her life as hierarchical – “my first identity is gender...my next identity is family member – my roots are very deep...white, all of the cultural things that are part of my [ethnic/religious] background, then probably, disability.” As a budding water colorist, Phyllis finally has language to describe the way she views her disability - “my gender and family are black, they’re very dense, they’re all colors, they’re core...If you turned me into a man, I’d have no idea of who I’d be. But if you took away my disability, I know who I’d be...in the sense of the color chart, its gray.”

Theoretical Field Notes

This being the first interview analyzed, I was reading, not only for themes within the interview, but also for themes that could possibly emerge as larger categories throughout the eighteen interviews, which certainly proved to be the case with many of the themes Phyllis articulated. The main themes I found in Phyllis’ interview included:

(a) practical talk (b) high expectations (c) supportive family (d) different experiences (e) unaware of difference in childhood (f) family silent on emotional/psychological issues (g) disability isolated aspect of self (h) no disabled friends (i) focused on strengths (j) new paradigm (k) radicalized (l) inaccessible environment (m) marginalization (n) disability - political identity (o) disability personal problem (p) different values - interdependence (q) disability community (r) delayed development (s) sexuality (t) under estimation of abilities (u) personal temperament (v) years of psychotherapy (w) disability interesting part/not all (x) shared experiences/humor/creativity (y) school discrimination (z) battling mother (A) integration of career/disability identity (B) aloneness (C) relational management (D) good planner (E) less concerned w/ others (F) adolescent awareness

of discrimination (G) silence (H) non-victim (I) normalization.

Phyllis' description of her early sense of her disability as an "isolated part" of her, not feeling different from the children around her, echoes the first stages of Cross' (1991) and Myers', et.al. (1991) models, in which a person understands themselves only through – in this case - her non-disabled environment. Phyllis' first knowledge of a "new paradigm" of disability "radicalized" her, echoing aspects of Cross' "Encounter" stage and Myers', et al. "Dissonance" stage, because it enabled her to reinterpret her disability experience from "a personal failing, or a defective human being," to a "political identity" that she positively shared with other disabled people. When she did encounter the "disability community," it was with other young disabled professionals like herself and that collective experience was also able to begin to see herself as a sexual being. What she had identified as a "lack of practice" in developing "dating skills," was, in fact, a lack of having any disabled role models that enabled her to see herself as capable of that role and activity in the non-disabled world she lived in (Bronfenbrenner, 1979). These disabled young adults took on the adult task of being their own role models, giving themselves permission to learn the social roles and activities society expected of other young adults, in addition to the professional roles they were already pursuing. It was the different beliefs, values and assumptions of this "new paradigm" that enabled Phyllis to blossom socially. She realized she would have to become "socially aggressive" if she was going to manage that sphere and address her delayed adolescence.

In spite of her strong family identification, Phyllis described a kind of "aloneness" she had in struggling with her adolescent developmental issues all by herself, which did not quite mesh with her story of family closeness. "Silence" within the family became a sub-theme of "aloneness" due to the absence of any discussion of psychological or emotional issues related to disability within most families of the participants. Such a silence meant that no one in the family was aware that Phyllis had chosen, as a

teenager, to focus solely on her academic strengths, when she realized she could not “win” at dating in high school. That lack of communication led to a painful prom experience being imposed on Phyllis by her mother because she was unaware of the different values Phyllis had constructed for herself in her “isolation” as the only disabled person in her world. An additional factor that “troubles” her image of family closeness is the fact that her childhood home was never made accessible for her and is still only “partially accessible.” These three emerging themes: “aloneness,” “silence,” and “isolation” all reflect the emotional and psychological experiences of participants’ growing up, or living in, a caring family of people unlike themselves that is unaware of the psychological and emotional realities of living with a disability (French, 2001). A non-disabled family may be unable to understand that growing up in an environment with no disabled role models means there is no one positively reflect the full range of roles and activities expected of adults in this society, as evidenced by the delayed adolescence Phyllis identified herself having in her mid-twenties (Bronfenbrenner, 1979). After Phyllis encountered the disability community, she also began to seek psychological help in dealing with her “loneliness” and the emotional and psychological struggles she had “no language for.” It was this psychotherapy that, over years, finally enabled her to validate herself as a “valuable” and capable member of society, despite all of the “negative input about who you are” from that society. This combination of “psychotherapy” and “disability community” became another emerging theme echoed in other interviews.

The intervening years between that period of time and her later reconnection with the disability community seem to have been lived primarily in a non-disabled professional realm that “reinforce” Phyllis’ non-disabled self-identification (Myers, et al., 1991) as revealed by her comments of irritation of always having “to do the crip crap first” before getting on with whatever business was at hand. It is not clear whether her irritation was at others’ preoccupation with her disability or that her disability interfered

with what was really important to her. Whichever, it seems to be linked to her earlier description of disability as an “isolated part” of herself that she viewed as having nothing to do with what she was about professionally. Interestingly enough, her disagreement with her friend, who was present during the interview, about her interpretation of colleagues’ view of her in her last job, is an example of her irritation at her disability being a factor in a professional setting where, she claimed, it had nothing whatsoever to do with her job as an administrator. Her ongoing irritation seems to indicate unresolved issues with her disability and is reminiscent of a resistance to any influence that would destabilize her non-disabled identity (Cross, Parham, & Helms (1991).

Phyllis’ disability only became a more positive and “interesting part” of her life when she was forming more friendships with disabled people who were also her professional peers in their mutual disability work. She bonded with these new friends, because she could discuss disability from the many different intellectual and emotional angles that she was intellectually engaged in professionally. Those discussions about shared experiences enabled her to begin to appreciate the positive qualities she shares with disabled people who have many different kinds of disabilities - creativity, flexibility, humor, skills, advanced planning, relational management, etc. It might be possible to interpret this position as reflecting Myers, et.al. (1991) “Immersion” stage characterized by bonding with others like oneself, if Phyllis were not also adamant about disability not being “what she lives for” and emphasizing that she has more non-disabled friends, than disabled friends.

Discrepant/negative case: The very language Phyllis uses to describe her disability leads me to many questions, because it does not echo how the majority of the other participants view their disabilities. She describes valuing her disability “hierarchically”, after gender, family/race/religion. That statement, coupled with her statement “if her disability was taken away, she would still know

who she is” does not reflect an “internalization” process in which disability has been incorporated into her sense of self with all salient aspects of the self valued as an aspect of the whole self (Myers, et.al, 1991) or even Gill’s definition of “a strong self in harmony with the experience of disability” (1998, p. 5). Her further description of her primary identities, in water colorist terms, of family/race/religion and gender as “black...core,” and her disability as “gray” reflects that same kind of hierarchy. I found that her further equating her disability with being African American, and describing both as “nurture” versus “nature” factors in her life that led to her having “different experiences,” began to raise questions in my mind about how issues of white racial identity development (Helms, 1993), white privilege (McIntosh, 1989) and non-disabled privilege may be functioning in this articulation of disability identity development.

Identifying herself, at the beginning of the interview, as “pasty white” did not seem to include any acknowledgement of the unearned privileges her whiteness afforded her in the very expectations, education and career opportunities she had had as a disabled white person. Those privileges were quite evident to participants of color who spoke clearly of the racism that exists in the disability rights movement in terms of the distribution of resources and opportunities. Equating her being disabled with being black and the seeming neutrality of the “different” experiences in each status seems to deny the full negative reality racism, and ableism, play in the lives of black people and disabled people’s lives. She is quite able to acknowledge male privilege in decriing her lost professional opportunities, but does not seem to be aware that her highly trained, intellectual aggressiveness as a white disabled woman afforded her a significant amount of non-disabled privilege in being appointed

chair of a university department at the age of thirty two. Given all of these factors, my sense is that Phyllis' disability identity most resembles Cass' (1984) Identity Tolerance stage that may result in reaching out to other disabled people for support, but is not a full embrace. Due to these unacknowledged realities, "racial awareness" became an emerging theme that noted whether European American participants' expressed an awareness of either their race or its ensuing unearned privileges.

Credibility

Member check. Phyllis' reply to my member check request about her profile was that no substantive changes were needed, except the removal of one slightly revealing piece of identifying information. She also stated how much she believed in what I was doing and looked forward to the final product!

Peer debriefing. Rereading Phyllis' discussion of disability as a "nurture" versus "nature" factor in her life, I realized I needed to explore issues of white racial identity development with a colleague, so I could tease out what bothered me about this analogy. Our discussion focused primarily on the issue of privilege, which functions unconsciously in the lives of European Americans as a result of birth. It began to stimulate my own theorizing on how unconscious striving for "non-disabled privilege" can function similarly to white privilege in the lives of disabled people who are able to achieve some semblance of functioning normally in the non-disabled world. I had begun to be acutely aware of the non-disabled privileges I had had as a walking disabled person without even being aware of them when I began to use a scooter at the age of thirty eight. That awareness began to expand to include the non-disabled privileges that are inherent in my being able to verbally articulate my thoughts and needs, understand and communicate without the assistance of an interpreter or reach objects in the built environment because of my long arms and elevating scooter seat.

Lauren

Contextual Field Notes: This 2 and a half hour interview took place in the participant's hotel room because she was in town for a national independent living conference. I had met Lauren through my late partner, but had only gotten to know her well after his death, as a disabled "sister" who supported me long distance in my grief. Because our conversations over the previous years had primarily been about Ron or political events on the national scene, I knew very little about her personally. Her participation in the study was important primarily because of the invisibility of her disability, in addition to her leadership in various roles she has played at the state, regional and federal policy development and implementation level over the years. The interview had a more serious quality than the first interview and periodically Lauren would express appreciation for the quality of a question or the personal insight gained from reflecting on it. The initial part of the interview involved much work-related information that seemed only tangentially related to Lauren's identity development, but I decided to follow her lead and see where it led us. When analyzing the interview as a whole, I realized that imbedded in all the free-form work-related information was a very clear description of her current identity development position, as well as where she had been in the past.

Another interesting aspect of the interview was Lauren's keen eye for observing other disabled people and various aspects of their identity development process. She had consciously thought much of her own disability identity development and therefore was aware of issues she and others had or had not have dealt with in their identity development process. This could be explained in part by her revelation that she, too, had found it most important to go to counseling for many years. I believe that Lauren's wide range of personal and professional involvement with disabled people over the course of her many years of work, in many different settings, also contributed to the sharpness of her observations, from directing a state system of independent living

centers to serving as staff in a federal disability agency and regionally responsible for training both disabled and non-disabled people in disability rights law for a federal agency.

Demographic Description

Lauren identified herself as a woman from an upper middle class family, with a Masters' degree in public health and a disability that has been virtually invisible for the majority of her professional life. She is also European American.

Chronological Disability Identity Development Profile

Lauren became totally disabled in her late teens from a sudden onset of a paralyzing neuromuscular condition – unable to speak, eat, breathe, move or even blink her eyes on her own. She described her life, up to that point, as one of white, upper-class privilege and herself as “a rockette, concerned about Saturday dates...being in the in-crowd...hair and clothes...a very banal, shallow world!” Her parents say she “was always such a stubborn, feisty, defiant kid - I would never do it their way”; an innate personality trait which they later admired as her “indomitable will” that enabled her to begin to regain muscle capacity after five years in the hospital. Her disability, she says, gave her “a path” that few teenagers experience, a path that was as much a spiritual journey as it was a journey of recovery. “It was like going to the mountain, like the gurus do, and sitting and getting it, getting what values are all about, what’s important and what’s not, what can be taken away and what can’t be.” Completely paralyzed, Lauren knew the only thing she could exercise control over was “my attitude...I still had a choice about how I was going to deal with it.” While she would never want to go through that “horrible experience” again, Lauren acknowledges “something good came out of it...it was a gift...a by-product of it, totally unexpected.” The response of her family and circle of high school friends was part of the horror of that experience, as friends never came to visit five years in the hospital, unable to “cope” with the change. For her family as a

whole, her disability “was never okay...it was shame, an embarrassment, unacceptance, unhelpful, a bother.” She remembers hearing herself described to others as “my invalid, indigent, crippled daughter” who was only given begrudging, martyr-like help. Given her family’s and society’s attitudes about her and disability, she knew she would have to engineer her own recovery, because “wasn’t nobody gonna’ bail me out - the medical profession didn’t know crap about chronicity!” Lauren already knew the prejudice and lack of expectations society had for disabled people - “‘cause I was one of them! And that was a double-edged sword – a source of sadness and a source of ‘I’ll show you!’” Her determination and efforts not to be “a shut-in” were viewed as so risky she was forced to sign papers absolving the hospital, doctor and her mother of all responsibility should she die in her attempt to live life on her own terms. She spoke of being driven by “pure anger” to prove to them that she was not a “victim,” not their “charity case” who should be kept safe in an institution. “Anger, yeah! I didn’t get here with love! No, no, no, no! I got it out of battle!”

Her struggle to live by her own vision was very much a solitary one, as few in her world gave her support. The many years of struggle to regain strength, to overcome her own embarrassment at her physical state and to get an undergraduate degree were spoken of as having “merely” happened. Graduate school, though, brought two things that contributed greatly to her efforts to reconstruct her life. First, she encountered a man who actually enjoyed helping her navigate school and who ultimately became her husband. His gentle support was something she never had in her own family - “he was like a guardian angel” who delighted in taking care of her. Eventually, the marriage changed into a close friendship because she realized her husband actually needed her to be dependent and she needed to continue rebuilding her own strength and independence. The other event – a graduate research project - introduced her to the independent living movement. She had insisted on investigating her experience of

disability, rather than limiting herself to the graduate program's narrow focus on disability in childhood or old age. A research visit to an independent living center, run completely by and for disabled people, connected her to the disability community and people who shared her values. The center was actually "helping people become independent – get out of town! I couldn't even believe my eyes!" Shortly thereafter, when she took the position of the director of such a center in her state, "it was like everything I had prepared for earlier was coming together!"

As her disability has become less obvious, Lauren has encountered negative messages from the disability community - "It's a very, very sad, lonely place to be – you're straddling both worlds." Within the disability community, some consider her not "disabled enough" and her accommodation needs not as essential as ramps or interpreters. Her family and the non-disabled world consider her "too disabled...not right!" Being "stubborn," Lauren has rejected that "you have to be a certain way to be accepted" in either world, a choice she describes as exacting "a huge price, lots of prices for not going with the flow." Through much counseling, though, she has learned how "physically, emotionally, spiritually and mentally destructive" it is to live out of anger at such things. She understands now that her strength comes from "a spiritual direction, very powerful, and always knowing that it would be okay." She is now "less sensitive" to other's negative views of her, which has required an "internal strength... there are more and more facets to 'overcome' and if you don't have internal endurance and strength to do it - its very hard work, it's a very hard road!"

It is this internal strength that Lauren knows she shares with other disabled people, as well as the common experience of struggling with society's discrimination and lowered expectations. She knows her disability experience has also engendered within her a compassion and a sense of commonality with other disenfranchised communities in this country, because of the similar experiences such disenfranchised groups share

with disabled people. In the disability rights work she now does, she knows there will always be another incremental step to take in the right direction that society's resistance actually provides the tension and direction of the struggle itself, and she accepts that the struggle for equality will be always be an ongoing effort.

Theoretical Notes

The themes that I found in Lauren's interview included: (a) current openness about disability (b) no disabled role models (c) disavowed as incapable (d) invisible disability – straddling two worlds (e) aloneness (f) unsupportive family (g) unconcerned about others' perceptions (h) stubborn, indomitable will (i) independence, (j) accomplishments led to positive sense of self, (k) self-reliance (l) not victim (m) abandonment (n) risk taker (o) shame (p) embarrassment (q) underestimation of abilities (r) creativity (s) choices limited by "helping" professionals (t) disability community (u) inner strength (v) spirituality (w) gender differences (x) self-defined (y) anger (z) context (A) sexuality (B) psychotherapy (C) acceptance of reality (D) change incremental (E) positive qualities (F) relational management (G) racial awareness (H) normalization (I) new paradigm.

Lauren introduces the emerging theme of "anger" and spoke of it at length, as part of her own and others' disability identity development process. It was an anger directed at the cultural beliefs that she knew disavowed her worth as a human being without any prospect of a viable future life. That anger was the catalyst that spurred her to devise her own means to get out of the hospital and prove to her family and society that their lack of expectations for her future was wrong. It was only after encountering the disability community, during research for her Master's thesis, when Lauren experienced a collective of people doing what she had been doing alone by the sheer force of her "indomitable will." Lauren's further observation that many people in the disability rights movement stay in that place of anger, began to illuminate an emerging

identity position similar to Cross's (1991) Immersion Stage, in which disabled people focus their collective identity on shared "oppression and discrimination, us-them thinking, victim mentality," etc. Lauren described other qualities of that identity position of people thinking there was a "disability litmus test" in which a person must have an obviously and visibly identifiable disability to be fully accepted as a member of the disability community. She related that this was initially a painful aspect of her having an invisible disability and not being fully accepted in her non-disabled family or the disability community - a "straddling of two worlds." She further described a "disability hierarchy" that functions as "internalized oppression" in which some disabled people replicate the larger culture's value-laden perceptions of disabilities being more or less acceptable to non-disabled society, the more "valued" disabilities being one's with a perceived level of acceptability in the non-disabled world, such as, polio or blindness, as opposed to cerebral palsy or mental retardation. It is a phenomenon similar to the color hierarchy that still exists in some parts of the African American community and can contribute to feelings of shame in disabled people with disabilities that are more devalued by society, as well as people in the disability community (Neal & Wilson, 1989).

"Spirituality," was another theme that emerged in Lauren's interview, first introduced as part of her identity development process when she described her years of total paralysis - "like meditating for days on end...going to the mountain, like the gurus do, and sitting on the mountain and getting it...getting what life is...what values are all about...what's important and what's not...what can be taken away from you and what can't be and I learned then, very, very clearly that no matter what they did to me personally, I had control of my attitude." This spiritual quality in her disability identity echoes the OTAID model Transformation Stage (Myers, et al., 1991). Although she acknowledged that her early anger at negating attitudes helped her regain physical abilities, through years of "psychotherapy" she came to realize how spiritually destructive

continuing to live in such an emotional place was to her. Her observation that that place of anger keeps one from realizing the universal human spiritual truths in issues faced by disabled people and that continuing to only reference disability interferes with developing a sense of connected and commonality with all of humanity. She credits her inner, spiritual strength with the wisdom she now has in knowing that working for social change is an incremental and interactive process, requiring listening to others' resistance and addressing that lack of understanding. Her response to my inquiry if her understanding of the incremental process political and cultural change came from her own inner lessons learned while incrementally rebuilding her own strength was to call me Dr. Freud. Her observations relating to this "position" of disability identity were repeated by other participants and contributed to a fuller description of most fully developed position in my working theory of disability identity development that was emerging, a theory that will be discussed in Chapter 5.

Discrepant Case. The begrudging support Lauren had from her family of origin did not fit my working assumptions about the role families play in the identity development of such leaders. While I knew that the disability community played a pivotal role in disability identity development, I had also thought supportive families would play an essential role, at least, in providing the kind of support that everyone needs to develop a basic sense of self efficacy. Yet here was a participant whose family of origin could not affirmatively support her; and whose husband needed her to remain dependent on him for support, rather than encouraging her to develop her own capabilities. I posit that the fact that Lauren was already 17, with a stubborn sense of self already constructed before she became disabled, enabled her to incrementally reconstruct her sense of self in defiance of the medical world's or her family's disavowal of her future. The innate, "indomitable will" she described as an element of her personality played

an important role in her drive to reconstruct her life on her own terms and enabled her to defy those disabled people who could not accept her as “disabled enough.” This information helped clarify the quality of support disabled people can benefit from within their families, but it also confirmed that individual “personality traits,” an emerging theme, also play a significant role in disability identity development, even when needed support is not present.

Credibility

Member Check: Lauren found that her profile reflected her voice and a correct chronology of her identity development. She expressed concern, though, that a section relating to the anger she had talked about having early in her disability experience. She wanted the profile to more clearly reflect that her anger was directed at the cultural beliefs held by her family, the medical establishment and the society that disavowed her worth and the possibility of her having a viable future strictly on the basis of her disability. The profile was changed to reflect that.

Leslie

Contextual Notes

This interview took place in my hotel room, during a national disability conference, in an atmosphere of warmth. Leslie expressed great appreciation for the overall project itself, and my involvement in particular. Throughout the interview, she expressed delight at questions asked and seemed to relish the insights gained from reflecting on the issues raised by the question. We had met through our professional involvement in disability studies and her leadership in that field and in integrating that social critique into other academic arenas was the primary reason for her involvement in the project. She had always been very open about her appreciation of the bond she shares with her disability “sisters” and, despite the perceived elevated position of her academic accomplishment, had always been warmly supportive of young women

scholars.

Demographic Description

Leslie described herself as a disabled woman, mother, and professor from a working class background who is relationally oriented and analytically inclined. She is also European American.

Chronological Disability Identity Development Profile

Leslie was born with a congenital disability, the only child of working class parents because her parents chose not to have any more children. They “didn’t want to have any more children like me,” though eventually they came to see her as “just like everybody else; you can do whatever anybody else can do,” which included the typical gender expectations that she would “marry well and be as cute as [she] possibly could be.” Leslie acknowledges that while such expectations were positive in enabling her to see herself as capable of doing whatever she wanted, that family script led to a “silence” about her disability, a “denial” of its reality in hers and their lives. In hindsight, Leslie believes that their silence was the result of her disability being “shameful and embarrassing” to them. Leslie describes her mother as “virulently unsentimental...you take your knocks and you keep a stiff upper lip.” So, whatever conversations did occur about her disability were “perfunctory,” dealing only with concrete things such as doctors’ visits, surgery and hospitals. While the family script was not to talk about feelings or ideas about anything, the underlying message she got was “we don’t talk about your disability, we don’t deal with it, it’s not supposed to have any effect on you and it’s not supposed to have any affect on anybody else.” Leslie described her disability was not “medicalized much” because she had little functional limitation, which she believes made it possible for the family, despite many surgeries, to not view it as “a huge deal.” Leslie herself “always felt whole,” not limited in any way, because it was the only way she had ever experienced herself. She did not feel herself “as having any loss,” though she was

aware others did not perceive her that way.

Popular throughout her school years, she repeated the family's "avoidance/denial" pattern with her non-disabled friends, never talking about her disability with them either. Leslie stated that while she had no language for "talking about my disability or how I felt about it for many, many years," she did feel uncomfortable when "patronized" with awards she suspected were given to her for "overcoming her disability." Awarded the "Most Deserving Distinction" her senior year, her inner response was, "I bet the reason I got this was because everybody thinks I was such a brave, you know, disabled girl!" With no language to talk about her disability, Leslie realizes now that it was impossible for anyone in her world to acknowledge its existence, much less understand how it influenced her life. Family expectations, in general, were not high, so she felt no undue pressure to perform, though she knew she was "supposed to be good and not get in trouble and go to jail – you needed to conform to the rules." It was only as she grew beyond those working class values, that she was able to appreciate how her disability had shaped who she was becoming.

Leslie's recalls "a strong sense of inferiority" in her extended family that had little ambition or expectation for achievement, so her choice to be the first to go to college was unusual. Her further academic endeavors of becoming a professor became yet another aspect of her life she could not really share with her family. The "class and gender-based assumptions" about education for women in her family was that it would help you support yourself... "if you didn't marry well." While Leslie sees such gender notions as potentially disempowering, for her it has become a source of pride and empowerment... "whatever I've made of my life is entirely mine. I'm never doing it out of someone else's script." Leslie did fulfill the expected family gender role by marrying well and being a mother, but the family script she created in her own family was quite different from that of her "family of origin." Her husband is "remarkably supportive...of

my career, it's always been, 'Go for it!'...which is a great message" and encouragement, as in her world women's work was never meant to be meaningful. The communication "ethic" she established in her own family was "relentlessly founded on talking incessantly about everything ...seriously, about how we feel...about psychology...about relationships"...even if they didn't want to! Their cultivated ethic of communication, then, expanded to include disability, when it became a conscious and integral part of Leslie's life and work.

Leslie describes herself as "relentlessly analytical...not so much because of the disability, but because of the way disability was responded to by other people...therefore I do what I do, which is talk and think!" When introduced to "intellectual feminism" in graduate school, Leslie began to see the parallels between feminism and her disability experience, using that critical framework to "understand disability as a social system, instead of a personal flaw... absolutely a conversion experience!" Feminism was "very liberating for me...it gave me a global kind of way of understanding a tremendous number of experiences that I had had." Because Leslie had always experienced her gender and disability with the same sense of inferiority, developing a social critique about disability was "tremendously empowering...it gave me a kind of theoretical paradigm, in a personal way...to explore this aspect of myself." Through disability literature, she came to understand that her need and ability to connect with other people was grounded in her disability experience..."what an epiphany! All of a sudden, I recognized who I am in a way that I didn't recognize at all before!" What she understood was that her own skills in "relational management" had developed from mediating herself and her disability with others..."what you have to do as a person with a disability is put other people around you at ease...assure everybody that you are not a freak, that everything's going to be okay." Initially, Leslie's work of incorporating the "category" of disability into her academic work was done in isolation - "it wasn't really being done at

all” - though she had “a lot of support” in her own department. Leslie, up to this point, had not “thought of herself as a person with a disability. I didn’t even know there were people in the world with disabilities. I don’t know where they were, it wasn’t like I avoided them.” So when she was urged to connect with a leading disability studies scholar on campus she had never heard of, who also had a disability, she admits being “nervous as hell to talk to him...because I was one person with a disability and he was a person with a disability. I was really scared about talking about this [her disability] in a public forum, even with the fact that I was intellectualizing it – that gave me a little distance - but I was really nervous.” Her passionate commitment to incorporating disability into her academic work won out – “I’m going to do this, damn it, somebody needs to do it!”

She found an encouraging mentor who introduced her to the current disability studies literature and to a community of other disability studies scholars...“the first time I went to SDS, I couldn’t believe it...felt a kinship right away! It was really fabulous! It was a community of people I had another thing in common with, in that we were all academics. I don’t think it would have been so great if I had met a group of disabled people who were plumbers or longshoreman. So, it was a transformative experience!” Despite the fact that no one in disability studies was yet working in the humanities, she experienced a sense of community she “was never allowed to share with anybody...a community that I had never had before.” For Leslie that community included a sense of “familiarity” that transcended the differences of disabilities, “we all had something in common...the emotional part that was so good was simply not being the only one...being with a bunch of people who understood the experience I had had in total isolation my whole life!” Leslie describes never having anyone to talk to about disability...“not that I tried and failed, it’s just that the way my life was set up that there was never, never an opportunity.”

As she integrated her disability into her life and work, Leslie started to think of herself as a person with a disability...“and I liked it!” and now finds it “impossible to extricate my being a disabled woman from who I am.” She had not anticipated renegotiating friendships with friends who were “mystified” by her new identity; girlfriends, who like Leslie, had never “thought of [her] as a person with a disability.” She even found herself “nervous to tell my mother I was doing this and I thought that was very telling!” which confirmed for her that her disability had been “a kind of family secret...this is something we don’t acknowledge!” Having always identified as a “girl’s girl,” Leslie’s circle of sustaining women expanded to include her disability identity - “it’s my girls, my disabled girls, that are really most important people for me.” Identifying as a disabled woman has brought a “tremendous focus” to her life and her work - “it feels like a kind of completion!” In her professional life now, she sees herself as having “an important role...a dual mission, to bring disability into literary studies and to bring humanities methodologies into disability studies. Its kind of like scurrying back and forth...there’s lots of people doing it now...so that makes it very exciting!”

Theoretical notes

The main themes I found in Leslie’s interview included: (a) normalization (b) silence (c) practical talk (d) denial (e) shame (f) embarrassment (g) relational management (h) equal expectations (i) gender identity (k) integration (l) disability community (m) no disabled friends (n) isolation (o) aloneness (p) emotional bond (q) shared experiences ® new paradigm (s) social critique (t) family secret (u) disabled girls (v) friendship renegotiation (w) profession bridger (x) disability/professional bond (y) colleague support (z) race awareness.

Leslie’s limited, and not overly medicalized, disability enabled her to benefit from non-disabled privilege by being able to participate in typical adolescent developmental activities, learning the roles and activities expected of females in her working class

world. Being exposed to larger ideas in college generated an new identity position for Leslie that was reminiscent of the OTAID model “Dissonance” stage (Myers, et al., 1991), which enabled her begin to see the parallels between her experience of disability with the socially constructed devalued status of women. Making the next step required connecting, first, with another disabled scholar who became her intellectual mentor and, then, introduced her to the disability community. Leslie’s initial experience with collective “disability community” was an instantaneous personal and emotional bonding experience of OTAID “Immersion” (Myers, et. al., 1991) with other disabled scholars who were also engaged in the intellectual enterprise of critically analyzing the social construction of disability and synthesizing their personal experiences into their professional work that made that bonding possible.

Leslie describes another emerging theme of finding her way to the “new paradigm” of disability through involvement in other political liberation movements. Her academic work in “intellectual feminism” exposed her to critical theory, which examines how social systems create experiences of oppression a process does not necessarily involve political activism. Understanding that social critique enabled Leslie to begin to see how the same system of oppression had functioned in her unacknowledged and unarticulated disability and the same critique could be applied to that experience. Other participants came to this “new paradigm” of disability through their involvement in the civil rights movement, women’s movement, farm worker movement, etc. It was a process of expanding their understanding of their own disability experience beyond perceiving it as their “personal defect” to seeing it as a socially constructed devalued position in society, parallel to that of other devalued communities. This particular identity “position,” in which the “new paradigm” of disability enables disabled people to see the disability experience within the arena of civil rights, echoes Cross’s “Internalization” Stage (1991) by acknowledging a commonality of experience between disabled people

and other diverse and devalued communities. That is not to suggest that disability identity development does not include, for some participants and disabled people, an identity position similar to Cross' Immersion/Emergence stage, but as Myers, et.al. (1991) state in their discussion of the OTAID model, identity does not develop in a linear fashion and everyone does not necessarily experience all possible stages.

Credibility

Member Check: I called Leslie when she did not respond in writing to my email member check request and she immediately acknowledged that she knew she still owed me something! She was finally admitting that email was becoming more difficult for her and we proceeded to review the profile together while on the phone. She expressed that it was all right and that the facts and the voice were correct, though I sensed she was less than enthusiastic about it. My attempts at reaching her to explore my hunch have proved unsuccessful, as she is out of the country for an extended time. So I can report that the profile is accurate, though perhaps not of the kind of analysis she may have been expecting at that point.

Carlota

Contextual Notes

Carlota and I met for our interview after a downtown demonstration about healthcare organized by the regional disability rights group she had served as president of for a term. Her participation in this study came primarily from her leadership, at one time, of this highly effective regional organization, as well as her involvement in national organizations, such as Not Dead Yet and ADAPT, and as a professor introducing disability studies into her university. We did an unplanned access survey of downtown restaurants looking for an accessible quiet place to do an interview, finally ending up in a quiet corner in a Barnes & Noble for an uninterrupted 1 1/2 hour interview. Our paths had crossed multiple times during previous years in DC at demonstrations, but this was

the first time we had sat down to an in-depth conversation. The bond of common experiences as polio “sisters” gave the interview a comfortable flow of story-telling and laughter that comes with shared experiences.

Demographic Description

Carlota identified herself as an Italian-born, middle-aged, disabled woman with post-polio who is a professor. She is also European American.

Chronological Disability Identity Development

Carlota was an only child, born in a small town in Italy and contracted polio as an infant. With no medical care available, Carlota’s parent’s focused their energy on going to America where Carlota would be cured and able to walk...“nothing else seemed to matter!” Her disability was a source of pain, pity, shame and guilt for her extended family that let her know, even though she was “the pretty little girl,” they knew she would never marry and raise a family - the only possible role for women in that world. At thirteen, Carlota and her parents immigrated to the United States, and because of that sacrifice she felt a deep sense of obligation to her parents to do everything the doctors recommended that might make her walk - “that’s all I heard all my childhood years...I felt like that had to be, otherwise I was no good the way I was.” She spoke of her 17 surgeries as “torture,” which she knew deep down would not work – yet always feeling “this better work and I better do everything right!” Carlota eventually did walk some, though the heavy braces and crutches proved too dangerous.

Beginning with first her hospitalization at thirteen, Carlota established her first friendships with other disabled children - “I felt so good seeing, being with all these other disabled kids...I was so happy!” Having disabled friends remained a necessary constant in her life, even while she was “trying to make it in this non-disabled world.” With her disabled friends, she was able to be honest about how hard non-disabled people made her life – “I could be truthful, you know, I could share experiences and that is very

important...to be able to talk and compare notes and you see that its not just you...they're not just singling me out and I found that very, very important!" With non-disabled friends, she felt she "was faking it in some way, that I had to suppress that part of me that was disabled in order to be accepted, that I had to make my disability as inconspicuous as...don't make waves. So I struggled – I was walking on crutches at the time – I struggled to get up those steps, to go to the restroom with them...whatever it took, I had to do that!" During those years, she spoke of her disability as "a source of pain to me...I didn't want it to be a part of me."

When Carlota went to college there were very few disabled people there and, even though she was aware of early disability rights organizing going on in the city, her focus remained on fitting in to the "non-disabled world." It was during her college training to be a language professor that Carlota finally refused to go along with her parent's dream of a cure. She had fallen constantly over the years, breaking limbs that required more surgeries, until at the age of 27, she finally refused to undergo any more surgeries - "Enough! I'm not going to walk! I'm an adult now and nobody's going to tell me I have to do this, I have to be cured - this is it!" Her choice made for "a difficult, very difficult kind of relationship with my parents...it was like a terrible failure. I don't know whether [my father] really believed it, he was a very intelligent man. How could he believe that I was going to walk?" Carlota described that decision as her first step toward "coming home to the disability community" and it was from the disability community that she got the validation she needed for her choice to feel good about herself as a disabled person and a disabled woman...just as she was!

As other disabled women became Carlota's role models of beauty, she discarded non-disabled standards of beauty --"I was kind of slow, but then I realized I could be beautiful as a disabled woman...I didn't have to strive to be someone else, I could just be myself. I wasted so much energy trying to fit in!" Previously "it felt like the two worlds

didn't go together, because if you were at the table, you were not quite seen as a woman, as a whole woman...not valued...not attractive enough to be considered a sexual partner." Accepting and embracing her disability identity led to her feeling "really good about being a woman – I think I kind of became a better woman...I certainly started feeling good about my body." She speaks of her pride in being a part of the disability community – "they're my people...each one so different, so beautiful in his/her own way!" Her involvement with her "brothers and sisters" in the disability rights movement is grounded in their "common experience of discrimination...the years of fighting in the same struggle...what it feels like to be in a body that's not as valued as non-disabled bodies." She also speaks of their shared internal struggle to "embrace their disabilities" that enables them to work together to change how society views disabled people. She describes her "chosen identity" as a disabled woman activist as something she consciously "forged...it didn't just happen, it took years and it's a precious thing!"

Carlota now finds that her deepest and strongest relationships are with disabled people in the movement, though she "feels a bond" and understanding with the majority of disabled people "who are out there fighting their personal battles...who do not feel any connection...are isolated and hate being disabled." She does not feel loss of friendships with non-disabled people, because to her "they don't know you, they don't really get it all the way." Even her parents could never appreciate how empowering her disability rights work in the disability community was for her - "I tried to communicate to them how important this was...look, I'm fine, just feel good about me – I'm fine...but I don't think they really understood." She does know that they were proud of the fact that she was a college professor. Her parents had always seen their role in life was caring for and protecting her, yet as they aged, "I was taking care of them...everything got turned around," and in that role they were able to see her in a different light – "that felt good."

At this point in her life, Carlota knows that her ability to feel good about being a disabled person – despite the physical aspects of aging with her disability - is a direct result of her involvement with the disability community – “I know that I never would have come to this point, if I was isolated...but it was only when I had a sense of belonging that I could really embrace – not just accept.” Neither does it mean that there are not daily issues to contend with that continue to generate struggle – “what makes it difficult to be disabled is the obstacles and barriers, the prejudice, the discrimination” by non-disabled people who do value her disability, “not only that, they don’t want me to feel good about my disability - they’ll do everything they can to make me feel bad about it...you are constantly coming across that, and its not easy, not easy!” Her personal life has become more fulfilling, because of her deliberate choice to be in a long-term relationship with a disabled man – “we understand each other perfectly, we know where we’re coming from and we also work together in the movement...a really wonderful feeling!” Yet even there, the systemic discrimination of government policies deny them the option to marry, because doing so would forfeit essential medical support – “the system, the whole way the government is set up...that makes it difficult to be disabled.”

In her professional life, Carlota is encountering an increase of discriminating attitudes as she tries to convince colleagues of the legitimacy of disability studies as a field of intellectual inquiry - “they have no inkling about what this course could be about. ‘Disability culture, what’s that?’” Her attempts to explain usually generate simplistic comments grounded in the medical model of disability - “the stupid things we’re so used to hearing...I’ll get those same reactions from these brilliant people!” Carlota sees her teaching a disability studies course as a “merging of these identities - disability activist and teacher – two identities merging.” She has known that her mere presence as a disabled professor in the classroom was an activist act, in and of itself, challenging colleagues’ or supervisors’ negative beliefs, which her students did not seem to hold.

Yet, in raising the ante by introducing a disability culture course into the curriculum, Carlota is experiencing increased dissonance on the part of her colleagues and realizes it will take time for them to grasp that their seemingly personal views of disability are, in fact, a devaluing social construct. She also knows that in coming home to the disability community, and in embracing herself as a disabled woman, she has actually realized her parent's dream – "I was cured, I was cured as can be! I couldn't be any better than I am! Not what they thought, a different kind of cure altogether."

Theoretical Notes

The major themes I found in Carlota's interview were: (a) discrimination (b) struggle (c) common bond (d) disability community (e) rejection (f) early disabled friends (g) denial (h) delayed development (i) integration – gender/disability (j) faking (k) cure (l) systemic discrimination (m) other's perceptions (n) aloneness (o) aging (p) under-estimation of abilities (q) medical model (r) street activism (s) normalization (t) no female role expectations (u) viewed as not sexually viable (v) cross-cultural issues (w) integration -disability/professional (x) intellectual resistance (y) embrace (z) new paradigm (A) no non-disabled friends (B) disabled female role models (C) medical abuse (D) daily discrimination/hostility (E) wanted to fit in (F) disabled partner (G) race awareness.

From the age of thirteen to twenty-seven, Carlota's life was medicalized in her parents' pursuit of a cure, a goal that seemed to her to be rooted in the belief that she not acceptable as she was. Their faith in American medicine seemed grounded in the belief that in America all things were possible, a view that possibly was fueled by exported cinematic representations of the cultural myth of disabled people being cured by self-sacrificing doctors or overcoming their disability by heroically accomplishing inspirational feats. She spoke of her seventeen surgeries as "torture" that she endured, always doubting and hopeful they would succeed. Her parents' inability to let go of their

dream and support her new positive view of herself - without a cure – was a reality other participants related, as well. The very themes of “normalization,” “medicalized childhood” that participants described, in which families forced or urged their child to become as normal as possible in functioning or appearance through years of surgery or therapy, such as Carlota and Phyllis endured, led to feelings of “shame” because the children understood they were not seen as acceptable as they were and needed to bring themselves up to non-disabled standards to benefit from its privileges.

Such a standard, within one’s own family, would also explain the theme of “denial” participants described by feeling the need to hide the full extent of their disability from their families and the amount of energy they spent proving to them and the non-disabled world that they are as “good as able-bodied people.” Being closer to appearing or functioning as a non-disabled person, means one is closer to benefiting from the privileges thereof – social and family connectedness, accessibility to greater resources like education, employment, sexual partners, information, etc.

As a child, Carlota had a deep sense of obligation, rooted in her family’s “old world” Italian values, to go along with the dream of a cure because they made the sacrifice to come to America for her. That she refused, as an adult, to continue to go along with the pattern of more surgeries disrupted her sense of connected with her parents and became her first step towards identifying with the disability community instead. Carlota expresses similar bonds of obligation and belonging in her identification with her disabled “brothers and sisters in the movement,” who are activists working for disability rights using street-fighting methods.

This disability identity “position” is reminiscent of Cross’ (1991) “Immersion” stage, which he described the essence as (and I paraphrase!), “everything non-disabled sucks!” Such an “activist” identity position is also reflected in the fact that Carlota has no meaningful friendship with non-disabled people. Carlota views non-disabled people “on

the street, in the stores” as her sources of discrimination, patronizing attitudes, obstacles, oppressive policies, and above all ignorance of what it means to be disabled and she feels little connection to them at all.

Another quality of this Immersion-like activist position, articulated by Carlotta, describes the common disability experience as the shared experience of “different bodies.” Within the context of a cross-disability movement, such a description renders people with other kinds of disabilities, and their issues, virtually invisible; a phenomenon that functions in the disability community very much as race functions in the larger culture. European Americans do not have to think (or talk) about race or the privileges of belonging to the dominant culture, which makes their silence a form of power that reduces other communities, and their issues, to invisibility (McIntosh, 1989). The physically disabled people who have historically been the dominant group organizing and leading the disability community have also been predominantly European Americans, which has created a form of “physically disabled privilege” that functions similarly to white privilege in both cultures. By not overtly including people with invisible disabilities in descriptions of the disability community, physically disabled people render people with other kinds of disabilities and their issues invisible – and their commonalities unknowable.

There are indications that Carlota may be beginning a transitional point in her disability identity development, because she is taking on a new role by introducing a course on the culture of disability and disability as a social construct into an academic setting of high-powered, non-disabled social scientists. The very development of such a course is requiring that Carlota learn new ways of articulating the disability experience, beyond the shared insider language of disability activists engaged in a common struggle. Unlike her previous covert action of simply being a disabled language professor, Carlota’s choice to overtly introduce disability into the academic discourse is generating

dialogue with her “brilliant” colleagues that she is finding less than satisfactory. Such challenges could eventually lead Carlota to expand her disability community frame of reference to include disability studies scholars, who could mentor her in examining disability within the broader scope of disability studies and critical theory, thereby increasing her ability to communicate her personal experiences as ideas more fully to her non-disabled colleagues...and perhaps even develop collegial relationship with them (Sprinthall & Thies-Sprinthall, 1983).

Credibility

Member Check: Carlota responded that the profile reflected both her voice and the chronology of her disability identity development. She also observed that any friends of hers who read it would be probably be able to identify her, though she was not concerned about that in the least.

Florence

Contextual Notes

The hour and a half interview with Florence took place in her office at the independent living center where she was the executive director. Florence had been recommended to be included in the study not only for her current leadership role, but also for her leadership in disability policy development and implementation in previous positions for one of the larger metropolitan areas on the east coast.

Demographic Description

Florence described herself as a wife, a mother, and a “liberal arts dim sum queen” whose life-long disability enables her to apply her “generalist” skills to the many intersections of disability with race, policy, gender, etc.

Disability Identity Development Profile

Florence, the youngest of three siblings, was born with a congenital disability that always gave her a “sense of otherness, of being separated from everybody and

isolated.” The only child in her family, school or world with a disability, her sense of self, starting in elementary school, was that of “looking through the fence and being separated from everybody – clearly a very negative, a very lonely and a very alienated and isolated image.” She spoke of living a “schizophrenic” life all the way through high school of a bright, involved student during the school year and fourteen surgeries each summer that kept her from spending time with her peers. Florence did not have a carefree childhood that allowed her to take risks and learn from failures. Instead, she had to learn to plan ahead for all contingencies, because “the price [of failure] was just way too high.” The physical aspects of her disability required her “to do things that were alien to kids that age...so I was very conscious that I was different...I had to hide all this, this was nothing I would ever talk to my friends about or share.” She knows that her high intelligence counter-balanced teachers’ prejudice about her physical disability and earned her positive reinforcement for which she used to “appear to be keeping up with everyone.” She had a group of friends – bright kids who were able to accept her because her disability required nothing of them. The “merciless teasing” of other classmates made school “just miserable...I internalized a lot of bad feelings about myself...I was unhappy and self-conscious!” Her friends and classmates communicated that she was to keep up with them and never expect to be accommodated - “we’ll be your friend as long as you do not call attention to the ways in which you need help.” The on-going message from her parents was to not plan for the future, a career, retirement – “Don’t talk about getting married, because you may never get married, because no one may marry you...don’t think that far ahead, because we don’t know what is going to happen.” Florence credits eleven years of therapy with helping her “start to undo” all of the internalized negative messages - “it’s a long process and it needs sustained effort with someone who can help.”

Multiple family crises and a series of personal physical traumas during her late

high school years added to the impact of Florence entering college. She discovered that she had been very “sheltered and ill-prepared by my parents for the activities of daily living - I didn’t know how to tie my shoe laces...didn’t know how to take care of myself!” and classmates at her highly competitive Ivy League school were not inclined to lend a hand. In her first two years of college, Florence struggled with depression brought on by increasing health problems that finally required she leave school to recover and catch up in the summer. A junior year internship in Washington, DC, with the senator who had oversight responsibilities for disability policy, was “a life-changing event” for Florence - “a real sort of wakeup call for me of raising my consciousness.” On her return to campus, she teamed up with disabled law students to form a student disability rights groups and their highly publicized legal battle forced the university to make substantial systemic changes on campus. Prior to these experiences, Florence assumed she gained much by not disclosing her disability, by “trying to hide and blend in,” she “cringed with being associated” in people’s minds with other disabled people and “would have been repulsed’ by large gatherings of disabled people. She learned that being open about her disability and working for disability rights was “enormously empowering.” Having strong disabled female role models among her classmates made it possible for Florence to begin to identify positively as a disabled person. She described the next few years as ones of “dipping my toe in and pulling it out of this identity of being a person with a disability.” Ultimately, Florence took positions dealing with disability policy that gave her a chance to work with the disability community and become ever more comfortable identifying as a member of the community – “we click around that commonality of what it meant to grow up with a disability...the kind of thought process and adjustment process and the coping skills that we all developed that has allowed us to be true to who we are, but manage and be out there in the non-disabled world.”

In her early isolation from the disability community, Florence “had been haunted”

by the question of motherhood as a disabled woman, “desperately wanting someone to talk to who’d been there and done that and could give me some wisdom” about being a disabled wife and mother. Florence met such a role model through her work, a woman with advanced degrees just like herself! The encouragement she got from this relationship, plus marrying a man who viewed her as a whole person, enabled Florence to be the whole woman – the professional, wife and mother she had always wanted to be. Florence’s role model, in turn, identified Florence a “future leader” of the disability community and mentored her on the importance of disability rights. The qualitative differences between their approaches to working for disability rights has convinced Florence the disability community is facing a challenge of how to nurture future leadership. She knows the adversarial struggle of earlier activists was necessary to raise awareness and get laws passed, but the work of implementing those laws now requires a more collegial, collaborative leadership approach. Over the years, Florence’s career in municipal government, which began with the single focus of disability, reached a senior policy position with no disability focus. As the only disabled person in such a senior position, her disability felt more obvious and co-workers’ reactions to her choice to direct an independent living center revealed that their professional acceptance of her required viewing her as an exception – “you don’t want to be a professional disabled person! We already think of you as being [in effect] better than that and different than that and why would you want to go backwards?” Florence is aware that her privileged education has given her both the skills and opportunities few disabled people have and her hope is that her effectiveness in those positions will have made a positive impact and open the door for other disabled people in the future.

As director of an independent living center, Florence has “found the perfect place” to integrate her professional training and her increasing sense of belonging in the disability community. Working with disabled people proved to be a “safe environment” to

process the many negative “images and ideas” she had internalized, both about herself and other disabled people whose disabilities she was not comfortable with. The supportive environment has enabled Florence to be more real about the physical realities of her disability “...and not have to worry that this is going to have repercussions, that you are letting down the entire community of people with disabilities by letting your employer know that people with disabilities have aches and pains and somehow this will be held against everybody else who comes!” Florence relishes working with people she shares the bond of understanding what keeps “us out there fighting this fight every day.” She knows that the independent living center “is not the real world...this is a terrarium” and envisions a future in which she will be doing work that may have little to do with disability – “not that I’ve tied it up in a bow, but the pieces have started to come together that I can start to look at another issue as a focus for awhile...or maybe not.”

Ironically, Florence finds that her life is more satisfying to her than some of her Ivy League non-disabled friends who “passively” followed familial career expectations and now feel trapped in lives not of their choosing. Her self-defined professional and personal success – “not that running an IL Center is anybody’s definition of a high powered career!” – has only now led to difficult discussions with these friends about their differing expectations which they never had during college. Florence knows that her parents’ belief she would not long live enough to have a career freed her from living an “unexamined life,” and credits her disability with giving her the ability to “be very reflecting, very inward turned ...in a good way, it makes you examine your life” and helped give her a clarity about choices. Managing her disability also trained her to be strategic in her thinking, a plus in her career - “a problem solver – it lets you get out of boxes...that’s a really powerful thing to learn to be.” The strong network and reputation Florence has built over the years has facilitated her success as a disabled professional,

though she imagines being considered less marketable beyond the world in which she is known. Balancing professions, family and disability is a challenge shared equally by Florence and her husband, as are the trade-offs required to remain a part of their supportive urban network. Florence began learning to honor her limits – “learning it’s okay not to go at 150%...at everybody else’s 100% is where I need to wind up - its going to start being deleterious to my health if I don’t... that’s an aging issue.” Florence no longer sees her limitations as a source of shame, but rather a part of the human condition that everyone has in one form or another. As she grapples with issues, she values the answers and understanding she gets from disabled friends who are having similar experiences – “a place that you can talk to somebody who is like you.” As changes in physical ability and career happen, Florence knows that the “flexibility” and “resourcefulness” she learned by living life with a disability will continue to generate creative alternatives.

Theoretical Notes

The major themes that I found in Florence’s interview were (a) disability important part (b) isolation (c) medicalized childhood (d) aloneness (e) denial (f) hide (g) ridicule (h) family issues (i) psychotherapy (j) good planner (k) silence (l) generational differences (m) motherhood (n) common history (o) no disabled friends (p) affirmation (q) disabled role models (r) juggling responsibilities (s) aging issues (t) family crises (u) loss (v) intelligence helped (w) problem solver (x) internalized oppression (y) dire/no expectations (z) marriage (A) common understanding (B) career expectations (C) discrimination (D) “dipping toe in” disability identity (E) marriage (F) disability hierarchy (G) normalization (H) race awareness (I) new paradigm (J) foreclosed career options (K) more conscious career choices.

Florence spoke of the “privileges” her education and career opportunities in relation to the limited career options most disabled people have, though she did not

acknowledge that white and non-disabled privilege were also part of that equation. She did see her privileges carrying a responsibility with them, though, to create social change at the policy level that would benefit other disabled people. She learned, though, as she moved up the ladder professionally and away from disability issues that her educational privilege also functioned in that sphere as a form of “non-disabled privilege.” When she chose to direct the independent living center, her colleagues called it a “step backward,” revealing that they viewed her as “better than that” - an “exception” who had overcome her disability and was no longer one of the great unwashed masses of disabled people with nothing to contribute to society. It is a classic case of how privilege functions in this society – one is expected to cut one’s ties with one’s group when one has earned the privilege of belonging with the elite (McIntosh, 1999). Florence had educationally joined “the elite” and demonstrated her abilities professionally, so her choice to professionally identify with disabled people was an unfathomable violation of that code to her colleagues who had generously thought of her as one of them. Yet for Florence personally, her choice enabled her to integrate her professional skills and her developing disability identity in an environment that proved “safe” enough for her to work through her own “internalized oppression” about herself and others’ devalued positions on the “disability hierarchy” she had unconsciously accepted. That choice, then, empowered her to make her next career step of working again in the broader professional world as a fully identified disability person and advocate.

Finding role models for the adult roles of marriage and parenting as a disabled person, as well as professional role models, is another facet of the important role the disability community played in participants’ lives and identity development. Completely surrounded by non-disabled women, Florence was unable to imagine herself as a wife and mother and needed to see and hear how it was done from someone disabled like her. Quite interestingly, her wife/mother role model was not able to also be the mentor

Florence needed in developing her leadership skills in the disability and larger community. Florence described their differences as “generational,” but I believe she was also describing qualitatively different identity development “positions” in which people who remain in a place of anger, with “us and them” thinking, continue to see the implementation of disability rights laws as a confrontational process similar to fighting for the laws passage. Florence acknowledged that her “collegial” and “collaborative” approach to working for change is a product of her privileged training, experiences, and growing influence within the city, but also because disability rights laws were already in place when she began her career.

Florence credited years of psychotherapy with her ability to understand that some of her issues are rooted in old family patterns, not her disability. That knowledge and her newly constructed disability identity also enabled her to clarify friendships with former classmates, by more openly discussing her disability and their perceptions and expectations of her because of it, something that they had never discussed while in school or in the intervening years since.

Credibility

Member Check: Florence is one of the participants I was unable to reach for member check feedback. She had left her position at the ILC for another with a university where I attempted to reach her by email and phone, only to find that she had left that position for health reasons. Since I did not know Florence personally, I had no other way to reach her to attempt to get her feedback on her profile, though it was not for lack of trying among my friendship network.

Lucy

Contextual Notes

My ninety-minute interview with Lucy took place in a borrowed apartment of a mutual friend who had loaned me her place while I was doing research in the city. We

had known each other, over the years, through our mutual involvement in disability studies. I was first introduced to Lucy's work as a therapist through her published work, which had been influential in my own academic work. She was included in this study primarily because of her work in organizing and education with disabled girls and women, for which she has been nationally recognized.

Demographic Description

Lucy describes herself as a slender, middle-aged woman who is reasonably attractive and quite healthy with a disability that affects her gait, hand movements, speech and facial gestures. She is also European American.

Disability Identity Development Profile

Lucy was born with her disability and her family which includes two siblings did not speak openly about her disability, "things that were problematic wasn't easily talked about" in the family in general. The silence encouraged her to distance herself from her disability - "it was something about me that I knew, but I really didn't want to acknowledge or talk about it...or whenever anyone talked about it, whenever it came up in any way, it was very upsetting to me." While she has always been very supported by her siblings, she still knows little of how her they feel or how they were impacted by her disability - "we've spent a lifetime not really talking a whole lot about it." Lucy remembers getting the message from her mother "that if I really worked hard, I could become more non-disabled - normal. It was an illusion that she had." At age nine, Lucy refused to do any more physical therapy and "really resented that she didn't accept me as I was. It was a big-time battleground for us." As the only disabled child in school and in her family, Lucy developed an "outsider identity...there was a certain pride in being...the exception', because there was such a negative image around disability." Lucy struggled with others' "gawking" at her unusual mannerisms and was "quite invested in 'passing' as normal and minimizing that part of myself and compensating

through academic achievement.” She knows that her innate intelligence helped her to “pass as normal” with teachers and get the quality education that she would otherwise have been denied, which also minimized patronizing behaviors from her extended family that “had more doubts about what my life could be or how sad it could be for my parents to have this kid...I only got glimpses of that from time to time.”

In elementary school, Lucy’s mother “had to do a lot of advocacy to get me into mainstream schools,” which meant Lucy knew no other disabled children. Lucy credits her mother with her problem solving skills by being “fearless” in teaching her whatever skill she wanted to learn, including driving a car after the family doctor refused to sign a permit – “if I were driving, he didn’t want to be driving himself...that was a wonderful validation!” Lucy’s father “supported any of my ridiculous vocational undertakings” not only because he believed in her intelligence and abilities, but also because he feared she would not find a partner to take care of her according to his “old world” notion of wife and mother. He only revealed his deepest concerns for her future “when he was very old, when his defenses were down...I think he had more reservations, but he didn’t verbalize them.” Her mother’s articulation of her future prospects was to find a husband who worked with handicapped children, who would then “understand me.” While Lucy internalized these attitudes about her romantic prospects, she ultimately crafted her own meaningful long-term relationship with a man, with the support of her disabled women role models, a relationship that has contributed to her positive sense.

Only after college did Lucy encounter positive disabled female role models who began to influence how she felt about herself as a disabled woman. The first woman who hired her out of college had the same disability, a powerful position and was married, none of which Lucy had thought were possible for her. “We didn’t do much talking about disability, but working with her enabled me to incorporate a positive sense of myself as a disabled woman.” After that job, Lucy moved and became involved in the

women's movement and found herself again the only disabled person in these groups. Lucy experienced similar "silence" about her disability in these groups as with her family - "God knows, I would never bring it up!" Hearing non-disabled women's stories enabled her to discover herself as a woman. While there are many issues non-disabled woman struggle with that were not part of her experience, being validated as a woman through her involvement in these groups empowered her to explore "that other missing piece of my identity which was disability." Lucy also discovered her capacity to give "counsel and wisdom that was helpful to them and it kind of gave me a real sense of womanhood." It also encouraged her to pursue her dream of becoming a therapist, which she "had always thought because of my disability, I couldn't."

During graduate school, she moved closer to identifying as a disabled person because of bonding experiences she had with a disabled student, as well as a disability community activist she met who had a similar disability. Lucy spoke of this as a time of "putting her feet into the water" of claiming a disability identity and began to envision working as a therapist with disabled people, which she admits "in hindsight was very absurd, because I was just barely grappling with my own disability...but it felt very natural at the time." She encountered prejudiced attitudes of faculty who were not supportive, as she did in seeking employment later - "I don't know why you ever decided to become a social worker!" Lucy found that her many years of therapy, begun during those graduate school years, were essential to her own disability identity development - "he helped to counter whatever negative stuff...I think he was a good counter force, he helped me to think I could have more..." After graduate school, Lucy pursued specialized psychotherapy training, only to be dismissed from the program on the grounds "I could never be a therapist because people would never stay with someone who had my disability...it was shocking to me...it sounded discriminatory and simple-minded." The experience became "the catalyst that catapulted" Lucy into seeking out

other disabled therapists to learn about their experiences as professionals. She began to realize that “discrimination had been there my whole life, but I had never really paid attention to it,” and was “empowered” by reframing disability as “a societal issue, no longer my problem.” and found a “real sense of community” in her organizing work with disabled women. She even gained a sense of empowerment by suing the institute for discrimination even though she did not win. In the end, Lucy’s personal need to connect with other disabled therapists became her path to developing skills as an organizer of disabled therapists’ professional groups and conferences to address their issues. She also began integrating her disability work into her work in the women’s movement by organizing disabled women’s groups – “it was a real asset to my work...I had a real sense of community and also a sense that I could do this...I liked bringing people together, I liked that kind of advocacy and it was a really great feeling.” The success she has had over the years of creating and running her own projects, such as one mentoring disabled adolescent girls, has increased her sense of self worth, as well as brought her recognition from the larger community for her contributions.

Lucy describes her disability as “only a part of my identity - I can’t easily separate out how much of my identity is gender, how much is disability and how much is parental values unrelated to either.” She notes that disability has not only shaped her work, but also her “values in terms of attitudes toward oppression and difference.” She admits to being “frustrated and more impatient” with still being the only disabled woman in the many women’s organizations she has worked with over the years - “I prefer to be a ‘part of’, not the only one. I see it as a problem, instead of a privilege.” Lately, Lucy is more aware of how much energy it actually takes to deal with society’s negative view of disability - “the disability itself is not the issue...it’s all the struggles that surround it!” She still struggles with some residual “internalized oppression” about society’s “disability hierarchy...physically, I haven’t had a terrifically hard time...its those repeated

encounters with people's negative reactions and questions, spoken or unspoken, dealing with that issue of difference and constantly needing to prove yourself - these things sometimes wear you down. I had a lot more tolerance for people's reactions when I was younger!" These changes have Lucy contemplating whether "after being an activist for a long time, people need a break, to do something different, I don't know. I just find it hard to sustain the energy." She questions her own "hesitation in going out there...looking for some kind of part-time job [is] because I'm anticipating these kinds of reactions...I can't tell how grounded they are." She has begun exploring these inner issues through artistic, rather than activist means, and has found it a more "healing kind of process" of transforming feelings, experiences and parts of herself that felt "ugly" into creative artistic expressions that are finally clarifying their meaning for her in her life. Some of her "outsider identity" still remains, but Lucy knows that its her innate shyness that makes her most comfortable being with those she shares "common values of fighting against injustice...disabled women's identity kind of issues...shared politics...it doesn't automatically happen and it is hard to find a group of non-disabled people who share the politics and identity issues!" Lucy sees her disability as giving her "an opportunity of womanhood in a broader way...and its hard to conceive of any identity that doesn't somehow include disability in some part of me – its very integrated in me." She jokes "that if I suddenly became non-disabled tomorrow, I'd be unemployed and in serious trouble!"

Theoretical Notes

The major themes I found in Lucy's interview included: (a) silence (b) resistance (c) aloneness (d) stigma (e) internalized oppression (f) disability hierarchy (g) disability an important part (h) integration – gender, disability, professionally (l) different values (j) outsider identity (k) disability pride (l) the exception (m) passing (n) women's movement (o) minimize/hide disability (p) intelligence advantage (q) discrimination

® new paradigm (s) non-traditional partner relationship (t) common values
 (u) empowerment (v) artistic transformation (w) activist (x) psychotherapy (y) still only
 one (z) tired (A) energy difference (B) disabled women role models (C) new paradigm
 (D) struggle (F) negative attitudes (G) normalization (H) artistic healing/integration
 (I) skill development (J) vocational exploration (K) supportive family (L) race awareness.

In childhood, Lucy internalized shame about her body, partly through her non-disabled mother's insistence on physical therapy so she would walk more normally, which made her feel that her mother didn't accept her the way she was. Lucy's mother tried to "protect" her from the negative responses of non-disabled people around her by urging her to be more normal, a response shared by many of the European American parents who did not know how to internally fortifying their disabled children to deflect negative messages from society. Lucy's refusal to do more physical therapy was an act of resistance for liberation (Robinson & Ward, 1991) that occurred outside a larger context of other disabled people who supported and validate her as a whole person. Her already internalized shame about her body was left to be dealt with later in life. The insistence on pursuing "normalization" led to Lucy spending enormous amounts of her energy trying to hide the full extent of her disability from others. She also did not share her deepest most thoughts and feelings about with her non-disabled family or non-disabled friends in the women's movement she became involved in later in life.

Lucy began exploring her disability identity because of what she learned from other women about their experiences in the women's movement, another facet of the emerging theme of "integration." Her involvement with another liberation movement enabled her see herself as a "real woman," discover her own skills and pursue a professional dream she had thought impossible because of her disability. She only became committed to identifying as a disabled person, though, after experiencing professional discrimination on the basis of disability. She had been "dipping in and out"

of a disability identity in an identity position that echoes Cass' stage of Identity Tolerance (1984), but now needed the support of disabled professional peers to validate her feelings about the discrimination she had experienced – Identity Acceptance (Cass, 1984). She found community with them and expanded her application of skills learned in the women's movement by beginning to develop consciousness-raising opportunities and doing community organizing with disabled people. Lucy used her experience as a therapist and her own experience of "aloneness" as a disabled girl to develop, at the community level, a structured nurturing environment do disabled adolescent girls could learn about their future roles and activities from disabled women role models (Bronfenbrenner, 1979).

In Lucy's discussion about her own struggle with her internalized oppression about the physical realities of her disability, she stated that therapy had been helpful in dealing with family and society's negative messages. The fact that she described this therapist as not disabled and not supportive of disabled people generally, though supportive of her personally, meant that the work she needed to do about her unresolved issues relating to her body would have to be dealt with later. As a child, she had a strong enough sense of "intactness" that made her resent and refused to do physical therapy, because it communicated to her that she was unacceptable as she was. Yet it was the legacy of sense of this very unacceptableness that engendered her lifelong struggle with shame about her body. In describing her current experience of "aging" with disability, she illustrates that disability identity development can be fluid, situational and recurring, as the physical toll of aging with her disability is bringing up those issues she never came to terms with in her younger years. It is a developmental process that reflects Parham's (1989) notion of "nigrescence recycling" in which new situations or realities generate the need to work through racial identity issues that were never resolved at earlier times in one's life. The physical and spiritual fatigue she now

has, as a result of her long-term entrepreneurial/ activist professional path, is making her contemplating a change of focus or work. Yet, the prospect of looking for different kind of work is bringing up the old internalized negative beliefs about her body and fears of others' negative perceptions of her physicality. The artistic approach she is now using to deal with these issues, as opposed to her previous activism and talk therapy, is proving to be a "transforming process" that is finally enabling her to make meaning of the role of her body in her life. It is a process that has the potential to enable her to grow into a qualitatively different position of disability identity development that incorporates her body positively, as it is, into her disability identity. Such an identity position was articulated by other participants who have experienced psychological healing/understanding on a deeper level, becoming less concerned with others' perceptions and expanding their careers into different kinds of relationships with non-disabled colleagues.

Credibility

Member Check: Lucy responded by email that she thought the profile reflected both her voice and the chronology of her disability identity development. She asked that the description of a particular attitude of her mother's be contextualized more clearly in proportion to other attitudes her mother had had in response to Lucy's disability. The profile was changed to reflect that context while we were on the phone together.

Gail

Contextual Notes

The ninety-minute interview took place in Gail's home. Near the end, I sensed her energy waning, so we did not talk about her many fruitful years working within the disability community on the west coast. Given the busyness of her professional life, I made the decision not to pursue filling in that gap, because I found the description of her early years of such importance for their striking difference to others' experiences, as well

as her expanding visions that are developing through her current international work. She had experienced disability community at a much early age than the rest of the participants and those experiences seemed to prime her to be able to take on the professional roles she has had later in life. Gail had been one of my late partner's oldest friends and we had spent a good deal of time socially with her and her husband over the years. So, our relationship and the atmosphere of the interview was that of a caring open friendship between two disabled women who share similar worldviews. While I knew the basics of Gail's public life and work in the disability community, the details of her early years and the meaning she had made of them, and was making of the changes in her professional and personal life, were all unknown to me. Gail's inclusion in this study was primarily because of her years of strong leadership in organizing the disability community politically both before disability rights laws even existed and up to her years of federal governmental.

Demographic Description

Gail describes herself as a 53 year-old, Jewish American woman who had polio and is a disability activist and change agent that has worked professionally in education, administration, and non-profits throughout her career.

Disability Identity Development Profile

Gail who contracted polio in early childhood was the older sister to two brothers. Her immigrant parents "decided early on that my disability wouldn't limit what their expectations were for me too significantly." Having lost their families in the holocaust in Germany, Gail's parents began to exercise their right to "question authority" in their new country, when doctors recommended Gail be institutionalized after the acute stage of polio had passed. It was a recommendation she only learned about later in life – "they tried to protect me from negative things, to the extent that they could." They reasserted what they considered their rightful role of determining what was best for their child and

evaluated any medical advice on the basis of their own common sense and eventually involved Gail in those decisions. Although she encountered many barriers in her environment away from home, due to her wheelchair, the entire family “took responsibility for removing them” at home by making the house accessible and adding a downstairs bedroom and bath for her – “I learned along the way that there were barriers, but they were removable.” Her parents were committed to the family sharing the same collective experience and did not allow her developmental needs to be “medicalized...they didn’t want me to be doing things that would be really different from what was going on with my brothers.” So she took piano and voice lessons to promote strengthening of her hands and lungs; lengthy recovery from surgery was at home; and any necessary inpatient rehabilitation was limited to week days when actual therapy was being done. Gail participated in Brownies and Girl Scouts with the neighborhood girls and her brothers Boy Scouts, the three of them attended Hebrew school together. Her brothers were supportive, driving her where she needed to go. Gail’s parents were instrumental in encouraging parents of other disabled children to “determine what was good for their children and fight for it.” The collective action of some of those parents forced the school system to open high schools to their disabled children, since even segregated, accessible classrooms were more desirable than the isolating “home instruction” considered sufficient by the system. In this environment, Gail learned to be a “change agent” from her parents’ who actively transferred that responsibility to her as she matured, playing a supporting role to her activism throughout rest of their lives. Gail’s political and leadership skills were also honed by frequently being elected president of her class in elementary and high school.

Gail grew up as an integral part of her close-knit, post WWII neighborhood, carried in and out of inaccessible houses, jumping rope and skating in her manual wheelchair, attending neighborhood parties, etc. She and her friends never talked about

her disability - it was just a part of the collective life they all shared growing up, though they began to talk about it in high school when changes were happening in their social circle. Neighborhood teens began going to different high schools, riding city busses Gail could not get on or riding in cars driven by friends from outside the neighborhood who were unwilling to include Gail. The broadening of their social worlds disrupted Gail's security, by bringing strangers to neighborhood parties "who didn't know anyone with a disability and that's when I would feel self-conscious about playing "spin the bottle" and some guy I didn't know - you just felt the vibes - that it felt weird to them and, subsequently, to me." Gail spoke of feeling "stuck...sad and depressed, not bad," when she was unable to do something with her neighborhood friends and "thought more of wishing people would accept me for who I am, as opposed to 'I wish I was them!'"

The neighborhood social changes was counter-balanced by the large, close circle of disabled friends she had through high school and disabled friends she had known through summer camp for many years. At camp, "we were the majority people in the community, although we had no power," experiencing all the normal teenage things - "dating and sex and all that stuff," as well as talking about their disabilities, how it affected their lives, their families and "how we wanted the world to be for us. It was like living in a couple of different worlds." Gail recalled times when she and one of her disabled girlfriends would overtly challenge people staring at them on the streets, gaining a sense of power and camaraderie in those collective acts of resistance. During those years, Gail "started thinking about what I thought was wrong and how I thought things could be right...so it was really a time when I started looking at disability as something that wasn't a bad thing." Her circle of disabled teenagers began to envision the changes they wanted to see happen in their world, knowing that only disabled people had "the drive, interest and motivation to want to make the changes" and they committed themselves to do it! The lessons learned from watching their parents fight for their

education was not lost on these disabled kids, as they grew into activists in their early adult years.

During high school, a motorized wheelchair was offered to Gail, but her parents refused it. Power chairs were so unusual in those days, Gail's parents uncharacteristically accepted the standard medical opinion that using a power chair "would make me dependent." When Gail bought her own power chair as a young adult, her parents regretted their resistance when they realized how much it contributed to her life. During her high school years, Gail experienced the usual testing for college entrance as a "harrowing experience." Her years of segregated classroom education left Gail under prepared for such academic rigors. Upon finally being accepted at a local college, Gail choose to live on campus during her college years precisely because she knew she needed that time for her own social skill building in the larger non-disabled world. Getting involved in the campus life of sororities, student government, organizing disabled students and campus politics stretched Gail beyond her personal comfort zones and accomplished her goal. Gail had to fight to live in the dorm her second year, because the woman in charge "didn't want me there...I got so upset," yet her one call to the President of the Board resolved the matter and gave her a personal victory against personal discrimination. Unwilling to endure being rejected as potential dating material from her non-disabled peers at college, Gail found spending weekends in the old neighborhood more emotionally satisfying. Gail discovered that as the only disabled person present in a given setting, such as trying out for parts in musical theater, she had a "shyness and insecurity" that involved more than not being able to get around physically. It was a kind of vulnerability she did not have when involved in collective endeavors with her disabled friends; it was a challenge that repeated itself when she left her work in the Bay Area disability community to work in a professional setting where she was the only disabled person.

Because Gail knew of no teacher who used a wheelchair, she knew she had to pursue her dream of becoming a teacher “in a very clandestine way.” To gain teaching experience, she and a non-disabled friend in college created an after-school tutoring program for neighborhood high school kids in the community near their college. Her intuition that the teaching profession would not welcome her was confirmed when she was denied a teaching position in New York City schools after graduating from college - “because she used a wheelchair!” Gail, with the support of her disabled friends, brought a lawsuit against the city of New York for discrimination and won and her first teaching job was in the very segregated basement classroom she had attended as a child. The collective organizing around Gail’s lawsuit resulted in the group forming a disability rights organization to promote the social changes they had “committed” themselves to in their early teens. It was an organization that fought for multifaceted systemic change that reflect the interrelated needs of their lives – “I could never think of only one thing...just architectural barriers?...what about the bus?...what about theaters, jobs or education or attendant services?” Their successful, ground-breaking activism became their training grounds for larger national activism they would be involved in during the coming years as the fight for disability rights laws began. It was the support of her disabled friends and her family that gave Gail the strength and confidence to “benefit from the lessons my parents had been teaching me.”

Nota bene: This time period of Gail’s story was not included in our interview, so I can mention only historical facts I know from public history and from her own inferences. [Because of her reputation as an effective disability community organizer, Gail was recruited to the west coast to replicate the kind of organizing work she had become well known for on the east coast . Gail’s lack of satisfaction with the lack of an inclusive community she has found back east later in her professional life, gives some insight into how rich her community life was, both disabled and non-disabled, on the west coast.

As her career has taken her beyond working strictly in the disability community, Gail has found it more difficult to find a disability community like the one that sustained her during earlier years. The lack of having a close-knit disability community has also brought into sharp relief the barriers that still exist, which make it difficult for her to connect with other facets of her life in the larger community. There is less opportunity to socialize with other women personally engaged in politics as she used to be, though her professional work has involved introducing disabled women's issues into the larger realm of women's issues. She is more able to participate in her neighborhood synagogue, as a woman of faith, and is helping that community move towards greater accessibility. Inaccessible homes and a general lack of willingness to do what needs to be done to open up social circles up to a broader spectrum of people, has created a sense of loss in Gail. She finds that her role as "change agent" is even required to just to develop more meaningful friendships with non-disabled people in more intimate settings in the larger community.

Gail's current work has expanded to include international economic development for disabled people in developing countries and is challenging her previous focus on disability rights. She growing knowledge of resources scarcity for basic survival in many developing countries makes survival a struggle for all people, not just disabled people. She finds herself "humbled" by the greater opportunities disabled people have in developed countries, due to the greater resources available to make such gains. Having responsibility to address the issues of limited resources for disabled people is making Gail keenly aware of how unconsciously privileged her life has been with the civil rights and resources that have enabled, first, to survive and then, to develop into a disability activist. Her sense of responsibility to disabled people has expanded to include global economic justice for all, as well full equality for disabled people. The strategies Gail's parents used to ensure her full involvement in the family, school and neighborhood

empowered her to take on the task of working to change her city's response to disability, the nations' and the world's.

Theoretical Notes

The major themes I found in Gail's interview were: (a) high expectations (b) accessible home (c) change agent/activist parents (d) own role models (e) non-medicalized development (f) question authority (g) early disability community (h) inclusive neighborhood (i) many young disabled friends (j) discriminatory schooling (k) collective family experience (l) disability just part of life (m) disability hierarchy (n) disabled boyfriends (o) self-definition (p) deliberate psychological education (q) typical adolescent development (r) involved in student government (s) more limited social opportunities - now (t) women's issues (u) expanding vision – economic/disability equality (v) spirituality (w) resistance (x) underestimation of abilities (y) positive early segregated experiences (z) appreciation of US resources (A) awareness of strangers discomfort w/ disability (B) race awareness.

Discrepant/negative Case: Gail's childhood experience was unusual both from my own theorizing, extensive reading of disability autobiographies and from other participants on several different levels. I believe that the fact that Gail's parents, who had experienced being devalued as Jews in Nazi Germany, deeply influenced their very different perspective on Gail's disability. Early on, they understood that society's negative perception of disability was the problem, not her disability. They also knew that some of the doctors' recommendations, as well as the discriminatory policies of the school system were the direct result of those negative beliefs. They asserted their own values in determining the course of their daughter's development, medically and socially, in contrast to the typical non-disabled American parents of participants' responses that were unconsciously grounded in negative beliefs about disability in society. Their

strategy to support her development in non-medicalized ways, such as voice and piano lessons, created a common family culture, while making their house accessible, involving her in community organizations along with her brothers and neighborhood children allowed Gail to be understood as a natural part of neighborhood life, as well as teaching her she was entitled to participate in all the roles and activities of life on her own terms. The inclusiveness of her neighborhood social life gave Gail the rare psychosocial experience (for physically disabled children) of being an integral, valued and contributing part of multiple social circles, which in turn fortified her to stretch herself to develop relationships with other non-disabled people in college and beyond. Gail never felt shame about her disability, but she was aware when others were uncomfortable with it and it generated a certain kind of “shyness” in her when around only non-disabled people.

The other unusual reality in Gail’s development was the supportive disability community of disabled kids she grew up with from elementary school into adulthood. Their weekly social club gatherings and camp every summer gave them a positive experience of being “in the majority,” structuring their social life together on their own terms that included all of the typical adolescent developmental experimentation. They also talked about their disabilities, their families, their dreams and how they wanted the world to be different in the future. They also realized that only disabled people had the passion and vision for to make the needed changes and committed themselves to do it. Gail described these friends as role models for each other and they were her disability community that was developmentally prepared to support her when she sued the city for employment discrimination. Their collective success in that challenge encouraged them to organize formally and fight for the changes they had

dreamed of in their adolescence.

Gail spoke of her parents as her “change agent” role models for organizing their fight with the school system for classroom education for disabled children in the city. They also taught other parents to claim their power to determine their disabled children’s own need. Their hard-learned lessons about the danger of complying with discriminatory government policies taught other parents, and their disabled children, that it is only through many voices of resistance that change can be forced on a discriminatory system based on negative social beliefs. And they prepared Gail to take on that role of change agent when it made sense and were the other half of her support community in their disability rights activism.

Gail’s parents may have known nothing formal about developmental psychology, but their approach to raising her seemed to me to be a natural form of “deliberate psychological education” (Sprinthall & Thies-Sprinthall, 1983). They not only understood society’s negative perception of Gail’s disability, but also knew how to fortify her against them by modeling behaviors, beliefs and values she would need to succeed and fight for change in discriminatory environment she would be living in as an adult (Phinney & Rosenthal, 1992). Her awareness of disability prejudice in the educational system led her to devise her own surreptitious means of getting teaching experience and prepared her to sue the city when she encountered employment discrimination. All of these elements were foundational for Gail’s psychosocial development and nurtured her ability to successfully take on the larger developmental roles and activities in the non-disabled adult world.

Gail’s current professional work is expanding her focus beyond the United States disability community and its struggle for disability rights and is exposing her to the

harsher complexities of basic survival issues the majority of the people in the world struggle for, including disabled people. Her articulation of developing a more universal human vision is a quality of a more complex identity position, similar to the Transformation stage of the OTAID model (Meyers, et al., 1991), as her concern for disability equality that is expanding to incorporate economic equality for all people. She has been sobered by the economic privileges she and other disabled Americans have had that enabled them to survive and much more, and for her to be able to do the work she has done with those economic privileges.

Credibility

Member Check: I contacted Gail by phone about her profile, she suggested several changes and additions to the profile to clarify some of the broader strokes I used in constructing it. She approved of the voice and chronology of the profile, to extent that she had related it to me during the interview, but wanted to add more information about the period of time we had not discussed. Our plans to go over that time period never materialized because of her schedule, though from my perspective, the most important and unique elements of her early and later disability identity development were covered during our interview.

Frank

Contextual Notes

The ninety-minute interview with Frank took place in the office of the national disability lobbying organization of which he is president. It is his leadership of this organization that led to his being included in this study, as well as the fact that he has an invisible psychiatric disability. The interview happened a bit spontaneously, as my previous interview had to be canceled because of transit system failures. We met on the street while I was looking for his office and he suggested we get an early start. We did not really know each other prior to the interview, though our paths have crossed

professionally over the years. Our sense of belonging in the same community made for an easy flow of conversation. I had expected the personal comfort he had with being open about personal issues relating to his disability as he is publicly “out” about his disability when he speaks publicly.

Demographic Description

Frank described himself as an Italian-Irish, disability rights attorney, husband and father with a psychiatric disability, who also feels his spiritual beliefs sustain him.

Disability Identity Development Profile

Born into an Italian-Irish Catholic family, to creative and entrepreneurial parents, Frank described himself as a “highly intelligent child [who] bordered on arrogance with his intellect.” He was both a football jock and an honor student, whose parents described him as an “over achiever,” while his best friend viewed him as a “macho, super human who liked playing football without pads.” His religious background has given him a spiritual understanding of a “greater presence out there that is making good stuff happen to me. When I talk about my disability and I talk about my heart, its important to me...I feel I’ve derived a lot of power from my belief in God.” Prior to entering law school, Frank was aware that a law degree would gain him a form of power that he “could use for good or bad and its up to you to figure that out.” Frank experienced the first episode of his psychiatric disability in his last semester of law school when he went from being “a cocky, smart-aleck law student” to someone who was barely able to get out of bed - “I had never felt that powerless.” The mental health services that he, but their pharmaceutical approach was unhelpful. He speculates that his Italian father had the same psychiatric disability, which he “self-medicated with Vodka and cigarettes...[a man] who had a very generous spirit, could be very destructive, very harmful, abusive.” His half-brother, with the same disability, has helped Frank understand managing his disability in non-medicalized terms. Frank knows that

strong emotions are a part of his Italian heritage, but he has come to see his own disability as cycles of energy that he is responsible to manage so as not to hurt those around him or cause damage in his professional work. The advice from his brother about managing his energy swings was - "in low energy you tend the crops, don't expend energy unnecessarily, don't try to do stuff that can wait...in high energy mode, that's when you are planting seeds and you are initiating things."

While Frank knows he would have been involved in some kind of civil rights or public interest law, he credits his disability with his focus on disability rights - "it would not have been as much of a calling as disability rights law has been for me." During his first job after law school, as a legal advocate representing disabled people, Frank experienced the second major episode of his disability, "I felt like I was omnipotent... there was no problem I didn't think I could solve in 24-hours." Frank knows that without his disability, he would have been "a pretty cocky person - all of the time" and that the fact he has produced many good results for disabled people enabled him "to get through the attitudes and barriers in our own community - they came to respect me...after a while the fact that I'm arrogant or depressed is not as important to folks." Being involved professionally in a coalition of disability rights activists challenged Frank to personally "come out" about his own psychiatric disability - "its all hypocritical...to not own that I was a part of it and I was going to benefit from it!" In that job, he encountered disabled leaders who clearly had power and credibility because of "being out" about their disability. Their willingness to mentor him challenged him - "I needed to be a disabled adult that was comfortable being out as that, if I really wanted this relationship to go to another level." Without that experience, he speculates it would have taken him "10, 15, 20 or more years to finally get it - for those two things to come together as neatly as they did for me...and in the process, I might have killed myself - that's the reality of depression. I thank God that it happened!"

Frank's parents rejected his identifying so openly about his disability, seeing it as a professional liability and also saw his first job in a disability rights organization as beneath his earning power. During years of estrangement from them, he was able to rely on the disability community for his emotional support, "the movement really helped me fight my parents...the disability pride thing, it gave me some inner strength and core convictions." While alive, Frank's father never could accept his openness, but his mother, bothers and friends are moving closer to appreciating him for who he is and what he does - because of his disability. He sees it as a process of them letting go of their image of him as the "mythical person" of his youth. Frank now feels his disability is "an advantage" in his life, giving him a capacity to connect with other people he would not have had otherwise; his marriage has a strength and he is a better role model for his children that he may not have been without the vulnerability his disability gives introduced into his life - the need for him to be aware "that I'm not hurting people."

Frank feels that his disability has, in actuality, "helped me move forward more quickly" professionally. He feels that his psychiatric disability played an important role in his being chosen for the leadership position he currently holds, because those who hired him knew that cross-disability organizing "is the future of this movement...I have a psychiatric disability, in a cross-disability movement that is still too dominated by white guys in wheelchairs and white women with mobility impairment." He sees his CEO role as "a test" for him in managing the depression side of his disability - "I'm basically trying to build a small business...there aren't really people sitting around not wanting you to do anything." His choice to take on such challenges is "if I don't take this chance I'll never know what I'm capable of." He has "matured in some ways in this job...I've mellowed," though his strong activist consciousness makes him uncomfortable with changing views of establishment organizations and his less confrontational approach - "I don't do it in as harmful, as zero sum game - I try not to think in zero games anymore." He has

established national mentoring programs because he personally benefited from being mentored – “I would not be where I am today, if I didn’t have my first supervisor at the disability law center who took this arrogant, cocky...obnoxious...guy and still saw the good in him that was worth cultivating.” His sense of responsibility to mentor and to leave the world a better place for the next generation is also grounded in the fact that his own children may very likely develop his disability. He wants his sons to understand his pride in being a part of the disability community and his commitment to making “concrete change in society,” hoping it will encourage them to find it important in their lives, in time

He is concerned with disabled people dealing with the issue of “seeing connections between one person’s barriers and another person’s barriers,” both within and outside of the disability community. For this reason, Frank is most comfortable in cross-disability settings, rather than in those focused on one disability, which he sees contributing to toxic in-fighting over territorial perceptions. He sees “a lot of energy, passion and fire in the belly...and more directed in a constructive way” in cross-disability settings that focus on the bigger picture. Frank’s bond with disabled people of color flows from feeling “connected with them at the heart level, as opposed to the head level. I feel more grounded – I don’t like it when everybody’s up in their heads.” Frank feels that the capacity to deal with issues of the “heart” is greatly lacking in the predominantly white disability rights movement - “lots of those fights are affecting people’s hearts, but they are playing out very much on a head level.” He finds it most satisfying connecting with disabled people who have achieved “a high degree of satisfaction in their life...rather than getting into jousting matches about how politically correct we are – we get right down to what the real issues are.” He finds it “psychically gratifying” that leaders of the civil rights movement appreciate his role “in bringing the disability movement into civil rights more broadly,” because he knows the disability rights movement must embrace its collective experience with the struggle for social justice for

all – “disabled people have an important role to play in that movement...because we all are in it together for something that is bigger than any of us.”

Theoretical Notes:

The major themes I found in Frank’s interview included: (a) privileged education (b) arrogance (c) family rejection (d) later in life onset (e) early mentoring (f) role models (g) energy cycles (h) disability management (i) greater awareness (j) greater sensitivity (k) responsibility (l) spirituality (m) beyond disability rights (n) big picture thinking (o) psychiatric disability (p) cultural emotionality (q) cross-disability emphasis (r) invisible disability (s) multigenerational view (t) mellowing (u) confrontational style (v) disability is an advantage (w) maturing (x) better husband (y) integration (z) personality trait (A) better fathering (B) disabled friends w/ positive forward focus (C) dislike of in-group dynamics (D) race awareness.

Coming to his disability later in life, Frank’s sense of self was already grounded in the privileges of his race, gender and education and he had far fewer internalized negative messages about his disability to unlearn, as many of the other participants described. He did acknowledge his educational privileges, but not those of his race or gender. Frank’s disability identity development unfolded alongside his professional development as a disability rights attorney, because his privileged education positioned him to be working collaboratively, on an equal footing, with disabled leaders who appreciated his work and were prepared to facilitate his coming “out” to the community about his psychiatric disability. Frank had witnessed the personal “power” of these leaders who were “out” about their disability and his role models, which in turn empowered him to be open about his psychiatric disability in a movement that had not traditionally included people with psychiatric disabilities.

The strong negative reactions of Frank’s family to his choice to openly identify with a psychiatric disability, and with the disability community, was a stronger version of

an emerging theme of non-disabled families being unable to grasp why their disabled family member is concerned with disability rights or expresses a need for disability community. Frank's father's horror at his being publicly out about his psychiatric disability was grounded in the cultural belief that it would harm his professional prospects of benefiting from non-disabled privileges of his profession. Frank's ability to personally separate himself from his family's negativity for two years after coming out publicly about his disability, was only possible because he had the emotional support of the disability community and also reminiscent of Cass' (1984) Identity Pride stage. Similarly, it also underscores the strong social injunction for gays and lesbians as well as people with invisible disabilities to hide them, precisely because it is possible to do so! The ability to "pass as normal" can increase barriers to developing a positive disability identity, because it is viewed as relinquishing one's position of non-disabled privilege for the devalued status that physically or intellectually disabled people occupy in society.

Credibility

Member Check: Frank responded to my member check request by affirming that his profile reflected his voice. He requested one small change in emphasis to clarify that the time frame it took for him to embrace his disability identity and belonging in the disability community, after experiencing his second episode, was much shorter than I had inferred in the profile. He also expressed a lack of concern about people identifying him from the profile.

George

Contextual Notes

I must comment up front that this was no ordinary interview; in the disability community, the interview had a bit of an air of an audience with the pope about it, though George himself would not approve of such a characterization. For myself, I was a bit uncertain about the questions I would be asking that I knew very likely not be the kind of

questions George was accustomed to being asked, as they were quite personal rather than political. The ninety-minute interview took place in George's home. His post-polio, in combination with other health conditions, had advanced to the point that he was unable to move his limbs without some assistance from the various helpers present in the apartment. His apartment was, in fact, a cramped working headquarters for the ongoing work of a large network of activists he had drawn together to move the cause of disability rights forward. George and his wife have, for years, shared their home, life and work with an ever-changing group of young ladies who silently moved in and out of the room during our interview, bringing tea or attending to some other need George may have had.

Another interesting aspect of this interview was that George's niece was present and made her own audiotape of the interview. She was writing an article about him and he wanted her to hear the information he anticipated sharing in the interview. I speculated that this was a means of him preserving his energy, by not having to repeat some stories. George had requested I send him the questions in advance so he could be prepared and, as it happened, he read the formal questions out loud to himself and answered them, while I asked follow up questions based on his answers. Whatever his stated motivation for having the questions in advance, this arrangement gave him the ability – and the power - to pace himself and his energy. While George was quite physically frail, his presence was most definitely not and neither was his command of the situation. He had orchestrated the event so that mutual friends of ours arrived for a visit at the time he had appointed for the interview to end and all of this was carried off with the gracious, quiet power of a man who knew how to accomplish his goal.

He began the interview by first expressing, in a most formal and sincere Japanese manner, his utmost respect for the brilliance of my late partner's work, and by extension the work that I was doing. In accord with another Japanese custom, at the

end of the interview, he gave me a copy of a speech he had given about that applicability of Ron's principles of universal design to public policy. Afterwards, we all went downstairs to visit in the lobby of the apartment building. During our downstairs visit, I publicly, but quietly, challenged a woman who had blocked the curb cut in the front of the building. On my returning to the group, George's eyes were twinkling and he was grinning broadly. He expressed delight at my actions, doubting he could ever do such a thing, but he loved watching me do it and was inspired by it! His delight compounded my sense of privilege of interviewing this man of such mythic proportions, and being able to ask him about psychological and emotional struggles he acknowledged having never been asked before, subjects that are so rarely talked about among many disabled people. I was moved by the spirituality George spoke of undergirding his actions, especially his praying to become "Wabi," as spirituality is another topic rarely spoken of among disability rights movement members.

Demographic Description

At 71, George described himself as an advocate and lobbyist, who had formerly been a businessman. He also was European American.

Disability Identity Development Profile

George described his family as a family of wealthy, attention-seeking "superstar" parents, famous for pushing multiple cultural envelopes - "very dominating types." He described himself before becoming disabled at eighteen, as a "spoiled rich kid...a juvenile delinquent who never found a rule I couldn't break...a person I couldn't insult...a superstar of the obnoxious!" After contracting polio, he was hospitalized in a church hospital where he met religious people who lived by values very different from his family's - personal sacrifice and love for others. In the face of imminent death, George "remembers distinctly" challenging himself to "try this love thing, see if you can have a few days of smiles and being happy like these people. It worked so well that I just went

wild...like a dope addict – suddenly I felt like a human being!” This value system based on love made such an impression on him that he saw getting a “disability as the first phase of happiness in my life...the beginning of the positive part of my life.”

At the time he got polio, George “had never met anybody with a disability in my family, no guest or no one who talked about it...I didn’t know anybody with a disability who had a job.” With his track record of dropping out of seven high schools before getting polio, George “doesn’t know what would have happened to me [without polio]. I hate to think of how I would have turned out!” Hospital staff encouraged him to dream big about his future, including offering to help him get into their medical school, which was “a big shock on me and started me to think about, maybe, I could do something in the world.” After returning home, he characterized himself as “a wild man...big macho stuff...driving a red pickup, go and sort of jump in, fold this 50 lb wheelchair, just flip it up in the front seat and roar off...do anything to prove what a big macho I was.” Although suicidal depression was a part of his family history, George reflects that he “never had a grieving period or a suicidal period or anything like that” after becoming disabled - “I’m convinced that all this love saved my life...and made it worth saving!”

“To be independent,” was George’s criteria in choosing a school after his recovery, so he went to a state university that “would let him in being in a wheelchair” rather than the Ivy League choices of his parents. He would not even consider an accessible university that had a program for disabled students, because he could not tolerate their regulations or the segregation of the disabled students. George was persuaded by reading about Ghandi’ emphasis on love during his rehabilitation and was convinced he could make a difference in the world by “finding his own truth and living it.” So he described himself going off to college “a rebel without a cause” - but looking for one! He soon found it in organizing for civil rights and fighting for the integration of the university, which eventually led to his getting very involved in state party politics – “I

became a flaming civil rights advocate...and it never occurred to me that I had rights that were being infringed.” Those years of civil rights activism became the roots of his later pioneering work in promoting of the cause of civil rights for disabled people.

Impatient with the pace of change through state politics, George decided he would “do good things in business. I will promote ‘truth’ in business!” Using family wealth for seed money, George spent many years successfully growing businesses in Mexico and Japan...”I became pretty flamboyant myself and I slid back into the family passion – I actually did have my picture on the cover of *Time Magazine of Japan* – even though I did have my aspects of radicalism.” George had become well known in Japan, not only for his business success, but also for hiring employees who used wheelchairs and sponsoring wheelchair athletes. While on a trip to Vietnam during the Vietnam War for the World Congress of Rehabilitation International, George experienced a spiritual crisis when he realized his own role in an economic system that exploited disabled people for the sake of making money. He and his wife retreated from the outside world for six years, in the mountains of Japan, to reorder their priorities and emerged intent on getting involved with the disability rights movement...“that’s when the really successful part of my life started.” Returning to the United States, he was unsuccessful in getting people to work “for the whole of humanity, but no one wanted to listen to it.” It was not until he got involved with the disability rights movement that he found people who shared his vision of justice for all - “I stopped pontificating, as if I was going to save the world, and started working with them on these projects...I was a pretty good project worker. I’m a pretty good promoter.” That work eventually led to many government jobs, presidential and congressional appointments, and heading a congressional task force that took him around the country gathering evidence from disabled people to support the passage of the ADA ...that was the one, where you loved the people and you helped them win and you listened and you joined the team...and you didn’t insist to have your

picture on the *Time* magazine every week.”

George considers the most positive things about his disability experience are the relationships he has with disabled people – “the best thing – and this is no bull – the best thing is the relationships with the people in our beautiful movement. I think they are the best people in the world – I don’t agree with all of them and they don’t agree with me, but I think they are the best people in the world.” He considers the leaders of the community to be “real geniuses...who are every bit as profound and passionate in principles as the patriots who founded this nation.” George expressed his deepest concern for the disability rights movement – it must continue to be an integral part of the larger civil rights struggle. He was one of the few people who opposed the partial rights of Section 504 - “I didn’t care much about one ramp! I wanted across-the-board civil rights, like the ones for black people and women and Jewish people...that’s what burned in my gut...I’m always looking at the rights of all people!” He has “no patience” with those who think only of disability rights, finding it “impossible to think in terms of disability rights... disability rights is always just a part of it.” For George, there is power in “complimentarity” and he has a great concern for those disabled people who see only “one-way” to work for disability rights “...there are thousands of different roles in the movement...we need many voices...that is strength - the strength of democracy – Dixieland jazz, you know, everybody playing what they want to play and it all fits together. Any time you try to regiment it, you immediately limit its potential – you worry about everybody saying the same thing!”

As George has reached an advanced age and the level of his disability has increased significantly, he came to see the earlier levels of disability to be “more symbolic than real...I never really considered myself disabled!” Now, totally dependent on others for basic needs...“I got real ones [disabilities], that’s not so funny!” He has been profoundly struck by how unfamiliar and unimaginable his new situation is to him,

despite years of working with people who have disabilities similar to his current - "it's different when it happens to you." He is still "inundated with love...and projects. I think some of them see me as a person who calls them to unity for the greater principles. They don't just come and cry about me because I'm sick – they come and say 'George, we love you, we need you, we don't want you to die, you got to rest...but one more thing - we want you to come to this press conference!' Along with his increasing loss of ability, he is struggling with his family's predisposition to depression - "a rough disability...it's like a black hole...it's something you fight through...I still feel like I did as a younger person – that I was not a worthy person, and so forth, - that's a tough deal." George spoke of another struggle, a spiritual one, of working to change his own tendency towards his family's ego-driven script of ambition. He prays nightly to be "Wabi" - a person, in Japanese tradition, whose life "blends in with the power of the universe and does not attempt to be flamboyant or fashionable, but is simple, powerful, true." George related that he never has been a person others feel comfortable "hanging out" with - "some people think I don't have a sense of humor," but has concluded that it has enabled people in the disability rights movement to "see [me] in a different light...to listen harder to the things I say that I think are profound."

In the last years of his life, physicians attempted to usurp his right to make his own end-of-life decisions, which he successfully fought with the help of loving hospice workers - "again, love saved me!" When he did not die within the predicted six months, his "flunking – or getting kicked out of hospice" was a triumph he spoke of with glee, never failing to use that personal experience to illustrate the dangers of institutionalized medicine's capacity to devalue disabled people. Even as he became very limited physically, George remained active in his role of elder statesman, which he thought contributed to members of his household family having "trouble feeling sorry for me...they know I'm no saint. I think they see my disability as less objectionable...much

less serious than I do.” George lived five years longer than the doctors’ dire predictions. He kept working from his bed every day on his vision of individualized empowerment for the 21st century until his last day at the age of 71.

Theoretical Notes

The major themes found in George’s interview were: (a) wealthy family (b) juvenile delinquent (c) transformational love (d) different values (e) spirituality (f) civil rights warrior (g) disability salvaged life (h) greatly increased limitations (i) reciprocity concerns (j) Asian wisdom (k) aging (l) macho man (m) high expectations (n) disability community (o) ego-driven family script (p) later in life onset (q) elder statesman (r) greater principles of unity (s) lobbyist (t) finding own truth (u) spiritual crisis (v) exploitation (w) drive to be independent (x) businessman (y) wealth = influence (z) self-sacrifice (A) need multiple roles/voices (B) positions of power (C) simple lifestyle (D) human rights (E) valued independence (F) normalization (G) race awareness

It has been difficult to analyze this interview, because I knew I was told a most distilled picture of a very complex life, a picture that seemed less personal in its content and images than the interview content of other participants. My theoretical musings on George’s disability identity development will be derived mostly from information he gave me in the interview, as well as some history known within the disability community.

George’s disability identity was grounded in a place of “love for all humanity” that he experienced in the rehabilitation hospital and that he also read about in studying Gandhi’s life and teachings – a position that echoes the Transformation stage of Myers, et al., (1991) George and his wife, in the end, adopted a simple and practical lifestyle quite similar to Gandhi’s – George ate one meal a day, never owned a car, used public transportation and was pushed around town by members of his entourage in an ancient manual wheelchair that did not fit his lanky frame. They lived that way to “leverage” his fortune to benefit disabled people - “we are a little disability PAC [that gets] more credit

for a dollar than the labor unions...since nobody expects to get even a cent from a disabled person.” The fact that George was older when he became disabled, to say nothing of being a privileged, confirmed juvenile delinquent scion of a wealthy family, with nothing of meaning in his life, made his disability identity development unique. He never went through a period of grief, shame or depression about his disability – because he considered it saving his life by introducing him to practical love. Some of this may be true because he came from a privileged position of one who did not have to fight for survival in a devaluing medical or economic system and therefore was never angry – until he had to struggle to get away from the doctors who were denying his right to make his own end-of-life decisions. Neither did he go through a period of time in which he identified solely with disabled people and disability in an “immersion-like” stage (Cross, 1991), which is not to say that George did not spend a majority of his time working on disability issues, in the company of disabled people whom he loved. The grounding of his vision, though, was always in the unity of all humanity – a spiritual truth that seemed to preclude any such exclusionary identity position being an option for him (Myers, et al., 1991).

The fact that George, and many of the other participants, actively mentored other disabled people is a form of “generativity” that actively cares for the next generation through their work and their concern for leaving the world a better place (Erikson, 1950, 1968). It was the privileges of George’s race, family wealth, combined with his own commitment to “love of humanity” and passionate vision for human rights, that made him an elder statesman of the disability community and a powerful voice for justice in places of power. People in the disability rights movement understand his affirmation of the unity of all humanity because they were fighting to be viewed as full members of the human race, though his spiritual grounding in love for all of humanity may have been lost on most of them. Perhaps this is what lies at the heart of George’s concern for the disability

community focusing solely on disability rights—he wants them to grasp the larger spiritual principles that unite all struggles for equality. For not only did George live like Gandhi, but he had also lived excessively like Siddhartha (Hess, 1951) and knew that the ego can delude a person, or a group of people, into thinking their actions are for the good, when in fact they are as self-serving.

Credibility

Member check: I belatedly emulated George's Japanese gift giving custom by sending him a copy of Ursula LeGuin's *Tao Te Ching*, because it was the closest articulation of "Wabi" I knew to share it with him. George died before I was able to complete his profile and send it to him for review. Because George had given me permission to use his name in writing about him [which I have not done for IRB reasons], and because some of the content of our interview was also included in the article his niece published about him posthumously about him, I sent George's profile to his wife for her review... How blessed I felt to have shared that time with him when he died. He was a giant of a man with a giant vision of justice for all humanity!

Garth

Contextual Notes

This two-hour interview took place at two different times, the first hour in a mutual friend's apartment where I was staying. Garth had arrived a bit late and had to leave for a dinner engagement before we could cover all the questions, so we finished the interview over the phone a few weeks later. Garth was included in this study because of his early leadership in crafting federal accessibility legislation and his role as a highly published historian of disability history. Garth was also someone I met through my Ron's wide friendship circle of disability leaders at a mutual friend's memorial service.

Demographic Description

Garth described himself as gay, a severely disabled with post-polio, a writer,

commentator, activist and a WASP, recently converted to Catholicism.

Disability Identity Development Profile

Garth contracted polio at the age of 20, during his first year in college. Prior to this, he had prided himself on using his “great will power” to accomplish hard physical challenges, a personality trait he believes has propelled him through much of his life. He described himself as a “creative, sensitive person” before getting polio and that becoming disabled was “a trauma...a severe blow to my self-esteem, to my sense of worth, to my sense of body, to my sense of manhood, to my sense of who I was!” Society’s view of disability at the time, he described as “an embarrassment...not spoken of in polite society, as venereal disease, as mental illness, as an illegitimate child.” Garth had held these views, confessing that he had a practice of crossing the street to avoid contact with someone in a wheelchair - “it was frightening, you know, they are visible symbols of frailty and death.” His was a family of civil servants who ascribed to the social injunction to be “polite, never mentioned that I had polio and they certainly never mentioned feelings,” though they did provide physical things he needed, like a hand-controlled car for college. Even today his family is unable to talk about disability realities in his life, “my father calls me every day and assumes I’m all right...he doesn’t want to know any detail!” Garth’s family believed from the beginning that “I would just pick up from where I was and keep on going – you don’t want any gaps in your resume, you know!” For Garth, his disability was “a trauma that [I] drag along – it’s always with me...well, my disability is me – it’s an integral part of me.” He sees disability as “a two-part thing – it’s the physical disability, a fairly cope-able thing...[and] there is a lot of psychological impact.” He says he continues to have a “mystic sense of being able-bodied...it’s like the amputee’s sense that his leg is still there,” which can still make him angry - “I’m aware of the anger and it’s useful sometimes...at the sense of what might have been, yep – no regrets!”

After a year of self-consciously “hiding in my hospital room,” Garth went to the nation’s leading rehab center where he found that “disability was the norm,” not considered “sick,” but part of a collective “banding together to figure out ways and means of continuing with our lives.” The disabled people who ran the center certainly ascribed to the belief that Garth would get on with his life, but they went about it quite differently than his family’s strategy of ignoring it. The community itself “was patient-run, patient-directed...patients hired the doctors, patients devised their own therapies and their own assistive equipment that would allow them to lead functional lives.” There were many different disabled role models at the center - from top administrators to those who demonstrated to new arrivals how to manage living with a disability – “how to get in and out of bathtubs or tricks to get in and out of cars.” In addition, former residents would return for check ups and vacations, while others chose to remain in town after leaving the center and held every conceivable professional role in the larger, local community. Community newsletters provided information from disabled people about useful equipment, traveling with a wheelchair, etc. – “it had a remarkably uplifting effect on our lives!” Having been abandoned by his first lover, Garth was disturbed to find that psychologists at the center were only interested in assessing vocational aptitudes, not in exploring or researching the emotional or sexual implications of disability in people’s lives. As it turned out, those emotional and sexual issues were also of great interest to the folks who came for rehab and they addressed them through the very social and personal life of the community – “the camaraderie, the examples of our seniors, the peer support...and there was sex in the bushes and things like that, so we saw that a normal life was possible. It was assumed by everybody that you would go back and finish college and get a job and get old.”

“Normal life began” when Garth returned home from his year away. His father found him a part-time job, which his mother drove him to every day until he developed

the strength to drive himself. He began his search for a college that would accept him in his wheelchair, refusing to even consider schools with “segregated” programs for disabled students – he wanted to be part of the whole campus life. The thought of going away to college “terrorized” him because he didn’t know if he could do it; he only learned how to do it, once he had “jumped” into it. Forty applications later, a college on the opposite side of the country finally accepted him, as did his non-disabled schoolmates, who actually elected him president of their dorm. During these years, Garth described his way of coping with his disability as “denial – ‘I’m as good as any able-bodied person and I can do more work and I can...so forth and so on!’” Starting with college, Garth lived independently, initially supporting himself with scholarship and fellowships, including one to Oxford. It was very important to him that people not see him as “helpless - I’m very vain,” though maintaining that image required he live “in performance mode...presenting a false self” which he thought protected him from others’ negative perceptions, though it also hid his own reality from himself.

During these years of “performance mode,” Garth relates that he also denied his homosexuality, because his ambition to succeed in politics “was eating me up, I couldn’t handle being crippled and gay at the same time!” He spoke of “shamelessly using his disability...winsome personality, manipulative, and reasonable good looks,” Garth lived quite successfully behind this “screen” for many years, building a meaningful political career in which he was also able to work for disability rights before there was a community fighting for them. While he knows his disability “shaped his career by limiting it, in terms of mobility,” he also says it “focused it.” His life has been far “more eventful than ever I thought possible when I was in the hospital – it’s just astonishing! And the goddamn events keep on happening – remarkable!”

In his early forties, though, Garth experienced a complete physical and emotional breakdown – he had been “pushing my strength totally beyond...I was living on will

power...emotionally I had been denying my weakness and I had been denying my loneliness - my social life had only been connected with work - my body broke down, my mind broke down – I just gave out!” The implicit message he recalls from his time at the rehab center was that the future was always framed as forward and upward movement; it had not involved listening to his body and being honest about his limits. He described how residents of the rehab center had developed a certain pride about being “polios,” with no sense of being “a victim or oppressed...back in the Roosevelt era, it was pretty classy to have polio...we were very snobbish!” So, it was only after his breakdown that Garth began to be “less leery” of disabled people who did not have polio and spend time with them. He related that he “always had polio friends...but polios never counted as disabled – we just got on about our business!” He has found that “identifying as a disabled person has been immensely important – politically, socially...being a member of a group that fares better than we did 50 years ago – we’ve done that by saying we have strength.” Early on in his connecting with disability community, he remembers a friend trying to “indoctrinate me into disability rights,” while also having to defend Garth’s disability status to other disability rights activists who did not consider him “disabled enough.” He speculates they wanted “oppression and discrimination,” but for him disability had “two sides” - one, it’s a bummer and two, it’s very useful.” And he admits he used it very well throughout the course of his career. Garth loved the irony of his psychiatrist’s joking assessment that “the problem with you is that you use your wheelchair as a crutch!”

After more than twenty years of psychotherapy and reflection, Garth sees himself, now, as “secure in my skin, as to who I am...not the person who is hiding his disability,” though he declares his disability is not “front and center” of who he sees himself to be. His writing has also been a part of this process – “I’ve written a great deal about disability...I write to figure out things I don’t understand. And so, in that sense,

disability has shaped my life.” A major lesson of those years of therapy has been “learning how to ask for help - no, no - learning how to receive help, learning how to receive love – learning how to accept the risks of feelings that are involved in that.” During those years, Garth became active in the gay community, as the AIDS epidemic was just beginning to devastate it. Over time, he found more acceptance as the epidemic challenged that community’s own stereotypes of good looks and virility, but at first he had to “put my head up and take comes bruises, but I ended up with some wonderful friends!” Garth considers that our society’s response to “disability has traditionally suppressed both sexuality and mind...the injustice of our society is nowhere written so clearly as how disabled people fare....when you look at other societies, they do it a lot better.”

After 50 years in a wheelchair, Garth believes his disability has made him confront existential issues that he may not otherwise have done, and because of that he has been “stretched - quite remarkable growth – personally and intellectually.” Garth acknowledges that life for most people is a “struggle - without struggle, life wouldn’t have much meaning. It’s the way you know you are alive.” He sees his own struggle with disability and loss to be only “a matter of degree, rather than kind... terribly important and has enriched my life greatly. I understand things about values of life and death and today, the now, versus the future...a lot better than do an awful lot of able-bodied people.” Even now, Garth can “get pissed” at the medical system’s capacity to make people feel “categorized and ‘dissed’ and demeaned,” but now knows how to interrupt that by his own creative means. As Garth observes the aging of our population, he feels a responsibility to those who are now grappling with the physical realities and existential issues of disability that he has already mastered, “to be with them and their experience and shock and to help them by example and empathy – sort of a payback for the help they gave us.”

Theoretical Notes

The major themes I found in Garth's interview included: (a) denial of needs (b) wisdom (c) years of psychotherapy (d) struggle – part of life (e) creative (f) sensitive (g) disability is trauma (h) blow to self esteem (i) disability had physical/psychological components (j) disability was an embarrassment (k) increased limitations (l) aging (m) isolation (n) ignoring of psych issues (o) comfortable in skin (p) independence (q) existential issues (r) silence – family (s) relational management (t) integration of sexuality/disability/professional (u) gay (v) abandonment (w) spirituality (x) universal human issues (y) high expectations (z) multigenerational role models (A) obligation to give back (B) family can't cope (C) not really disabled (D) non-victim (E) disability hierarchy (F) gay community (G) disability community (H) hide psychological issues (I) normalization (J) race awareness.

Discrepant/negative Case: Garth's description of his rehabilitation at the rehab center is most instructive in understanding what is needed to facilitate a newly "disabled" person's, or any disabled person's, sense of self-efficacy, as well as more positive sense of self as a disabled person. The center was a "multigenerational" disabled community with a culture constructed by the disabled people who lived and worked there, with its own values, beliefs and assumptions that reflected their lived experience of disability, i.e. sexuality was a part of disabled lives, disabled people are not "sick," people with polio were not victims, problem solving self-sufficiency was highly valued, skill building, "get on with life," etc. This environment had disabled role models defining and demonstrating the "tasks and activities" members were expected to take on with their new bodily configurations, such as how to get in and out of tubs or cars, etc. These role models were fulfilling every conceivable social role expected of adults in the larger society and were providing the practical guidance and

encouragement that would enable residents to take on such roles when they returned to the larger society. In a process that echoed Erikson (1959), new residents first learned to trust the restored level of ability in their new muscle structures. They were then expected to learn how to devise solutions to their own practical problems of moving through the world and accomplishing their goals - a new form of "self-efficacy" would be required they make their environments work for them when they returned home. Developing such skills is a qualitatively different developmental task than Erikson imagined for his Stage 2, which he envisioned as learning to "control" the muscles of elimination (Stevens, 1983), but rather how to redesign one's environment to make it work for you. This was not a culture that relied on medical professionals to define the extent of their physical abilities or future prospects, but rather it was assumed disabled people had abilities. Residents developed a confidence in those abilities to devise creative solutions and manage all kinds of situations and when they left that knowledge enabled these "polios" to take on whatever roles and activities they chose. This identity developmental process of "polios" who had been at this center, led them not consider themselves disabled or victims who got on with constructing the lives they wanted. Only later in their lives, when the late effects of their polio overcomer lifestyles, such as Garth's complete physical and emotional collapse, began to emerge did they begin to see themselves as having disability, as Justin spoke of, and found the medical establishment was unprepared to their new physical limitations and their ensuing emotional realities.

This is not to say that this "polio" community was completely devoid of cultural antecedents rooted in larger cultural beliefs that shaped how the residents rebuilt their lives after they left the rehab center. Garth described coming to the realization, after his physical and emotional collapse, that the unspoken rehab agenda he had internalized

there was the requirement to constantly push his body “forward and upward,” never listening to its signals of pain and fatigue. It was this pattern of denying his physical limitations, attempting to hide them from himself and others the real extent of his disability that, over time, led to his collapse. The same denial kept him from using a power wheelchair for many years, instead of a manual one, which had contributed to his fatigue. When I tried to explore that internalization of society’s silent injunction to hide one’s disability, or at least the full extent of it, as different kind of oppression, he jokingly referred me to a chapter in a book he had written on the subject. There I found that he discussed his resistance as rooted in the same shame other participants had articulated about appearing to be “crippled” (Gallagher, 1998), but even then he did not articulate that as a form of “internalized oppression” perpetrated on him by a society that devalued him as a disabled person.

Credibility

Member Check: Garth responded that the profile reflected his voice and the real trajectory of his disability identity development. He jokingly requested a different pseudonym and commented, “You know me better than I do!”

Lena

Contextual Notes

This 90-minute interview took place in an empty classroom at the university where Lena works on a project the deals with aging and developmental disabilities. She was chosen to participate in this study because of her strong leadership role of national president of People First, an international self-advocacy group that promotes self-determination for people with developmental disabilities.

Demographic Description

Lena described herself as an outgoing person who enjoys her work and loves to travel and party. She also identified herself as having an intellectual disability that is not

obvious. She is also European American.

Chronological Disability Identity Development Profile

Lena was born with her developmental disability into a family that “doesn’t really view me as any different than anybody else, so that’s really good.” She spoke of “not liking” school because of all “the labeling stuff behind it.” Even though she was in only one special education class, “people treated me differently, they don’t like being associated with you in that classroom. It’s a lot harder to make friends outside of that classroom. It was such a separation.” Lena regrets there were no “supports” for her and her mother when she was in school -- “mom didn’t know all of the stuff to help out with -- you have a right to say things, you want to be a part, that you even participate in those things, like your [IEP] goals.” During those years, kids told Lena “‘you can’t’, and ‘you are stupid’, and they didn’t want to hang around with you.” She described being perceived negatively made her feel not “like a very strong person, not like you could do a lot of stuff – it just didn’t make you feel very good.” Lena thinks she’s not “any different from other people, but sometimes people feel different about me.” She describes her disability as “not obvious” and admits that can cause problems, because some people do not believe she has a disability and others forget she has one and “need support or help to do things.” Given her leadership position, she has learned to be cautious about discussing her disability with people whose views or motives for asking about disability she does not know - “how they’re going to talk about it...as long as they are not going to use it for -- ‘look at this poor person who can’t do anything and look at what they are doing now!’ – or something like that.”

While still in school, Lena got involved in a self-advocacy group that has helped her feel good about herself as a disabled person. She was initially suspicious of the new advisor who introduced them to the self-advocacy movement, because she thought the teacher was just another professional who was going to tell her what to do. Her initial

interest was only in the “stuff – T-shirts, jackets, baseball hats...no clue about the other stuff – how to speak up for yourself or running a board meeting!” Now she wishes “this group was around when I was younger,” because she would have learned to speak up for herself and what she wanted sooner.” Her motivation to work in the self-advocacy movement is to bring these ideas to other people, because she didn’t know them when she was younger – “it makes you feel good that you can give that to somebody else.” The friends, support people and advisors she has met through the self-advocacy group, both locally and nationally, have taught Lena the value of “having people around who can support you no matter what.” Lena knows that without these people in her life, she would not have grown the way she has – “they become more like your family instead of your friends.” Lena’s leadership in her local self-advocacy group eventually led her to leadership roles at the state and national level and gave her the opportunity to travel, which she loves, while serving on multiple national boards.

Over the years, Lena learned how to “speak up about something you don’t think is right” and has learned that, unlike her early training, it is okay to disagree with “authority figures.” In previous jobs, Lena experienced quite of bit job discrimination, which she attributed to her having been in special education classes. The self-advocacy skills she has learned helped her negotiate terms in her current job that enabled to fulfill her work responsibilities and continue to travel doing self-advocacy training. As an integral part of her university research team, Lena has also learned to speak out - “go up against something that you really don’t believe in.” She knows that her personal knowledge of disability is an important contribution to the team’s work –“you have to offer them different ways of saying what you want to get across, by rewording...figuring out. She is learning in this job to deal with issues that are wrong in a work situation - “how to still be in a job and explain to people why you feel different about that situation – it’s difficult.” For example, when she insisted a non-disabled professional colleague use

Special Olympics as only one option for physical exercise in a conference presentation. She relates that there is always a struggle to get non-disabled professionals to treat her and other people with intellectual disabilities with respect - those who “just assume” she will not be able to keep up with the work – “you are not given an opportunity. It gets really frustrating at times, when you have to keep on proving yourself and everybody else doesn’t.” She believes that the presentations she makes in university classes and at professionals meetings contributes much to their understanding about the very people they are supposed to be working with, because it is “a whole better picture than what they get out of the textbooks!”

Lena’s non-disabled family and friends do not always understand the work that she does, “because I don’t think they automatically get it...it’s hard to explain, like if it’s discriminating against somebody and they’re really vocal about it...it could end up in a major argument.” She admits that now she is more inclined to confront people who say negative things -- “I don’t think anybody should be discriminated against because of something they have no control over.” Lena also described discrimination she has experienced and observed among disabled people – “people avoid being with people who have a more severe disability ‘cause they don’t know how to interact.” She sees people with physical disabilities not wanting to be around anyone with retardation and visa versa – with both groups not wanting to deal with the other because they don’t not know how to interact with or support the other – “you have these two bridges and they need to come together and there are things you can work on together...how to see the common goals.” Lena has been working to increase opportunities for people with different kinds of disabilities to work together, “that’s kind of neat when you figure out how to communicate together and how to work together.” Lena especially likes hanging out with her friends in the self-advocacy movement, because they have all “gone through some of the same things together and you know how it feels.” For Lena it has been

important to be able to talk about such things with her disabled friends and she considers it an important obligation for her to teach younger disabled people how to feel good about themselves – “if they can get self-confidence before they go out there, then that’s really good.”

As Lena’s national leadership role in the self-advocacy movement came to the end, she found she needed to have other things in her life besides the self-advocacy work. Learning how to balance work and other interests has been a challenge – “you can’t do it morning, noon and night every single time – you have to have other things and other friends to help that, because you lose yourself and aren’t good for anything.” She knew that other leaders in the movement were struggling with the same issue and she organized a retreat to help them learn about “life after leadership.” Lena is currently expanding her self-advocacy training skills to become a certified trainer for a national leadership-training program, which traditionally has not targeted disabled people. She’s finding that the ideas and language in that training program are very accessible to people in the self-advocacy movement and plans to introduce it to the self-advocacy movement. Lena appreciates the fact that her disability and learning to be a self-advocate has given her a capacity to understand people a lot more than some other people do; she’s learned to accept people more and how to support them – “I think it helped a lot with understanding in relationships and friendships – things like that.”

Theoretical Notes

The major themes I found in Lena’s interview included: (a) negative labeling (b) special education (c) treated as different (d) discrimination (e) low expectations (f) peer rejection (g) teased (h) lack of support (i) redefinition of self (j) speaking out assertively (k) disagree with authority figures (l) built self confidence (m) silenced (n) segregation (o) normalization (p) disability hierarchy (q) actively confront discrimination (r) training skills (s) always prove abilities (t) token (u) support others

(v) expanded interests (w) mentoring others (x) finding new interests (y) balance work/life (z) new paradigm (A) race awareness.

Lena's shame at being labeled a "special education" student was generated by a school system that treated her as different and forced her into a segregated education setting that reflected society's negative beliefs about her abilities. Her family had treated her "like everybody else," but her non-disabled peers in school treated her as someone less than them because they too held society's negative beliefs about her. Their rejection and teasing undermined her self-confidence and communicated to her that she was being defined by what she could not do. She spoke of having "no support" to help her negotiate this non-accepting environment, until she encountered a respectful, non-disabled, support professional who also played an important role in her developing self-confidence and assertiveness in speaking her mind. This scenario is a perfect example of Bronfenbrenner's (1979) description of the problems that arise when there is insufficient support for a person to successfully transition from one sphere to the next. Such a lack of support exists when the cultural beliefs, values and assumptions differ between spheres, such as between the culture of one's family and the dominant culture that shaped school experiences of many of the participants. Non-disabled families do not know how to fortify their child to deflect the negative messages of the dominant culture, nor do they have the knowledge of the roles and activities their disabled family member are actually capable of taking on with their disability.

Lena's disability identity development may have first been triggered by "cool stuff," but over time it developed into the inner strength and vision of a leader of the self-advocacy movement who could identify issues that needed to be attended to by the movement. Lena was introduced to other people with cognitive disabilities who were learning from and teaching each other about disability rights and self-advocacy skills and in that affirming environment she began to develop skills she did not know she had

because she had been denied opportunities to learn such roles and activities from people like herself (Bronfenbrenner, 1979). Within her self-advocacy group, she began to learn about legal rights she had possessed while in the school system, but had never been informed of them by the school system or other local organizations working with people with intellectual disabilities. The group members began to define themselves positively and learn that it was okay to assert their own voice in decisions that involved them, an activity that had never been allowed because their role, as people with cognitive disabilities, was to comply with prescriptions of the “helping” professionals in their life because society believed them to be perpetual children. Lena had initially viewed the support professional who organized their group with suspicion, because she thought she was just another one of these kind of professionals. The people in their self-advocacy groups became role models to each other in developing their self-advocacy skills and were a supportive community to each other. They also began meeting other self-advocates from around the state and the country who also became role models and began to expose them to many new ideas about who they could be and what they could do.

Lena’s leadership abilities were developed in the self-advocacy movement as she took on state and national leadership roles. Those same skills gave her confidence to work in a university setting where she had to use her assertiveness skills as a member of a team with many non-disabled professionals who had misconceptions about her abilities. She learned she was able to articulate her point of view, as a disabled person who understood the personal implications of proposed actions, and advocate for presenting a broader range of options disabled people, and their families or support professionals, needed to be made aware of, such as Special Olympics not being the only possibility for physical exercise adults with cognitive disabilities had in their communities. Lena’s understanding of the common experiences of all disabilities has

given her a means of communicating her ideas to physically disabled people and being able to work with them in cross-disability settings, which has expanded her vision of the disability community. She knows that two-way internalized oppression has kept from the two movements from working together, historically, but she wants to create more opportunities for that to happen. Her expanded goal of working together with the disability rights movement, as well as taking her role as mentor to younger self-advocates and former national leaders of the movement quite seriously, are qualities of a more complex disability identity position that has expanded beyond identifying solely with people who have the same disability that is reminiscent of the movement from Immersion/Emergence (Cross, 1991).

Credibility

Member Check: Lena approved of the profile I sent her and thought it told her story in her own voice.

Claudia

Contextual Notes

This ninety-minute interview took place over the phone, after many unsuccessful attempts to schedule it due to Claudia's busy work travel schedule. Claudia was chosen to participate in this study because of her leadership in disability community organizing, both on a national and international scale.

Demographic Description

Claudia identified herself as a woman who is blind and Latina/Native American, with a wonderful family and many good friends, as well as a musician and a mother

Disability Identity Development Profile

Claudia was born blind and grew up in a large working-class family with parents who had a strong work ethic, which they passed on to all their children. She describes her Latino background as the family's dominant culture and her blindness as, "something

I've been able to integrate into the person that I am since birth." Claudia has a sister who is also blind, "I think we were both very lucky" to have someone with whom to "compare notes...it didn't make me feel abnormal, because there was somebody else like me...to bounce things off of." With a large family, Claudia's mother didn't have time to give her blind daughters special treatment. They were just part of the "group...we were not supposed to stop what was happening because of our 'needs.'" Developing as many skills as possible was a priority, so they had chores to do within the family – "we had a family that expected us to participate – like we had to wash the dishes, so we learned skills as kids...we had roles." Claudia's mother was horrified by what she saw at residential schools for the blind and refused to separate the family. Her "resolve, her integrity to find people to help" moved the family to a state where mainstreaming was just beginning to be implemented in public schools and the teachers who wanted mainstreaming to work had expectations as high as Claudia's parents' expectations - "we were pushed very hard by our teachers...it was instilled in us that we could do things and they had big expectations of us." Claudia took judo and drumming lessons, was on a swim team, and participated in a mountain climbing Girl Scout troop, because her parents were committed to her "full development." Their social lives were rich with a large extended family and many blind, and sighted, friends all the way through public schools. The practical and social skills Claudia gained from such high expectations gave her a "very positive self-identity...we also learned, unlike kids who go to a segregated school, how to deal in the world of sighted kids, how to survive...the onus was on us to figure out how to get through the world."

Running through these high expectations, though, were subscripts of negativity and shame that were grounded both in the family's church and in the larger society's stigmatized view of disability. Claudia described feeling badly about causing family members "pain" because people were staring at them in church. She believes that her

older siblings “had issues of shame and feelings of being ignored,” while her younger siblings do not, because blindness and helping were always part of their lives. Claudia believes that much of the staring they all endured was due to the fact that she and her sister did not use canes for mobility. School officials had urged her mother not to “encourage her to get dependent on a cane...which is so ridiculous...people didn’t know what was wrong with us...we were encouraged as kids not to appear blind! You didn’t want to look blind. It was cool if you were like everybody else!” Undertones of shame were even present in family instructions to “not appear blind” – look at the person being spoken to, care of clothes, weight consciousness, no rocking, no sticking fingers in one’s eyes, etc. While valuing the social benefits of such training, in that “people don’t see you as much as a freak” - Claudia knows that the negative undertones bred “a little, not elitist...but a little self-hatred or internalized ‘ableism’ or something.”

As their world got bigger, Claudia and her sister began using canes - “you couldn’t inform everyone around you that you were blind.” For Claudia, it was a huge “relief” when she began using a cane in college, “like OK, I’m blind,” people no longer wondered if “she was high or drunk.” Claudia believes her parents never expected them to marry...“I think, sometimes my parents treated us more like you treated men...really encouraged us to go to college...I don’t think our non-disabled siblings were programmed to do that.” After finishing high school, Claudia went to a residential training program to develop her daily living skills...“how to use the cane properly and cook as a blind person...and it was very helpful.” During these years, Claudia was reading writers in the farm workers and women’s movements and got involved working with them, but she felt “I wasn’t really taken seriously because I was a blind person.” It was not until she joined a more radical political party that she found her skills were appreciated and respected – “I felt like I was valued, even though I was a blind person...I felt very good about myself.” Claudia’s first encounter with the disability

community, in fact, came through an invitation for the organization to participate in a historic disability rights demonstration - "it was a huge turning point in my life. It was okay to be disabled, people were doing positive things and people were fighting for civil rights...I was converted, it was like a new religion!"

Claudia found "an understanding, a camaraderie based on being different and dealing with shame, having to explain yourself." She also appreciates the sense of belonging to such "a very resourceful bunch – we know how to do things and we can strategize. We are very good at figuring things out for ourselves...just a companionship and camaraderie in seeing things change." One of main mentors, Ed Roberts, "knew how to develop people," and encouraged her to be a "bridge" between the disability community and the women's movement, as well as the Latino community, which she was already a part of. The chronological sequence of her identity development is something that Claudia really appreciates, "I was able to identify and focus on other parts of me...so it was good the disability was last and sort of what stuck." She also feels that her earlier organizing experiences gave her "a good sense of myself as a skilled person, as a person who could contribute" to the disability rights movement, which has been an important part of feeling good about herself as a disabled person. Eventually, Claudia fulfilled her parents' dream of becoming successfully employed and no longer receiving Social Security Disability Income. She admits "it was very traumatic getting off, 'cause it was something that was really kind of regular and something you could count on." Claudia credits her family with her ability to make that transition..."we were expected to get up and go to work in the morning, even if we were on SSI...Most of the [disabled] people who are employed in a major way, who are over 30 or 40, come from families where they were pushed pretty hard."

Claudia's work through the years has focused broadly on disability rights, both nationally and internationally, in many different settings, on many different projects and

in many different countries. Living and working internationally has taught her that “our fights for civil rights cannot be the fight for everyone – you can’t compare yourself to other people – you don’t know what their circumstances are!” She sees her role internationally as a “conduit, giving and receiving information in which I benefited from knowledge gained in working with people around the world...you got to let folks make their own plans.” She appreciates being stretched by working internationally and learning about the different values disabled people have around the world. And she also appreciates unexpected result of her taking on the role of disability advocate in the women’s movement and Latino community that actually “integrates different parts of me.”

Claudia views being a disabled person and a woman as equal experiences, “I can’t separate them,” though she thinks her blindness has probably generated more discrimination. “I might be reacted to because of my cane, that’s the first reaction people have.” Even then, she finds that “context” determines which part of her is most salient at any given moment, such as being a woman in an all-male band certainly highlighted that aspect of herself. As a Latina who values family and interdependence, Claudia feels “the lack of understanding, when I’m around a bunch of white disabled people” who espouse the American value of “independence” that has shaped the rhetoric of the independent living movement. She also is disturbed that the predominately white leadership of the disability rights movement has not made a priority to nurture disabled youth and expresses concern “that the disability elite, that the disability leadership is still very physically disabled. I know very few blind or deaf people who have risen to that level of leadership in the cross-disability movement. I wish there were more Latinos in leadership positions...more diverse leadership in the movement.” As a disabled mother, Claudia’s interdependent cultural values enabled her to keep her son from being in a helper role for her - “I really didn’t think it was fair to expect a three year old or five year

old kid to take on responsibility of being my attendant - and I still don't," though she readily admits calling him "my cleaning slave" now that he is nineteen! Claudia has been the only disabled person in many social situations in her life, whether it be hiking, spelunking, bands, Girl Scouts, etc. in which her disability necessarily became part of the group experience - "I was not sorry about that," as it required everyone develop a comfortableness with her disability – she did not become the focus of attention for a "caretaker" personality. And it is that level of comfortableness with her disability that Claudia requires of any friendship with disabled or non-disabled people alike – "with an acquaintance you can handle anything, but with a good friend - I tend to not become close to people that I feel are uncomfortable with my disability." For Claudia, her disability has "given me a lot...I think it has enhanced my life...I'm a complicated person, because of all that I've been given. I think that disability is a facet that has worked well for me - or I've worked well for it - I'm not sure which!"

Theoretical Notes

The major themes I found in Claudia's interview included: (a) shame (b) high expectations – parents/teachers (c) Latino collective culture (d) mainstreamed (e) values interdependence (f) context determines saliency (g) denied use of cane (h) religion (i) skill building (j) collective responsibility (k) college (l) disability community (m) self definition (n) disabled sister (o) musician (p) embarrassment (q) internalized "ableism" (r) shared experiences (s) women's movement (t) farm workers movement (u) normalization (v) skills appreciated (w) expanded disability values (x) staring (y) broadened by international work (z) helping (B) a contribution to make (C) nurturing youth (D) comfortableness in blind community.

Discrepant/negative Case: Claudia's family's Latino culture gave her very important perspectives on the disability identity development process. The fact that she had a sister to share her disability experience was also an unusual and

beneficial fact. Claudia's mother's refusal to send her children to residential schools for the blind came out of her cultural commitment of keeping the family together, as well as her innate belief in their right to develop their full potential. Claudia did not experience any lack of support in transitioning from her family's cultural environment of belief in her abilities, as her teachers in the mainstreamed schools were as committed to their development as her parents. The fact that Claudia and her sister were the only members of her working class family to go to college indicates that her parents also were aware that employment discrimination against blind, working class, Latino women would limit their options in life and sending them to college would give them the more tools to counter such discrimination. The family's culture and high expectations required that Claudia learn to be a responsible member of a collective, both within the family and in other social settings in the larger community. That learning of "activities and roles" laid the groundwork for Claudia being capable of playing contributing roles in the political movements she later became involved with as an adult. The variety of group activities Claudia was involved in as a child, and continues to be as an adult, gave her a much stronger sense of belonging in the world socially than other participants who were encouraged, consciously or unconsciously, to focus solely on their intellectual abilities for a sense of accomplishment, which ignored their adolescent skills building and delaying their social development (Bronfenbrenner, 1978).

Claudia's concern that the predominantly white disability community leadership is not reaching out and nurturing young disabled people – her own "generativity" concerns (Erikson, 1958), I believe came from her own experience of having been fully nurtured within her Latino culture. Hers was not the experience of an isolated nuclear family, but rather a large extended family and community that treated her as a valuable member of

the group, thereby contributing to her whole development, very similar to Gail's experience. The fact that Claudia did not experience her disability alone in the family also meant that she did not grow up in the emotional isolation other participants talked about feeling in their families. The existence of emotional isolation during crucial developmental years, as well as early isolation from other disabled people many of the participants described, may very well be the reason the predominantly white leadership of the disability community are not attending significantly to the next generation's psychosocial development. Having not experienced such nurturing or without the years of psychotherapy many of the participants reported having, would not necessarily possess the experiential, or emotional, knowledge of how to give such nurturance or how important it is for one's psychosocial development at an early age.

Claudia was another participant who came to the disability rights movement through her involvement with other liberation movements, reflecting the OTAID Integration stage (Myers, et al., 1991) and the Internalization/Commitment stage of Cross' (1991) from the beginning. Arriving in the disability community having already embraced other aspects of herself, Claudia expressed an appreciation that disability was her last identity to integrate into her whole sense of self. The timing forestalled her going through any "Immersion/Emersion" stage (Cross, 1991) in her disability identity, because she was already integrated into working to eliminate oppression for many diverse groups. Her further identity development, from that point, was expanding her awareness beyond the American concept of disability rights by working in many other cultures' values

Credibility

Member Check: I phoned Claudia to find a time I could get her feedback on the profile I had emailed. I read the profile to her and she suggested a couple of changes – one chronological and the others clarified the whole family's role in her success. She

went on at length enthusiastically about how I had “done such a good job” of telling her story!

Lennie

Contextual Notes

This ninety-minute interview took place over the phone, because our original face-to-face interview had to be canceled because of transit system breakdowns many months previously. Lennie was asked to participate in this study because of his initial leadership role as director of an significant independent living center that primarily served African Americans; a role that recently had led to his taking on a more influential leadership role at the federal level. We had met eight years prior, at a ground-breaking conference on racial and gender identity, when I was just beginning my doctoral studies and he was director of an independent living center. At the time, it was Lennie’s disability that I commented on, as I was acutely feeling the complete silence about disability at the conference. It did not escape my attention, though, that he was also a tall, African American man with dreads. Over the years, our paths have crossed professionally at national conferences and I was marginally involved with facilitating introductions to leaders of the disability community who wanted to recruit him for his current position.

Demographic Description

Lennie identified himself as a professional, middle-aged, African American man who is disabled, with varied interests in the arts and culture.

Disability Identity Development Profile

As a youth, Lennie was disabled in an accident, an event that exaggerated the impact of the typical adolescent changes he was beginning to go through, as well as cutting him off from the usual things young African American males in his circle did to gain confidence. He described it as a time of “hormones going crazy, coming into

puberty...all the normal things regular kids go through, I went through. The traumatic change from being a energetic, hyperactive 'bad boy' to becoming a person with a disability – I had to work through a lot of that, in terms of what I am.” Lennie found ways on his own to be part of his social group - “other things that you had to do to make your rights of passage...there had to be a progression there, in terms of developing different social skills.” Lennie had a sister with a more involved disability than his own and he found his family was unsure about how to respond to his limited disability, “they dealt with it at a distance. I don’t know that we ever had any real conversation about my disability or about what I was going through.” He had to find his own way of dealing with it - “I’ve always been sort of a fighter anyway, so it sort of helped me along to do this.” His circle of friends remained supportive though they did not talk much about his disability, they simply encouraged him by helping him figure out how to do things. An aunt, who was a nurse, was the only person he remembers having any kind of conversation with about his disability. “She was always very supportive that I needed to do what I needed to do.”

During those early years, Lennie felt there were those who made a point of overstating his accomplishments, painting him as being “so strong and you’re an example and you’re doing great things and you become this super gimp.” All of which created “an undue burden...a double-edged sword” of expectations for him that Lennie acknowledges, on one level, “motivated him to become more,” but the exaggerated praise was “really negative, I think, that was the worst thing that could have happened. They tell you you’ve got to be strong and how wonderful you are and keep a stiff upper lip...you’re not allowed to grieve appropriately.” With no one to really talk to about his emotional issues, the hero perspective made him think he couldn’t have “normal feelings... you may want to cry at times, so you suck it up, you keep going.” He spoke of such pressure as “giving him a fear of failure...’if I fail, oh my god, I’m not going to be

super gimp anymore!” It was the overall supportiveness of that world, though, that ultimately made the difference – “I don’t know that I would have made it without that.”

Lennie’s mother was clear and pragmatic about her expectations for him - he would support himself with a job - “You better get one, because I ain’t taking care of you!’ My mom was good!” Even though the limitations of Lennie’s disability were minimal, she urged him to pursue a white-collar job, instead of a trade that African American youth were routinely encouraged to go into. At the time of his accident, he had applications in to a trade high school to become a mechanic or a high school of the arts and the assumption was that neither was considered an appropriate option afterwards. Only after experiencing discrimination in his job search was he convinced he needed training to do a different kind of work. “It was always forced upon me that I had to seek out an administrator’s job, because I was not allowed to do manual labor - I couldn’t be a tradesman - it became a self-fulfilling prophecy.” He experienced similar barriers with “helping authorities,” who also had limited assessments of his abilities, learning strategies to get around their disbelief in order to accomplish what he wanted!

Lennie got a degree in teaching and found that as he began to accumulate achievements, he also began to believe that “I can - being successful helps build a little bit more self-esteem.” He encountered people who deliberately gave him opportunities to demonstrate his abilities, accepting him as a disabled person without making it “a big deal...I remember having an internship that was supposed to last six weeks and it ended up being eight years of my life. Yeah, that was extraordinary!” During those years of teaching, Lennie came to accept his disability - “‘this is it,’ with time, I was able to become more comfortable with it.” He reflected during the interview, for the first time, that his years of coaching and teaching children from toddlers and middle school were “a milestone...a healing process...children are so gracious...real and straight. They will tell you exactly what they think, more so than adults will...[my disability] being a part of the

children's learning process had something to do with me becoming more comfortable with it." That is not to say Lennie did not have difficulty encountering the negative attitudes of the parents about his being black, being male, and being disabled - "dealing with all those kind of pre-conceptions and not having any models in terms of how to do that or anyone to talk about this." Lennie did not know other disabled people during these years "I was always the minority, in terms of a physical disability...didn't know that people with disabilities really existed."

When he became the director of an independent living center, the experience of his solitary journey gave Lennie the understanding of the need for support groups for disabled people where they can be real about their inner struggles, with people who understand - "people with disabilities are not allowed to be 'normal', they have to be stronger and more success-oriented." Creating such opportunities for disabled people is important to him, as Lennie knows that "one develops an image of themselves from reflection of others...being in a supportive environment and developing." For the past twenty years, Lennie has worked in the disability community, but before that "I was never quite too disabled...it's always that in-between area, never really fitting anywhere." For him, finding disabled role models and "seeing other disabled people who are doing things, that was very helpful...when you can internalize it because you actually see it happening, then it clicks...your parents can tell you a hundred times, or forever and ever, but it doesn't click for you until you can see it actually working...be a part of it." Spending time with other disabled people, Lennie appreciates the shared perspectives - "when other gimps are around me, we may fool around and joke about things...nothing sacred! People with disabilities are funny." Yet even within the disability community, Lennie finds there are those who make their disability "the issue, you don't see the person anymore...a victim personality, the "poor-me's" or its something that society/people are doing..." He has never viewed himself that way, and even as a newly

disabled young man, Lennie always chose to “find a different method or do it differently. Now, its engrained into my personality.” His friends, African American and disabled, are people who share those same values.

As an African American man with a disability, Lennie has found that context determines which aspect of himself is most salient in any given situation, depending on the person or the setting. Because of the not-so-obvious nature of his disability, his “black maleness” is generally the aspect of himself most immediately apparent, that he knows is accompanied by all the usual prejudiced assumptions about who he is or what he is about. Yet when his disability becomes apparent, he knows a whole other set of assumptions come into play about what he can and cannot do. The parallel lessons that Lennie has learned through his race and disability, is to resist “being judged by someone else’s eyes or let them put limits on you...you are constantly resisting redefining yourself to meet others’ perceptions.” For Lennie, race and disability “are always interchangeable - sometimes one more than the other, but there’s always a close second. They are both important in the dynamic of social exchange.” Even in his current professional work, Lennie must continually shift his focus between race and disability. As a disabled man, he advocates for the concerns of the entire disability community, but as an African American, he must address the racial inequities in service and resources provision that negatively affect his community. Formerly, in his work in the black community, Lennie considered “‘advocacy’ as a white, middle class value...a lot of the issues out here benefit some people, but not all the people...the same ‘isms that exist, whether you have a disability or not, you still deal with.” The multiple-layers of his race, disability, and gender always shape peoples’ interactions with him and Lennie, at this point in his life, is no longer willing to play the role of “Joe Good Guy,” the passive recipient of others’ perceptions. Instead, he actively chooses to address the realities of such situations, deciding whether “to make them feel at ease...to let them off the hook or

not. I am who I am and the secondary part is, without a doubt, I am a person with a disability.” Although Lennie did fulfill his mother’s prediction of becoming an administrator, with a white collar job, he never did gave up his love for the arts. He’s just found other ways to be involved with it, just as he creatively found ways to continue to be an integral part of his childhood circle of friends.

Theoretical notes

The major themes I found in Lennie’s interview include (a) resist others’ definition (b) context determines saliency (c) relational management (d) problem solving (e) achievements (f) supportive community (g) silence on inner struggle (h) denial of emotions (l) job discrimination (j) disability only an annoyance sometimes (k) underestimation of abilities (l) race/gender assumptions (m) disability litmus test (n) role models (o) context (p) destructive hero role (q) race/disability interchangeable ® high expectations (s) racism (t) assumed limited options (u) solitary (v) fighter (w) shared perspectives (x) more disabled friends (y) student’s acceptance of disability (z) alternative rights of passage (A) aloneness (B) emotional support (C) job opportunities (D) self-definition (E) comfortable w/ disability (F) creativity.

Lennie, too, was already a member of a family and cultural community that was prepared to nurture and fortify people considered “different” by the dominant culture. He attributes the “good positive social interactions...the supportive environments” with his developing the positive sense of self that he has, even though none of his early environments existed within the context of the disability community. They were simply nurturing and accepting environments, on a fully human level, that was culturally fortified to support his unique psychosocial development and gave him the necessary support he needed to take on adult roles and activities (Bronfenbrenner, 1979. The one negative reality he encountered his African American community was the role of hero assigned to him. for simply getting on with his life. It is a perspective based on the cultural belief that

having a disability makes one completely incapable of taking on the typical roles and activities of a non-disabled person and any disabled person who does is viewed as heroic or exceptional. The unrealistic emotional burden that role placed on him forced him to deny the very real emotional and psychological struggles he was having, which was compounded by having no other disabled person in his life to talk to about them. That experience, though, gave him the insight of how to provide for the emotional needs of disabled people who came to the independent living center her directed years later, a form of generativity many participants described of giving to the next generation or other disabled people the kind of support they had needed in their earlier lives.

Lennie saw his race, gender and disability as being integrated, “all one in the same” within himself. It is the perceptions of others, that insist on focusing on one aspect or another, that determines which aspect of himself was most salient in any given situation (Cross, Strauss, & Fhagen-Smith, 1999). The fact that they all functioned similarly within a cultural system of devaluation that could otherwise have fragmented him, taught him “parallel lessons” and “code switching” skills (Cross, 1991; Cross et al., 1999) required of a disabled, African American man successfully taking it in the dominant culture. Lennie was well supported in successfully learning the roles and activities expected of him as an adult in society, quite possibly because his disability was not that noticeable or physically limiting. And he, like Claudia, came to the disability community with a sense of his own competency already, but it was the disabled role models he found there who demonstrated concretely for him the larger tasks he was capable of taking on. He spoke of well-intentioned, but “disembodied” (Lakoff & Johnson, 2001), words of encouragement from caring non-disabled people in his life, ceasing to be meaningful to him, because they did not come from that place of “knowing” that he came to know he shared with disabled people. It was only when he became an integral part of the disability community that it “clicked” for him, that he gained an

experiential knowledge of all that disabled people are really capable of accomplishing.

As an African American leader in the disability community, Lennie is very aware of the racism in the disability community. In the past, he has viewed the singular focus of the community on disability rights advocacy as a “white middle class” agenda that only benefits some disabled people, but not all or all equally. His current leadership role, for which he was recruited by disability community leaders, is a role that gives him more of an ability to address the racism of unequal distribution of resources in the disability community, as well promote disability rights in the larger community. It is a dual role that he is committed to as a disabled African American male that exemplifies the Integration stage of the OTAID model (Myers, et al, 1991).

Credibility

Member Check: I phoned Lennie to get a response to my emailed “member check” request. We read through the profile together and he approved of the voice and the chronology with some changes of emphasis, which were made while we were speaking. He then reflected on the whole process, both the interview and reading the profile, “In reading through this now, I see how important it is to say these things - having never said these things before. To see your words come back to you in this way is very powerful. When I was at the Independent Living Center, I could convey these things one-on-one to people, but to know these words will be published is a good thing.” He went on to say he had never been asked the kinds of questions he answered in our interview and found them valuable personally in understanding interconnections of events in his life.

Don

Contextual Notes

This ninety-minute interview took place over the phone. Don’s participation in the project was based on his national profile in creating a media presence for the disability

community, in an industry that traditionally has not included positive disability content.

Demographic Description

Don described himself as an intelligent, funny, good-looking, African American man, father and media professional, who uses a wheelchair.

Disability Identity Development Profile

Don was born with his progressive disability into an African American family that maintained their high expectations for his future...“go to college and graduate and get a good job, and I did that.” As a child, he remembers viewing his disability as something “wrong” with him – “I was really ashamed of it, because I didn’t want to associate or identify with it. I was my own lone, lone dog out there - in the sense that I didn’t really identify with other people with disabilities.” His parents facilitated a strong sense of independence in him and “empowered” him with their expectations of him going to college and having a career. Yet, he had no one to help him with his self-esteem issues as a disabled adolescent - “an age when you are defining yourself and who you are, what you are going to become.” He knows he would have benefited from “the guidance and directions and understanding of acceptance of disability” from older disabled mentors, as well as the disability community’s definition of “independent living...I think that it’s taken me many years to reach a level that I should have been at earlier, in terms of my own confidence about myself.”

Don had some disabled friends in high school, though not ones he remains close with and spoke of experiencing relationship strains with non-disabled friends - “there’s a lot of physical hassle involved in being my friend.” Inaccessible environments create problems for Don in being an integral part of any social scene and contributes to non-disabled people being uncomfortable in friendships with him. Such hassles can create a “small barrier...hurdle to get past” that can arise from others’ unconscious expectations or confusion about the meaning of “helping” and “fair trade off’s” in a friendship with him

– “like, if you are going to cook the meal, I would buy.” In his job search after college, Don encountered obvious disability discrimination, despite having a much broader range of experience than any of his non-disabled classmates. The “good job” he finally “landed” happened through his own activism, though the same discrimination of “limited expectations” in finding a job blocked his “upward mobility in career and income” for years. In the end, Don decided that he “had to do something drastic...I decided to take the very thing that limited my career and make it work for me!”

In his early working years, Don had begun to meet other disabled people and “became more comfortable with the fact that I’m part of a community and that there is nothing wrong with me; there’s a place for me, just like there’s a place for everybody else.” Don had also married and became a father – accomplishments that built confidence in him - “I’ve done pretty good – I have three wonderful kids, I was happily married for a long time.” The relationship with his wife developed while Don was “totally integrated” into a non-disabled, professional world, but did not endure his career change when disability and disabled people became a major element of his professional work and life – “the stigma against disability that exists in our society, I think, became activated in her mind.” Don had developed a “passion for the disability rights movement” which he turned into his new career and began traveling a great deal, connecting with the disability community - “I became more aware and proud of membership in the disability community...I’m happy to be a member of a community that has added a lot to the world and to the human spirit.” With disabled people, he experienced “no animosity... stigma...or feelings of uncomfortableness; he found they “shared on a level that non-disabled people simply can’t share with you on – we have an understanding about things...similar challenges and frustrations, you can talk about your experiences and they can understand.”

As Don ages with his progressive disability, though, he is grappling with slowly,

but steadily, losing his physical abilities – “I think I have to deal with the aging in a more rapid sense than most people do.” Don spoke of being “content with who I am,” yet he finds the increasing restricted use of his body and breathing is beginning to challenge that contentment and even, at times, his pride in being a disabled person. The fact that his decreasing abilities are also having an impact on his sexuality also contributes to that struggle, as it is a loss that he feels deeply. He frankly admits there are times that he would take “the magic pill to get rid of my disability,” because he does not think that being without his disability would fundamentally change who he is now. He acknowledges that, as his disability progresses, he has more understanding and compassion for the people who “want to be cured. I think I am allowed to enjoy certain things about life a little bit easier.” As he struggles with these changes, Don hesitates talking about them with his disabled friends – “we all have a tough time with whatever and I don’t want pity and I don’t want to give it either.” On the other hand, he knows these same friends understand and are forgiving when he has a bad day and is not able to function – qualities that he values more as time goes by.

Don expressed pride in being black and in the accomplishments of the civil rights movement, yet he knows that “a lot of work needs to be done in terms of disability awareness in the black community.” Within that community, he feels that disability has always been viewed as making one “less,” which he speculates may be rooted in his community’s focus on physicality – “the way that you look, the way that you dance or the way you move and you can’t do that as a person with a disability. There’s points against you, I think.” Don contemplates being a part of the change in how the African American community views disability perhaps as the kind of mentor he never had in his youth to other disabled African Americans. In describing the various roles he plays in his life, Don sees a “pie chart” with his identity as an African American man and as a disabled man being equally significant, while being a father and a professional have much greater

slices and significance for him. Don chooses to stay “focused” on his goals in the midst of additional losses of physical abilities, raising his children and “staying stretched out physically... enjoy the things in life that I can enjoy.” He says that as he has “become older and wiser, you realize other things are important, as well...I’ve come to terms with my own mortality.” Parenting is one of Don’s great pleasures in life – “I would gladly deal with what I have to go through that have the thrill to watch [my son] play basketball.” His children know he’s dad - “what I say goes...they totally accept [my disability] and understand and they know my limitations...their expectations of me is just to be dad.” Don is working towards having his own home again with his children on his own, though he knows his parent’s doubt that a career focusing on disability issues will be lucrative enough to support himself and his family - “I understand that doubt, but the hell with their doubt.”

Don believes that the very fact that he has had to learn to navigate the world and juggle his many roles with his disability has contributed to him developing a “sense of imagination...I’m more innovative than non-disabled people...more creative” - the barriers he encounters require “energy and skills and problem solving to overcome.” Don knows he “interprets the world differently - a lot differently than non-disabled people” who oftentimes view him as having a “lesser quality of life.” “I’m a fighter and have made a significant impact on the way a lot of people in the world think about disability - despite my challenges, I’ve done pretty good. My career has had a major impact on the world, I believe.”

Theoretical Notes

The major themes I found in Don’s interview included: (a) problem solving (b) creativity (c) different view of life (d) fighter (e) shame (f) aloneness (g) lone wolf (h) avoidance (I) high expectations (j) delayed development (k) integration (l) disability pride (m) disability community (n) parenting (o) aging w/ disability (p) loss of ability

(q) greater imagination (r) race/disability equal (s) less content (t) cure (u) different view (v) different pleasures (w) inaccessibility (x) relational management (y) denial of emotional (z) new paradigm (A) supportive family (B) independence valued.

Don described dealing with issues of shame and low self-esteem as a young man, which seemed qualitatively different from the other African American participants. Although he valued his race, gender and disability having equal value in his “pie chart” of life, his roles of father and professional were given greater value, a valuing that seemed similar to Phyllis’ hierarchical valuing. This valuation, combined with his assessment of disability being devalued – “points against you” - in the African American community on the basis of external criteria, such as how one looks, or dances, or moves which seems to reflect an uncomfortableness with his own physicality, similar to that expressed by some of the European American participants. He spoke of his career, marriage and fathering children as “accomplishments” that he was proud of which seems reflective of valuing such things as external criteria of one’s own worth. It is a perspective the other African American participants did not share, folks whose sense of purpose was expressed as focusing their efforts on the ongoing project of promoting social justice for all, both within the disability and African American communities and the larger human community. Don’s described his family as “empowering” him to develop a sense of independence by going to college and pursuing a career. Yet his description of himself as a “lone, lone dog,” struggling with self-esteem issues as a disabled young man who did not want to associate with other disabled people led me to question where his sense of belonging derived from. It seems that his family, and the community they were a part of, were not prepared to support his development, as Lennie’s did. Don’s career change that focused strictly on disability ended his marriage and created conflict within his family of origin, which seems to indicate that disability was viewed as problematic in the family system and certainly not something to incorporate positively into one’s life if one was to

be economically viable. Since our interview, Don has profitably moved on from his professional focus in the disability community and redirected it outside the disability community with an emphasis not directly related to disability, although his disability is indeed a part of the presentation. Don, like Phyllis, stated that if his disability were to disappear, he would remain who he is, which again seems to indicate that Don's disability has not yet been incorporated into his whole sense of self. My growing sense from Don's valuing of external accomplishments is that it reflects a "sub-optimal worldview" that does not yet embrace an understanding of the intrinsic value of all life and may involve family racial identity issues, as well as issues of non-disabled privilege.

Don's progressive disability is both heightening his awareness of his disability and making him struggle in a different way with its meaning in his life, as George and Garth spoke of experiencing at much older ages. Those changes are affecting how he views himself as a disabled person, because he is able to do less of those things that have given his life meaning – moving his own body, working steadily, sexuality, dancing, living independently, etc. The re-emergence of old limitations or the gradual development of new ones presents disabled people with the need to rework or readjust their disability identity; to deal with unresolved emotional or psychological issues; to develop or discover new areas of meaning – as Don talked about in having pleasure watching his children play. The pain of his losses, though, is real and significant, as indicated by his admitting he would take "the magic pill" for a cure - a statement that is anathema to the disability rights activist party line, which has internalized its own version of the "ever forward and upward" and "stiff upper lip" rehab agenda Garth and Lennie both described. The fact that Don hesitates to share his inner struggles with his disabled friends indicates an unwillingness, or perhaps even an inability, to deal with the very real psychological aspects of the disability experience that still exists within himself and in parts of the disability community. Garth expressed a concern about this very issue when

he described his experience of being accused, by some disability rights activists, of “abetting the enemy by airing our dirty laundry” because he had the temerity to openly discussed his own psychological struggles with losing physical abilities due to post polio. Don seems not to have found a disabled role model to turn to in struggling with these issues; someone who is already in the process of reworking disability identity issues around having a body that can no longer fulfill the activist agenda and are willing to talk about. Neither has he found other ways of working through these issues, such as the spiritual or artistic approaches that other participants have spoken of pursuing. Since our interview, Don has professionally moved away from strictly focusing in the disability community to reaching a broader audience with a media message that use his living with a disability as a springboard to addressing the challenges everyone experiences in their lives.

Credibility

Member Check: I called Don to get his verbal feedback to my emailed member check request, the easiest and most direct way I have found to accomplish this with the busy disabled professionals in this study. Don read the profile while we were on the phone and did not request any changes; he also approved of both the flow of chronology and the content as being his story and his voice. He congratulated me on a good job of representing the story of his life so well.

Peer Debriefing: I was puzzled by the shame Don expressed having about his disability in his younger years, as the other African American participants had not related having those feelings. Discussing this with a peer confirmed some intuitions that racial identity issues within his family may be playing a role in those feelings, as well as his seemingly highly valuing of external accomplishments that is so much a part of the standard of “normalization” in the white, non-disabled culture (Myers, et al., 1991). Don’s unusual admitting to wanting “the magic pill” seems, on the one hand, to be a very

real acknowledgement of the growing difficulty of his physical limitations and quite understandable. Yet his belief that becoming non-disabled now would not fundamentally change who he is seems, on the other hand, to reveal a lack of appreciation of the role his disability has played in making him who is now. It also echoes Phyllis' belief that even if her disability was taken away, but her gender and family/race remained intact, she would still know who she is. Both statements reveal a sense of disability not being an integral part of their sense of a whole self, and that its erasure (which I posit – as Phyllis did about her family memories) also involves the erasure of the memories of lessons learned through living life with a disability, which would fundamentally change their sense of self.

Karla

Contextual Notes

This two-hour interview took place over the phone, on two different occasions, a couple of weeks apart. Karla had wanted to think about several of the questions before giving me her answers, so we planned to talk after I returned home from working in Chicago. Karla had been recommended to me by several of the leaders already interviewed, as an African American leader who has played significant roles at the federal and international level, as well as in addressing the inequity that exists around disability issues within the African American community. We had never met, though being a part of the same sisterhood network made our initial contact open and quite comfortable, with Karla enthusiastically expressing a willingness to participate.

Demographic Description

Karla described herself as a black woman with a disability who is committed to creating equal access for folks with disabilities around the world.

Disability Identity Development Profile

Karla was born into a family that collectively was committed to education and to

making contributions to the African American community, so “their expectations of me were always high.” When she became disabled at the age of nine, she had “no perceptions that this was a bad thing, just it was going to be a little different.” The “good self-esteem” her family had nurtured in her early childhood carried Karla through the transition of becoming disabled overnight, since she related never having a sense that “this was my problem, that I had to be responsible for fixing or controlling it.” Karla’s grandmother once told her “there might be something wrong with you’re your legs, but there is nothing wrong with your mind,” giving Karla the sense that disability would play an important, but not negative, role in her life. From the beginning, Karla said her family “gave me unqualified support and a lot of confidence to be an individual with a disability” and she was empowered by that. Karla learned early that the world outside her family “did not see her disability as they did,” which was reinforced by her rarely seeing any other disabled people out in her community. Because Karla was mainstreamed, the only time she was with other disabled kids was at a summer camp for disabled children. Her parents “ wanted me to make sure I was connected with the community of people with disabilities,” thought they did not discuss their reasons for sending her to camp, it was simply a decision she went along with. Neighborhood schools were inaccessible and the segregated schooling available to disabled children was not acceptable education to her educator mother, so her family fought to get her into an accessible all-white school across town, where she was the only African American and the only disabled student. It was “a hostile environment,” with kids on the playground telling her “you both a nigger and a cripple!” Her “marching orders” had been to get a good education, despite the racism her parents knew she would encounter - “the ‘ableism’ part, my parents did not know I was going to deal with” and that became part of the ongoing civil rights discussions at the family dinner table – “we all know that everyone had their little battles that they had to fight and that was one of mine.” She described those years as “having to

juggle a multitude of worlds – opposite-end experiences that caused me – my life was quite, you know, a split life...the focus of children’s racist and ableist ”attacks” in her all-white school, then home to the “love, comfort and good friends” in her all-black neighborhood. During those elementary school years, Karla usually chose “to fight the advocacy battles on my own,” learning invaluable negotiation skills, although she knew her parents were always available “to get somebody straight.” Eventually her community benefited from Karla’s solitary fight for an accessible school - as African American parents learned of the quality of education she was receiving, they fought to integrate the school so all their children could get that same quality education. Despite the fact that the needs of her disability experience opened doors for all the children in her community, Karla sadly observed that it did not “transform into a more general philosophy in terms of the larger community of people with disabilities,” either within her family, her circle of friends or within the larger African American community itself.

In high school, the negotiation skills Karla learned in elementary school gave her the unique ability to “bring fighting factions together, when we really had significant white race riots.” Because she already knew the “unimportance of the external,” it enabled her “to work toward trying to get to know the person first – so that’s white folk, too;” an attitude that continues to be applicable in her work and travel with people who have many kinds of disabilities around the world. Being very active in the civil rights struggle was a way of life for Karla’s family, so Karla’s decision to focus on disability law when she went to law school continued that family tradition. Karla saw it as a way “to pull it all that together and use the civil rights experience in terms of helping my career and disability rights.” She made a pragmatic choice to use a wheelchair in law school, after walking with little stability for many years – “bouncing off the walls, never standing up and walking with support - I think everybody thought walking was important, but for me walking was misery.” For Karla, using the wheelchair simply made life easier – “okay,

this is just another phase in my experience,” but for family and friends initially it was a sign of “a worsening of one’s condition - I was glad to be sitting down!”

After law school, Karla worked for a public advocate office representing people with developmental disabilities and began to compare and “massage” her parallel experiences of being black and disabled – “reviewing the larger issues around folks with disabilities.” She “became more group collective” personally when she encountered the “collective of people with disabilities” at an annual meeting of the National Council on Independent Living – “this is where I need to be, ‘cause it’s the same attitude about disability. These are the people I’ve been looking for - 500 people with disabilities talking empowerment and politics...the collective camaraderie of people with disabilities, finding that collective family has truly bolstered my ability to know I am right!” It means much to Karla to be with people who share the understanding that we all have “to prove our worth in the world – the connection is we know what our value is...what it means to be a whole person out there.” Yet even in finding such community, there also exists “a level of struggle in dealing with the racism within the disability community, while still having that commonality, is always an interesting challenge.” Karla values having “people of all ilks in my life” and it remains important for her emotionally to stay connected to the disability community, despite that racism.

Karla credits her “multiple-world skills” in enabling her to juggle the social and professional aspects of her life within the African American community, where she finds that her race, gender and disability intersect on many different levels – “a lot of times you struggle within and against the same communities. I’m often struggling with [disability] discrimination from that community.” She knows that negative views of disability have made men in the community not view her as a potential partner, something her education and family’s economic status would have influenced positively. “The black community definitely has some archaic set views of disability...about ten years behind in

the attitudes around disabilities than the majority community. A lot of black communities still hold fast to the concept that the mother must have done something wrong, if the kid has a disability.” While Karla’s non-disabled African American friends do not view her as “an inspiration – they don’t go that route with me, ‘cause I do believe they know I don’t ascribe to that philosophy,” yet they are amazed at how she manages the “social stigma thing...we can go out somewhere and all of these people are staring at us, gawking, and they want to say something!” Within her community, Karla still encounters “the barrier of amazement” at her ease in moving through life in her wheelchair. The “old attitudes” that equate disability with inability are only dispelled when she can work professionally with people in “an equitable setting.” The work she is now doing is to create greater physical access within the community, as well as more educational and economic opportunities for disabled people in a community that faces resource deficits, in general. Because the African American community is as “bottom of the totem pole” for all resources, Karla oftentimes finds resistance when she introduces disability issues into the mix of community concerns. She states that her hope for the future lies in “the new generation of kids with disabilities coming into their own,” growing up with a greater sense of entitlement to participate in all of community life – “we will see more great progress!” While the advocacy of older disabled adults has made that sense of entitlement possible, Karla knows disabled African American young people will need mentoring by that older generation to guide them through the struggle in the midst of community resource deficits. “Its just mind boggling that it takes the same level of intensity twenty years later – to get [disabled, African American] people jobs, housing, transportation – whereas for others [whites], it’s just automatic.”

Karla accepts that living with a disability will always involve re-educating people, and re-adjusting herself, as circumstances change. In situations where she first encounters non-disabled people, she knows she must be prepared “to command,

deserve their respect – you have to break down that first barrier in people. It's just like a routine – you know its going to be there and be ready to address it – challenge it and deal with it...we educate and redirect their understanding or just let them keep their attitude and do what I need to do and move on!" Karla's life, in any given day, still intersects with multiple worlds, from high level government work with colleagues who have never worked with a disabled person to an encounter with a grocery clerk across town who treats her with a "baseless bias about disability...silly little stuff that could blow you away - if you let it! You know it's going to be there and be ready to address it - it's a wonderful ability to be able to know it's out there, challenge it and deal with it everyday with a positive attitude."

While "disability is always present and an issue," Karla is finding that new aspects are becoming more salient to her now. In her younger years, her concern was more about other people's attitudes towards disability and social relationships - "nothing would slow me down...physically it wasn't an issue." Now her awareness is "readjusting" more to the physiological aspects of her disability, as the "dailiness" of disability becomes "more effort-laden. It might be wear and tear, but you notice these things. I see now that I'm in a new territory – I will have to revisit old things and plan differently, because of the disability." Karla's own view of her disability is that it is a "wonderful experience to be able to tap into a knowledge base of a sense of knowing what determines the whole person. And to be able to have a different lens on to what people's abilities are." Her disability has given her "a clarity of a vision of what's important, for what's the human spirit," a truth she has encountered in her work with disabled people in many international settings. She defines her identity as that of a black woman whose disability is "very interrelated" with her race and professional work, and that she seeks to change our cultural paradigm about disability and race in whatever way she can by how she lives her life and by using her professional skills. "If people will

understand the ‘whole person’ concept, then all the ‘-isms’ would dissipate...on both sides.” Karla believes strongly her that work within the disability community is situated squarely in the midst of the larger picture of the international struggle for human equality, “the collective camaraderie of people with disabilities - we’re right about what is human rights, what is civil rights, and who was really part of the divine plan!”

Theoretical Notes:

The major themes I found in Karla’s interview include: (a) different /not negative (b) strong self-esteem (c) high expectations (d) no disabled friends (e) summer camp (f) fight for accessible education (g) hostile ed environment (h) negotiating skills (I) family communication (j) multiple worlds (k) code switching (l) unimportance of external appearances (m) relational management (n) path of knowledge (o) different lens (p) empowered by family (q) parallel experience ® solitary (s) integration dis/profess (t) whole person concept (u) less desirable (v) aging (w) disability community racism (x) bottom of resource ladder (y) accept social reality (z) later wheelchair use (A) disability community (B) denial (C) spirituality (D) positive contributions (E) aging realities (F) concern w/ others perceptions (G) mentoring (H) money privilege (I) human rights (J) revisiting/reworking identity issues (K) walking important/misery (L) supportive family.

Karla acquired her disability in childhood within a family that was already culturally fortified to deal openly and constructively with the difficult realities of racism and the struggle for civil rights. It was the security of this capacity for dealing openly about such things that “empowered” Karla to deal with her disability in the same way, bringing her school experiences of “ableism” to the conversational mix at the dinner table and educating her family which she knew they would take seriously as a part of the whole family experience. Hers was also a family of “change agents,” like Gail’s, that fortified Karla to take on the role of constructively dealing with both the racism and the

ableism she encountered at school. At nine when she became disabled, Karla had already developed a sense of self capable of deflecting the racism and that racism was far less horrifying to them than the lack education she would have received in the segregated schools for disabled children. Within her family system, Karla never experienced her disability as an overtly negative reality and understood from the beginning it was another “difference” that would play an “important role in her own life.” As African Americans, her parents knew the importance of Karla bonding with other disabled people like herself (Cross, et al. 1999), though their uncharacteristic silence about their reasons for her attending camp indicated some ambivalence either towards the disability, or the segregated camp itself, for which they had no experiential knowledge or language with which to discuss it. The possibility of such ambivalence could also explain why her family and friends never incorporated disability rights into their larger picture of the civil rights or expanded their circle to include other disabled people - a fact she noted with some regret.

Another fact Karla noted with regret is that the men in her African American social and educational circles do not view her as a viable partner. Her response, though, underscores the strong self-esteem her parents had nurtured in her at an early age that others' like Lucy and Carlota did not possess in their younger selves. Rather than internalizing this negative response as a reflection of something lacking within herself, Karla lays the problem directly in the unexamined negative attitudes towards disability within the African American community, which the men themselves have not yet discarded. Conversely, such discriminatory attitudes have not been a significant issue for Karla professionally, an arena in which many disabled people usually encounter it. It has actually been in such professional settings that Karla has been able to bridge the perception gap within her own community, demonstrating to folks she works with that she brings skills and abilities that can benefit the whole community.

Karla's response to others' preoccupation with her disability within her community, and professionally, reflects a disability identity that has been integrated her disability into her whole sense of self (Myers, et al., 1991). It is a qualitatively different response than Phyllis', because Karla accepts that dealing with others' preoccupation with her disability will always be a part of living life with a disability and she is simply prepared to deal with it positively (Cross, et al., 1999). That Karla views her disability as an integral part of herself, as an African American woman, reflects the OTAID Transformation stage (Myers, et al., 1991) and carries with it the cultural commitment to the next generation of disabled African American youth and the inequity in resources for disabled people within her community, as well as disabled people around the world

Credibility

Member Check: After emailing Karla's profile and a follow up call to get her member check feedback, we finally connected by phone. I read her profile to her over the phone, as she was on vacation with no internet access. She requested two minor clarifying changes that I did while we spoke on the phone. She then expressed appreciation for "such an excellent and off-the-chart rendition of her life" from the mass of information she had related in our interview!

Fiona

Contextual Notes

This one-hour interview took place over the phone, after our initial conversation when Fiona agreed to participate. Fiona was asked to participate because of her strong leadership role, both historically and currently, in the psychiatric survivors movement. As a note of process, this was the one interview I felt I did not completely develop an open rapport with the participant, though I am uncertain about why. It could have been because of some clumsiness on my part in contextualizing either my place or the study's place in the community or it could have been result of a pre-existing hesitancy on her

part to open up to someone in the disability rights movement that she did not know already, despite my name dropping of who had referred me to her – or a combination of both! Its not that I didn't get good information from her, its just that during the interview itself I sensed a reserve on her part – a withholding of fuller information that may have been more personal in nature. She spoke of being a mother and grandmother, though she never mentioned her family beyond the few comments about her supportive parents and the fact that “her family” doesn't get the fact that she has an ongoing disability. It could also be that, like so many other activists, her focus is so strongly on her work that she just assumed I was only interested in information about her work, despite the kind of questions posed.

Demographic Description

Fiona identified herself as a psychiatric survivor, writer, researcher, mother and a grandmother, with many hobbies and interests. She is also European American

Disability Identity Development Profile

Fiona was born into a liberal, politically active family who brought her up “to say what I believed in and stand up for what I thought was right.” At the age of 21, Fiona was diagnosed with a psychiatric disability and hospitalized for a time. Early in her hospital stay “it clicked that something was very wrong here...somebody else has the power – not a good place to be!” She describes the psychiatric hospital environment as “Kafkaesque,” in which one's “sickness” was confirmed by any objection to forced treatments or “if you don't think you are [sick], that just indicates how sick you are.” Fiona consequently “put all my energy into getting out – that sounds flip, but it was survival!” She learned that the way to get out of the hospital was convincing the doctors she thought they were right - “playing the game,” a fact that she learned reinforced their own self-perception – “they're so easy to fool.” The doctors' prognosis, at that time, was that she would be “sick” the rest of her life – “I was never going to get better - I was

going to have to take medication for the rest of my life.” Fiona feels “very, very lucky” that her parents are “really skeptical of authority” - they did not automatically believe all that the doctors said, just because they were “experts.” Therefore, they were not invested in keeping Fiona locked into the psychiatric care system when she began to question the doctors’ prognosis and methods - “I think those kinds of things – which are just luck of the draw – play a big part of the outcome.” She acknowledges there have been times when her family was at a loss as to how to help her “when I was really messed up and not functional – ‘Oh god, what do we do now?’” Yet their belief in her played an important role in her living her life on her own terms. Fiona is also convinced that the values her parents lived by, and taught her, empowered her to take on the leadership roles she has done later in life.

Fiona described how “aloneness is a big part” of having her psychiatric disability – “not just feeling down, it’s the feeling that nobody will understand...are not going to care or be helpful.” When Fiona got out of the hospital, she viewed herself as “recovered,” no longer “sick,” and eventually became involved with others who were organizing the “psychiatric survivors movement” - people who had had a similar experience in the psychiatric system and shared her negative assessment of it. Their collective experience “generally hasn’t found it good” and they viewed their psychiatric diagnoses as “just labels, none of it’s real – putting labels on people, I don’t think helps any...and for some people, their only problem is that they were given a label and the label is interfering with their life.” The civil rights, gay, and women’s movements of the 60’s became models for the burgeoning psychiatric survivors movement, which viewed the coercive methods used by families and the psychiatric system as “oppression” and violations of their civil rights. Fiona’s local organizing work eventually expanded to networking and organizing psychiatric survivors across the country, and eventually organizing conferences, a task they had to undertake with none of the financial support

other disability groups got to organize themselves. They collectively had to create their own role models their movement needed, which ultimately led to Fiona feeling good about herself as a disabled person, learning that “I could do it and I liked it!” It is work that has “led to a lot of interesting opportunities...getting opportunities to do things I might not have done otherwise – like I said, I’ve made a career of it.” She knows that having people in her life - predominantly other psychiatric survivors, “who believed in me when I didn’t believe in myself,” has been an important factor in her continuing to live life on her own terms.

Fiona’s perspective on her disability has developed through the years, in the beginning of the psychiatric survivor movement “we denied that there was any such thing as a psychiatric disability” – we were just people who had been labeled and oppressed.” Over the years, her perspective has broadened and she see it as “a bit more complicated...people really do need to figure out what works for them - if you are having some sort of difficulty, then figuring out what helps.” For herself, she knows it “is real and its ongoing and that I’ve got to figure out how I’m going to deal with it.” Through the cross-disability work Fiona has done over the past few years, she has come to understand that all disabled people are labeled by society as “not capable or competent.” She now views herself as a “part of the disability community both because I still sometimes experience disabling periods, and because the label affects how other people see me.” She still will have nothing to do with the psychiatric system, because their practice of forced medication and involuntary commitment for anyone who admits to suicidal thoughts has created a barrier - “they closed that off by the way they operate their system!” At those times when her disability is active, “life is just not easy...and I wonder why I’m having such a hard time...why I can’t do this or that...there are times when I feel its holding me back from doing things I want to be doing.” Most people do not consider her a disabled person, because her disability is invisible and because of the

way she experiences it – “I lay low...its too difficult relating to people.” Fiona believes that her family considers her as “someone who had a disability, rather than somebody who has a disability – that’s one thing they don’t get!”

During her early years of organizing the psychiatric survivors movement, Fiona did not have contact with the disability movement – “it wouldn’t have made sense at the point we were at in our development.” Increasingly, though, Fiona has been doing cross-disability work, which has further influenced how she views her disability. She has found that disabled people “even if they don’t know a lot about our issues – they get it, they get it right away! They know locking up people against their will is wrong. Its not complicated!” She knows she shares the common experience of society’s low expectations of disabled people – “you’re not capable, competent...” She also appreciates that the independent living movement affirms that those who live with a disability are the experts on that experience, not medical personnel – “if you want to know what its like to live with a disability – you ask someone who’s had the experience.

Fiona is discouraged by the fact that a highly organized institutional coalition of families and psychiatric professionals continues to denounce psychiatric survivors and “blackballs” their participation in the national dialogue about mental health– “it makes you wonder if you are getting anywhere!” Yet, her increasing opportunities for national and international coalition building with other disability groups creates an encouraging counter balance to that systemic oppression – hearing “of course you’re part of this International Disability Alliance! Of course, you’re part of this, obviously’ – that just feels wonderful!” Fiona knows there are still many people in both movements who are not yet able to see the commonality of all disability experiences, “I think it takes a certain kind of sophistication...the leadership does get it and knows we’ve got to stick together.”

Fiona’s frame of reference has continued to grow from its beginning in the struggle to organize the psychiatric survivors to now working to incorporate disability rights into the

international human rights campaign – “precisely because the human rights community just didn’t get disability and trying to bring together the human rights community and the disability rights community.” Fiona considers her disability “a part of who I am, just part of my identity...it shaped a lot of who I am, it affected my view of myself, my worldview, my activities.” Fiona responds to questions about how she got involved in disability rights work by quoting JFK’s answer to how he became a naval hero – “It was involuntary – they sank my boat!”

Theoretical Notes

The major themes I found in Fiona’s interview included (a) no rights (b) viewed as sick (c) self definition (d) psych survivor movement (e) disability community (f) accomplishments built self-esteem (g) supportive parents *vis a vis* psych system (h) family silence about her ongoing disability (i) forced medication (j) coalition building (k) initial denial of condition (l) integration of work/disability (m) struggle to organize (n) invisible disability/family denial (o) segregated within psych movement (p) expansion to human rights (q) expansion to disability rights (r) recovered/not sick (s) common understanding of issues (t) rejection of labels (u) disability management/not cure (v) experiential knowledge (w) low expectations (x) unable (y) powerful resistance (z) coalition building (B) forced hospitalization (C) race awareness.

Fiona was fortified by the social justice beliefs and values of her parents - right and wrong, and standing up for what you believe in – and used them to evaluate her experience in the psychiatric system that she found herself trapped in at the age of 21. Her deeply held convictions were such an integral part of her personality and worldview that they functioned like the personality traits other participants credited with enabling them to reject society’s negative assessment of them as disabled people. Fiona’s capacity to see her hospital experience as injustice so quickly was also rooted in her earlier non-disabled life, in which she had been treated with respect and as someone

capable of making her own choices. The contrast between the two very different realities generated her outrage, much as it generated Lauren's, and both resolved to extract themselves from places and worldviews that saw them as sick, with no viable future! It should also be noted, though, that it was an outrage generated by the fact that these were two privileged, white young ladies had not experienced such systemic devaluation before this in their lives, a fact that neither identified as such in the interview

Fiona contributed much to my understanding of the dynamics of the identity "position" in which one identifies only with the segment of the disability experience that resembles or is one's own. She spoke about that insular "position" of her many years of singular involvement with the psychiatric survivors' movement as being an essential place for herself, and the movement, in its early developmental process. It was a movement whose members needed to articulate their own self-definition and self-worth and consolidate their collective strength, before the prospect of getting involved in the larger disability movement would not feel like too much of a risk. The fact disability rights movement, at that time, was itself primarily concerned with only physical disabilities, made it not a safe place for psychiatric survivors either. It was the later leaders of the disability community who were able to accept and work with both Fran and Fiona in expanding the vision of the disability rights movement. This individual and collective identity development process reflects that of Cross' Immersion/Emergence stage (1991).

Fiona's description of her own growth mirrors the development of others' disability identities by the expansion of their capacity to embrace and work within the cross-disability movement, and, then, be part of that coalition reaching beyond itself to work with the larger civil rights movement, as well as beginning the work to engage in dialogue with the international human rights movement that has not yet been able to fully understand or embrace disability rights in its scope. Fiona articulated this expansion of

collective identity as a form of cognitive “sophistication” and maturity that reflects the 6th Stage of Myers’ OTAID model (Meyers, et al., 1991) and her acknowledgement that many individuals in both movements have not yet developed that capacity. She knows there are those who remain focused on their own particular disability experience who are as yet unable to acknowledge the common shared experiences that all disabled people share, which transcends the differences between disabilities.

Credibility

Member Check: Fiona responded to my emailed profile and follow up phone with this written response: “I think you did a good job with the interview and captured my experiences well.” She also requested two changes for clarification of her descriptions of her, and the movements’, early view of psychiatric disability and her learning that labeling affects all disabled people negatively.

Clyde

Contextual Notes

This hour interview took place over the phone, to Clyde’s office, where he had an interpreter doing simultaneous interpreting of me and he verbally responded himself. The interview flowed as easily as all the other interviews I had done by phone, with Clyde verbally responding for himself. There were just a few times that I had to ask for clarification of what was just said. Clyde was chosen to participate because of his leadership role in policy development for a federal disability organization, as well as for his role in the Deaf President Now movement that had demanded a Deaf president for Gallaudet University. Clyde is also one of the very few Deaf people who also claims dual membership in the disability community, a criteria for being a part of the study. Clyde and I had first met when we served together on a national advisory group for study on the implementation of the ADA several years previously and our familiarity with each other was limited to that work.

Demographic Description

Clyde identified himself as a member of the Deaf community, a person with a disability, a husband and father who is committed to the civil rights movement and human rights.

Disability Identity Development Profile

Clyde was born multigenerational Deaf family, with parents who were Deaf and active members of the Deaf community. "I was born thinking I was normal...there was clear, ongoing communication between me and my family because of the use of sign language. I didn't have to struggle to participate in my family – there was very clear ongoing communication between me and my parents." Clyde also had a large extended Deaf family, "a lot of cousins and Deaf aunts and uncles, my grandparents are Deaf." Within his family, Clyde described having "a very strong innocence about my deafness. I felt it was a very natural human experience. I didn't have to struggle with confusion about identity, because they very clearly pointed out to me the strong tenets of my identity as a Deaf person." The entire family was involved in a "huge" Deaf community that gave Clyde a sense of being a part of "a very strong heritage of sign language, cultural identity and of brotherhood and sisterhood with Deaf people." He learned from his hearing peers and friends how the rest of society viewed his deafness – "they used to mark how different I was – at a young age, you are not as articulate or rational or able to use reason as effectively, you just resort to fisticuffs - I was in a lot of fights growing up," though the fights never destroyed his friendships with those hearing friends. He recalls encountering negative attitudes on the part of the leader of a Boy Scout troop and, unwilling to be treated differently from the others, "I only lasted one month!" Negative experiences like these led him to read civil rights leaders to learn how they dealt with such treatment and the lessons he learned through those writers led him to decide to work for civil rights - at the age of eight!

Clyde initially went to deaf schools, but his parents saw his academic needs were not being met – “I was doing sixth grade work in kindergarten!” So he went to a neighborhood school, where the only accommodation afforded him was to be seated in the front so he could read the lips of the teachers...if they looked at him! He thinks he was only able to get about “thirty to forty percent of what was being said – it was just basically sink or swim;” but actually attributes ninety percent of his learning to his being “an avid reader – that’s really how I acquired my knowledge.” His hearing teachers consistently underestimated his academic abilities, encouraging him to take less challenging classes despite test scores that placed him in advanced classes – “they were quite surprised when I continually did well in academics!” He credits his parents with having “a strong hand” in crafting his character that never took the “easy route,” parents who never communicated to him his deafness would limit what he wanted to do or be - even when it was to be an astronaut! “My parents gave me a lot of interest in achieving my potential because of my capacities” and he always sought out challenges with the motivation to learn, though never “to prove to people that I was capable. I was driven to succeed!”

At fifteen, when socializing with Deaf peers became important to him, Clyde chose to go to Galludet University. He found it “liberating” to be in an educational environment that had no communication barriers. It began to dawn on him that he had never been able to have the kind of relationships with hearing classmates that he was finding with deaf peers at Galludet - “I realized the disparities between my education, my knowledge, was very much advanced than my personal growth...my own personal emotional issues, it was much more of a blank. I didn’t have the depth of interaction that would allow me to understand what kind of person I was...I found that I was book smart and worldly stupid!” In addition to opportunities for emotional growth, Galludet opened up the world of politics, culture and world events – “I really was able to discover different

aspects of myself – doing things with deaf peers I learned more about myself.” Clyde deliberately sought out deaf professors - “because they were the only ones who refused to under-estimate deaf students.” When Galludet ceased challenging him, Clyde transferred to a university on the west coast where he was again the only deaf student. The local Deaf community further nurtured his social development – dating Deaf girls at the community college, playing ball, president of the Deaf Club, etc. – “Hey, I had to have a youth somewhere!”

Clyde stated that he “never really had an identity crisis,” because his parents had demonstrated to him that he could be a “happy, Deaf adult. I felt oftentimes regret that I was misunderstood, but I didn’t take it as a sign of a defect in myself.” Clyde observed that over the years he has known many deaf people who grew up in hearing families who “were completely alien to me,” deaf people who adopted hearing identities to please parents who never learned sign language so they could communicate with their child; deaf people who had never had the benefit of Deaf role models or experienced the sense of belonging in the Deaf community! “There’s a lot of shame about disability in this country, there’s a lot of disappointment and remorse – and that fucks up a child more than anything else!” Growing up, Clyde had no contact with the disability community - “I never really felt any affinity for the people who were disabled, not at all. I didn’t have a very clear way of connecting to them.” He never encountered “celebrations” of the collective experience of disability, such as those in which he participated with the Deaf community, nor did he encounter any literature that addressed a collective disability experience - “the lack of [disabled] people writing about identity issues led me not to be able to participate more broadly in the [disability] experience growing up. Instead, I turned to other minority groups...these people spoke to me in a very important way and I was able to understand better our experiences in society through their eyes, their description.” Clyde also observed that having a disability or

being deaf does not automatically make a person “more enlightened - we are subject to the same kinds of mixes that mainstream society have...there are a number of people who have very racist views, oppressive against other minorities. ”

Clyde chose his profession because he “thought that it would give me the tools to make change happen...to protect myself, and to be able to continue to help to develop and progress and move on.” Yet during his professional training, he found he was “denied opportunities to participate in the trappings being afforded to other students” and experienced the same kinds of discrimination in the job market. It was only with the passage of the Americans with Disabilities Act, overtly linking disability with the larger issues of the civil rights movement, that Clyde began to explore what he had in common with other disabled people – “continually relegated to second class citizenship in terms of education, treatment in terms of their ability to aspire to certain things in life.” He found common ground with other disabled professionals who were experiencing the same kinds of discrimination in employment - “a very positive experience to be able to relate to other groups of disabilities.” While Clyde attributes his sense of belonging to the Deaf community, he ascribes his “battling attitude” to a personality trait that got him into those fights growing up, which he continues to “quite confrontational in many ways, but I use reason, I use argument, I use the law, so I have different tools to combat attitudes that oppress me.” His current national and international disability rights work is also giving him the opportunity to develop a sense of connectedness with the international disability community – “a unique type of deaf association with people globally.”

Clyde knows that growing up in the Deaf community has given him a very different values than most Americans share, which “led to somewhat of a detachment from American society...I’m not totally in the mainstream, so why should I buy into those values, those emotional issues?” At an early age, Clyde rejected society’s views and

values, “because it would be very damaging to my psyche. I thought it would corrupt me, if I bought into what people thought about me – because they could have made it seem that I was really stupid.” He attributes his different cultural values with finding a non-American wife who also had different values and together they have two hearing children. Having hearing children, Clyde admits was a “disappointment,” but when he heard his oldest son’s response to a question about his religion - “I’m half Jewish and I’m half deaf” – he was delighted. Clyde is concerned that his hearing children - “being that they’re white and living in the suburbs! - understand the importance of diversity in society “...there’s a lot of stuff going on that’s not peaches and cream, hopefully that will sensitize them.” Clyde believes it is impossible to “appreciate diversity and give it support,” if people are unaware of “what you can do to another person because they are different - the viciousness, the overwhelming destructiveness of oppression and discrimination.” He is encouraged that his work to legally implement changes in society’s values is beginning to be manifested in everyday life. Hearing students, in his own children’s school, come up to him now and communicate with him in sign language – “I never saw one single person signing, growing up, in the public schools – never! So, I think that’s very remarkable that we have more emphasis on diversity - that seems to be a progressive difference!”

Theoretical Notes

The major themes I found in Clyde’s interview included (a) no identity crisis (b) personally driven to succeed (c) highly intelligent (d) Deaf extended family (e) Deaf culture/identity (f) innocence about deafness (g) under estimation of abilities (h) Deaf role models (i) delayed relational development (j) educational discrimination (k) rejected society’s values (l) different values (m) African American role models (n) civil rights movement (o) progressive change (p) new paradigm (q) professional discrimination (r) commonality w/ disability community (s) reflected self (t) committed to emotional/

spiritual growth (u) international expansion (v) professional tools to fight discrimination
(w) personality trait.

Discrepant/negative case: Clyde was the only participant raised in a family that shared his deaf experience and belonged to a culture and community that was able to reinforced his positive sense of self as a Deaf person. He had positive Deaf role models who taught him all the roles and activities he could take on as a Deaf adult. He had full communication with his parents, extended family and community, and never had an identity crisis or struggle with feelings of shame about his deafness, as other participants raised in non-disabled families described. His Deaf family and community taught him values that fortified him to counter the negative, traditional American values that devalue his life experience. Those different cultural values enabled him to see the world from a broader perspective at the age of eight and understand the commonalities between his deaf experience and the experience of African Americans in this country. They also fortified him to be successful despite the lack of support for him in transitioning to hearing-only neighborhood schools and challenge the negative attitudes of his hearing classmates without totally rejecting their friendships. He spoke of his innate high intelligence as enabling him to do well in school by using his own means – a capacity other participants describe using to help them navigate school systems that were unwilling to support their different way of being in the world.

The “delayed adolescent development” Clyde discovered in himself upon entering Galludet University, was the result of him having been primarily around hearing peers during his elementary and high school years with kids he could not communicate with about inner emotional and psychological issues of growing up, much less growing up with a disability. The discovery that he had not fully developed in the language or

skills for that activity, merely challenged him to begin exploring and developing multiple facets of himself with Deaf peers he could communicate and grow with. Clyde described the many deaf people he has met over the years, who grew up in hearing homes, as culturally “alien” to him; deaf people who had never been a part of Deaf culture, had been forbidden to learn sign language as children, could not communicate fully with anyone in their families and embodied the same shame other disabled participants had learned in their non-disabled families. While Clyde may have felt emotionally and psychologically behind some of his peers at Galludet, he never felt linguistically or culturally alien from them, as non-culturally Deaf people he had met.

Discrepant/negative case: Clyde’s willingness to identify as a member of the disability community is unusual for a Deaf person, as the Deaf community generally does not view itself as disabled, but another linguistic group with its own culture (Ladd, 1994). Clyde articulated that his identification with the disability community was only possible after the passage of the Americans with Disabilities Act, in which the “new paradigm” of disability equated disability as a class requiring civil rights protections against discrimination, a theme articulated by every participant in this study. The fact that he had never seen evidence of a positive, collective disability culture in his youth, as existed in his Deaf community, or found any literature about the disability experience from a civil rights perspective, made connecting with other disabled professionals who were experiencing similar employment discrimination his first positive connection with other disabled people who viewed their disability experience through his civil rights lens.

Clyde was the one European American participant who expressed a consciousness of his white privilege and expressed a concern that his “white,” hearing children, living in suburbia, understand the reasons for the importance of

embracing diversity in our society. His social justice consciousness, rooted in the lessons learned from African American civil rights leaders, about how to struggle against oppression with strength and dignity seems to have made that collective racial wisdom his initial reference point, before the disability community, and a body of truth he is committed to his sons having access to, even if their privileged, non-disabled white lives might rob them of the experiential knowledge. Clyde, too, is at the point in his disability identity development that reflects the qualities of the Transformation stage of the OTAID model, that is grounded in a spiritual awareness and appreciation of his culture and history as a Deaf/disabled man as a part of the whole of humanity (Myers, et al., 1991)

Ray

Contextual Notes

The hour-long interview with Ray took place over the phone, after first arranging to do so in person at a national conference we were both attending. Ray had been chosen because of his leadership role, both at the state and federal level. This interview was limited by the participant's health and I was unable to follow up for further conversation, as he was hospitalized for an extensive period of time.

Demographic Description

Ray identified himself as an African American man who had always been committed to working for civil rights, and then disability rights.

Disability Identity Development Profile

Ray was wounded in combat while in the military, at 19 years of age, and spent a year in rehab at a veterans' hospital before returning to his hometown in the south. He recalls the doctor giving a rather dire prediction of his life expectancy - 5-10 years, though his mother chose to believe "that some day God would heal me." He had been totally unprepared for what life would really be like outside the veterans rehabilitation

hospital – “I didn’t know what I was facing until I was...I guess the most awfullest thing back then was the barriers from the wheelchair standpoint.” Prior to going to Vietnam, Ray and his extended family had worked for civil rights in their community – “civil rights from a minority standpoint was an issue for me back then and it didn’t surface that my disability would also intertwine at that particular time. It didn’t take time, once I got home, to see how it would.” Ray quickly saw the parallels between his experiences as an African American man and his new disability status – “I went to battle right away, because there were so many places I could not get into...this is wrong for the buildings not to be accessible, just like it was wrong to keep African Americans out of places.” During those early years, Ray knows his family “tailored their views towards mine out of love, but not because they had some dire commitment to the cause itself.” He spoke of his mother just “being happy to have me getting involved in the community, doing things. She was just happy I was alive.” There were times during those years when he struggled with depression about not being able to do some of the things that had personally given his life meaning, “but I don’t get depressed about it now.”

He remembers getting more than his fair share of “pats on the head, you know, pokes kind-of-thing” when he first returned and found there was little support in his small town or county for his concern about inaccessibility. Ray stated that he had always “felt good about myself” and disability didn’t change that sense of himself. He described himself as “always a pretty confident person” who had always chosen to take the lead in combat situations, a pattern he repeated in choosing to lead the struggle for physical access. “I never had any real doubt in myself – I pretty much feel that same way now, just in a different capacity.” What he came to realize was that he would have “to get political” if he was going to be to affect the changes that were needed. It was the refusal of the Chair of the County Commissioners to install a ramp into the new Social Services building that galvanized him into action. The Chair’s reasoning was that “it was taking

away from the look of the building! That didn't sit well with me, you know, being a male and eventually they did put the ramp on, but I decided right then and there, if we are going to have people like that making decisions, I needed to be there in the decision-making process!" He ran for several public offices before he was finally elected to the County Board, a seat he held for 11 years, serving as Chair his last year. From his years on the Council, he was appointed to a more influential position that enabled him to address legal issues that affected the entire community.

Ray had learned from very strong role models in his family about serving one's own community and working for social change in the civil rights movement. So his resolve to work to "be a full part of the community...I did not want to accept that I couldn't get into a meeting of my county council, because there was not ramp – not just for me, but for other people." He stated that his early activism was do pretty much on his own and he was committed to making changes for other disabled people in the community who were not in the privileged position he as a disabled veteran. He had access to medical care and an income – "I knew that there were others out there who had none of that – that was really, really scary! That's why the disability community wasn't as big as it is now, because most of 'em died within a couple of years." During his years on the County Council, Ray also began working to organize disabled people in his state. He encountered the organized disability community when he began training to be a trainer on a national project educating disabled people about their rights. He met disabled people from around the country and those trainings helped develop a coalition of many disability groups around the state. That coalition was able to enact a "Handicapped Bill of Rights" in the state legislature years before the passage of the Americans with Disability Act. For some time, he worked for the state Protection and Advocacy agency charged with implementing disability rights laws and advocating for disabled individuals when their rights were being violated. "People with disabilities were

babies in the disability rights movement...and being able to give them that information that they could use to fight for their rights and to fight for the rights of others. That was real, I guess, real therapy for me.” After his successful work at the state level, Ray received a presidential appointment to a federal position advising the federal government on disability policy and working for implement change at the national level

Ray knows that his disability has made him “a stronger, determined person than I probably would have been. I’m probably more determined in accomplishing what I set out to do, than if I had not joined the ranks of the disabled community.” Since retiring, Ray has found that aging with his disability has made the issues that everyone deals with as they age “more apparent - it gets to be you need more and more of you just to be independent. If a person is paraplegic when arthritis starts affecting them - that’s a real complication!” Recently a prolonged illness and hospitalization has forced Ray to stop his work in the community and once again deal with the basic physical realities of his disability. He still remains connected to the disability community through disabled friends he has made and worked with over his years.

Theoretical Notes

The themes I found in Ray’s interview included (a) determined (b) discrimination (c) always felt good about self (d) self-confident (e) fighter (f) lead in combat (g) accessibility battle (h) supportive family (i) had to get political (j) privileged position as veteran (k) parallel experience (l) disability community (m) disability community organizer (n) trainer (o) depression (p) public service (q) later in life onset ® aging (s) integration (t) sense of responsibility (u) stronger, more determined (v) greater accomplishments because of disability.

Ray’s immediate response to inaccessibility he experienced after coming home from the rehab hospital was to link it to his experience of discrimination as an African American. He was already culturally fortified, as an African American man, to deal with

discrimination from a civil rights perspective. His “strong, confident” sense of self was an identity that had been forged by his family and their involvement in the civil rights movement and it gave him the inner strength to take on the role of addressing inaccessibility in his community from a position of personal power. He had already developed activism skills and a sense of collective responsibility, which coupled with his acknowledgement of his privileged position as a veteran, empowered him to singularly begin to take positive action that would benefit other disabled people. His introduction to the collective disability community came through the national disability rights training project he became involved in that gave him a larger vehicle for using his organizing skills. It connected him to the larger community of disabled people who already understood the “new paradigm” of disability as a civil rights issue, unlike the disabled people in his community. In time, his effectiveness in his chosen role of disability rights worker in his state led to his being appointed to a federal advisory position that enabled him, to work for the benefit of the national disability community, as well.

Ray never did identify solely with the disability community and did not limit his involvement in the larger community strictly to disability issues. While it may have been the catalyst for his getting involved in politics, he affirmed his disability as a part of his whole self that reflects the Cross’ (1991) Internalization stage and Myers, et al.’s (1991) Integration stage. Ray applied this expansive view of what he had to offer to serving in elected and appointed positions that gave him the capacity to influence many issues that involved social justice, throughout the whole community. There were times when his professional work and disability identity were integrated; at other times he worked professionally in the disability community at the same time while serving the larger community in his elected and appointed positions and *vice versa*. At all times, his life was one of service that benefited the entire community, which her knew included disabled people.

Credibility

Member check: Ray is one of the participants that I was unable to follow up with for a member check, because his health took a turn for the worse and he has been in the hospital for an extended period of time.

Summary

In this chapter I have analyzed each participants' interview for individual and emerging themes that were "discovered" in the process of constructing each individual disability identity development profile. In my theoretical notes I analyzed the content of the interviews for their reflections of other identity development models from other diverse community. In Chapter 5 Results – Disability Identity Development Model, I will synthesize those positions into a "working model" of a cross-disability identity development articulated by these leaders of the disability community. I will then chart each person's identity development process by creating a matrix the various identity "positions" they described in their interview and approved in their member check responses.

Chapter Five

Rejection

Society rejects me for being Deaf.
 The Deaf community rejects me for being Lesbian.
 The Lesbian community rejects me for not being able to hear them.
 The Deaf-Lesbian community rejects me for being into S&M.
 The S&M community rejects me for being Deaf.
 Society rejects me for being Chicano.
 The Hispanic community rejects me for being a Lesbian.
 The Gay Hispanic community rejects me for being Deaf.
 Patriarchal society rejects me for being a woman.
 I am rejected and oppressed,
 Even by those who cry out readily
 Against rejection, oppression and discrimination.
 When will it end?

Dragonsani Renteria

Chapter 5

Results –Disability Identity Development “Working Model”

In this chapter I will synthesize the qualities of the disability identity “positions” articulated by each participant that emerged from the process of constructing the narrative profile of their disability identity development. This “working model” of disability identity development that emerged represents a cross-disability identity development process these leaders articulated collectively. Some of the identity “positions” articulated by these leaders are not ones they themselves occupy or have necessarily gone through themselves, but rather are positions they describe other disabled people articulating or demonstrating; members of the disability community whose identity development is at a different place than the leaders of the community.

Disability Identity Development “Working Model”

Exploring the disability identity development within this group of disability community leaders was done from an *emic* perspective that sought to include the widest possible range of disability experiences, such as age of onset, type of disability, etc., type of leadership role in the disability community, as well as other diversity factors, such

as race/ethnicity, gender, sexual orientation (Lincoln & Guba, 1985; Myers, et.al, 1991). Synthesizing the eighteen individual disability identity development processes of these leaders has revealed that, for them, it is a developmental process that is dependent on complex elements both within the disabled individual and in the environmental context of that disabled person, rather than in the disabilities themselves. In analyzing each participants' interview, I was looking for their articulation of qualitatively different, and more complex views of their disability, or disabled people, in general (Sprinthall, Sprinthall, & Oja 1994); the articulation of other's views of them as a disabled person that had been internalized or actively resisted and why; significant events or people that triggered a change in their self perceptions; participants' feelings about themselves or their place in their family, community, or world and personal characteristics participants attributed to their own identity development process (Bronfenbrenner, 1979).

As I read the interviews, I began to think of the qualitatively different views participants articulated about themselves and their disability as "positions" of disability identity development they have occupied, now occupy or see other disabled people occupying in their identity development process. I did not find that there was a pattern of predictable, inevitable development that was either epigenetic in origin (Erikson, 1968), *vis a vis* passage of time living with a disability, or stages that all participants necessarily went through in their identity development process (Myers, et al., 1991). Rather, their developmental process was dependent on the interaction between their disability and their environment (Gill, 1998; Corbett, 1994; Myers, et al. 1991). The variables in their environment that were most influential in how they viewed themselves, from the initial point of their disability identity development and on through the developmental process unfolding over the years were: (a) the values, beliefs and assumptions of the cultural/familial/ relational context of their life at the time of the onset of disability (b) education (c) age at onset of disability (d) gender/sexual identity (e) participant

personality traits (f) the presence of role models, disabled or non-disabled (g) new paradigm of disability (h) disability community.

The “working” model of disability identity development that emerged from the participant interviews reflected a dual process of integrating aspects of oneself into a larger, more whole sense of self and, at the same time, another ever expanding process of a growing awareness of and commitment to an increasingly inclusive experience of all members of the disability community with all of its diversity and variations that continued to expand and include the national civil rights movement and the international human rights struggle.

Position One: Disabled people, in this position, are embedded in families of people who are unlike themselves, living in communities of non-disabled people who all unconsciously share negative non-disabled cultural beliefs, values and assumptions about disability. The disabled people, in this first position, view themselves and their place in the world from that perspective, in a pattern that crosses gender, sexual orientation, racial, and economic lines. The people in this position view being non-disabled as superior to being disabled and adopt a non-disabled identity to mirror, or please, their family and get by in non-disabled society. They adopt non-disabled standards of beauty and are ashamed of their difference, viewing their disability as a source of pain. They resist the use of “stigmatizing” technology they perceive will increase the visibility of their disabled appearance (Onken & Slaten, 2000). They pursue “normalization” strategies to either appear or “pass” as non-disabled; or bring their physical functioning as close to the “normal” standard of functioning as possible through such means as physical therapy, speech therapy or surgeries. They seek to minimize or hide the full extent of their limited functioning, either physical, emotional/psychological or cognitive from themselves, their families and the non-disabled world around them (French, 2001). Disabled people in this position have internalized the non-disabled

culture's "disability hierarchy" and value, or devalue, themselves on the basis of that hierarchy. They do not associate with other disabled people and view themselves as the "exceptional" disabled person who is superior to disabled people with more obvious disabilities. They are concerned with how non-disabled people view them and their disability and seek to prove that they are "as good as" non-disabled people. They accept that external criteria, such as employment or career status, as primary external criteria for demonstrating their worth and the path to assimilating into non-disabled society.

Disabled people in this position are unaware of the existence of, or their isolation from, the disability community and have no sense of a need to connect with other disabled people. Although they experience a sense of emotional and psychological isolation within their families of origin, they have no means to positively make meaning of their disability. The whole family is unaware of their need for disabled roles models to positively reflect themselves back to them and their primary group identification is with non-disabled people. They have a limited grasp of what roles and activities they are capable of fulfilling as disabled people and do not perceive of themselves as sexual beings or capable of adult gender roles.

Position Two: Without a sense of needing and actively seeking disability community, disabled people finding their way to the community can be an indirect and "serendipitous" path. The unifying theme that wends its way through all of the paths disabled people take to finding a place of belonging in the disability community is the "new paradigm" of disability that reframes the disability experience into a civil rights issue and a positive collective identity grounded in the social model of disability. For some disabled people, their first search for a greater sense of belonging begins in identifying with other liberation struggles and affirming their commonality with that collective experience beyond their family of origin, primarily another aspect of their self

they value, such as gender or race/ethnicity. For many of the participants of this study, working in other liberation movements was also a function of the historical *zeitgeist* of the time they were beginning to deal with issues of self-definition. There was no disability community or disability rights movement to identify positively with at the time. Their sense of commonality with other groups or aspects of themselves arose unconsciously from the isolated emotional and psychological experience they had experienced in their own families, for which they, as yet, had no language. Lucy was involved in the women's movement, Claudia in the farm workers, women's and socialist workers movement; George did civil rights organizing; Over time, they experience a dawning awareness that their disability experience has strong parallels with the experience of these other devalued communities or they encounter members of the disability community who are engaged in the same kind of liberation struggle through the disability rights movement. Other disabled people are engaged in intellectual endeavors and begin to understand the parallels between their intellectual pursuits and their disability experience and are able to reframe their personal experience within that critical cultural framework. Other disabled people experience a crisis that forces them to evaluate who they are and the role disability has played, or is playing, in their lives. The blatant professional discrimination experienced by Lucy in her psychotherapy training, complete physical/emotional collapse, denial of civil rights in psychiatric system, etc. For George, it was a crisis of faith in which he realized his actions reflected the exploitative values of the non-disabled culture and he was not living by the spiritual truth of loving all of humanity that he claimed to embrace. For Lena, it was being exposed to other self-advocates who had "cool stuff" that she wanted.

Position Three: Disabled people in this position experience a deep sense of belonging in the disability community, though that sense of connection is oftentimes limited to people who share the same disability or ones that are easily identifiable or

understood through their own experiences. Disability has become a master status in their life and their identification is only with disabled people in the community who share their particular viewpoint, such as other self advocates or activist disabled people involved in the disability rights movement. They view the common experience of disability to be one of oppression and discrimination and view living with a disability from the perspective of struggle. They manifest an unreflective, self-righteous attitude of anger and “us and them” thinking, unconsciously evaluating other disabled people based on non-disabled culture’s disability hierarchy. They manifest a “victim mentality” that is preoccupied with entitlements and personal rights. They apply a “disability litmus test” to membership in the disability community, i.e. not disabled enough or not oppressed enough to be really disabled. Non-disabled people are viewed as ignorant about the disability experience and the source of disabled people’s discrimination and devaluation. They have difficulty celebrating the progress that has been made by the disability community because their focus is on the struggle. They are unreflective about who they are as a person, unable to appreciate inner personal growth issues that all humans struggle with and resist addressing such realities of their human and disability experiences. Disabled people in this position are also concerned with how others view them and their disability, are very aware of being viewed as “less than” and see that perception as the source of the discrimination they experience from non-disabled and other disabled people alike.

Position Four: Disabled people in this position are developing a broader view of themselves and have expanded their appreciation and understanding of the disability community and its place in the larger world. They are able to honor the full range of disability experiences as having inner commonalities that transcend disability differences and support other disabled people in ways that are appropriate for their particular needs. They have also worked through any unconscious internalization of the disability

hierarchy they may have had. Disabled people in this position have a growing appreciation of the inner qualities living with a disability has engendered within themselves and others, i.e. creativity, shared humor, flexibility, problem solving, planning skills, strength, etc. People in this position are more self-reflective and many have found psychological help essential to processing the emotional and psychological issues in their lives that may or may not derive from their disability experiences. Disabled people in this position may integrate their disability identity development with their professional identity and begin actively working to integrate the new paradigm of disability into their particular area of professional interest, or within the disability community itself, from an identity grounded in a positive sense of self.

Position Five: Disabled people in this position affirm their common bond with other culturally diverse communities, nationally, and acknowledge their shared humanity with all peoples in the world, particularly those struggling for justice. They have developed a less radical, more collegial capacity in their working for social change and understand that the process of social change is long, interactive and incremental. They actively work toward the common goals of the disability rights movement within the larger national civil rights struggle and within the international struggle for human rights. Disabled people in this position accept the fact that living with a disability will always involve positively managing others' perceptions of them and their disability. Their accomplishments have engendered a sense of self-confidence and a capacity for positively juggling multiple worlds that enables them to work with disabled and non-disabled people alike on common goals. They are no longer concerned with others' perception of them as disabled people and are comfortable with their limitations and open about their need for various kinds of supports. Disabled people in this position may begin dealing with issues of aging with their disability, which requires a reworking of their sense of themselves in relation to their disability and their roles in life. In this

position, disabled people have or are developing a capacity to view the disability community within a critical framework of concern that can honestly assess its strengths and weaknesses, i.e. racism, sexism, inability to address unresolved personal issues, etc. Disabled people in this position do not perceive themselves as victims and are selective in their friendships with people, disabled and non-disabled alike, who share their sense of self that is balanced and secure. They also view the non-disabled cultural value of “independence” to be harmful and unrealistic, embracing interdependence as a cultural value that acknowledges the true nature of human life.

Position Six: Disabled people in this position have developed a capacity to view disability from the spiritually-grounded perspective of the unity of all humanity. They acknowledge that disability is a part of the human experience, one of many factors that can generate oppression, as well as transformational wisdom. Disabled people in this position have an appreciation of the spiritual and emotional lessons they have gained through living with a disability and see them as issues all humans grapple with in the journey to becoming fully human (Vash, 1994; Toombs, 1994; Olkin, 1999). They have embraced their disability as an integral part of their whole self and view their disability experience as the source of their compassion, sensitivity, awareness and bond with all humanity, as well as other oppressed peoples. People in this position have a multigenerational view of the disability community, express concern for, and are actively engaged in mentoring and supporting the next generation’s development. People with physical disabilities in this position may be dealing with significantly increased limitations of their disability due to aging and experience arriving back at a place that is qualitatively similar to the beginning point of their disability experience, which was focused primarily on coping and adjusting to new physical realities.

Discussion

A closer examination of the eight factors that figured most significantly in the

disability identity development of these eighteen leaders will illuminate how these individual disabled people developed their disability identity development. It will also shed some light on the conditions present in the environmental spheres that have had positive and negative effects on that disability identity development.

Values, beliefs and assumptions of cultural/familial/m context: Because disability becomes a part of participants' lives at different points in their life, the cultural values, beliefs and assumptions present in many different kinds of environmental contexts played the most important role in disability identity development. For children who are born with or acquire a disability in childhood, family is the single most important environment that influences their disability identity development. In Bronfenbrenner's (1979) theoretical framework, it is assumed that the culture and/or lived experiences of people within a given family are the same, but in the case of disabled children who are born with or acquire a disability in childhood or adolescence that is not true. It is not dissimilar to differences in life experiences that exist in families in which one is the only person adopted (Grotevant, 1992), biracial (Kerwin, Ponterotto, Jackson, & Harris, 1993) or homosexual (Brown, 1993). In this study, the critical factor in the disability identity development of the leaders who were disabled as children was whether their parents had developed the capacity to be critically aware of, and reject, society's negative cultural perceptions of difference in general, not necessarily disability. Along with that critical awareness, it was the fact that the alternative parental cultural values, beliefs and assumptions that enabled them to actively fortify their disabled child to deal positively with negative social realities they would encounter in the larger world beyond the family. All of these participants lived in family cultures that valued and modeled interdependence and none of them expressed a feeling of aloneness, alienation or isolation within their families. Clyde, who was the only participant born into an extended family and community that shared his Deaf experience, never felt negatively about his

disability and never had an identity crisis. For Gail's parents, who had the experience of being despised as Jews in Nazi Germany, their refusal to comply unquestioningly with physicians' and school officials' devaluation of Gail's developmental needs led them to create communities that supported Gail in ways that reflected their values, both in their neighborhood and in the community of disabled children and their parents. Gail's parents helped create in their city; Lennie's and Karla's families, already culturally fortified as African Americans to address racism, lived in communities that collectively supported both of Lennie and Karla during their development in dealing with both racism and ableism. Lennie also noted that it was the open acceptance of him, by the children he coached and taught, that further enabled him to become comfortable with and accepting of his disability as a part of his whole self. Claudia's Latino family was also prepared to collectively, and educationally, fortify her and her sister to deal with the additional discrimination they would experience as disabled Latina workers in Anglo society. These five disabled children and youth, also, were empowered by their highly developed social lives that gave them a sense of competency and belonging in multiple worlds. Of these four, Claudia was the only one who spoke of any sense of shame about her disability, which was more than offset by having a blind sister to share thoughts and feelings with, as well as her full life of social skill building within her extended family and in the local community that was able to positively include Gail on her own terms (Phinney & Rosenthal, 1992).

The seven other participants with childhood disabilities lived in families that valued independence and their strategies reflected a high valuing of external criteria of worth. Six of them are European Americans - Lucy, Leslie, Lena, Carlotta, Phyllis, Florence - and Don is African American. While they are cognizant of the social stigma attached to disability, the family cultural contexts were not prepared to positively fortify them against society's negative perceptions of them. Unconsciously, non-disabled

parents responding to their child's disability in ways that reinforced the non-disabled culture's values, beliefs, and assumptions about disability, made its sub-optimal, external criteria for determining one's worth a priority in their child's sense of self (Gill, 2001; Myers, et.al., 1991). The parents pursued strategies of "normalization" to bring their child up to normal functioning or appearance standards, using rehabilitation/medical strategies, i.e. surgeries, physical therapy, or functional skills development that Longmore (1993) describes as achieving only "some semblance of normalcy." Other less overt strategies required that the disabled child deny, hide, mask, or diminish the full extent of their limitations, so family life could remain as normal as possible. Unaware of the shame these strategies engendered in psychosocial development of their, the parents were also unprepared to deal with the full range of inner psychological and emotional issues their child was struggling with during their development (Gill, 2001; Murphy, Scheer, Murphy & Mack, 1988). Lucy, Leslie, Phyllis, Don and Florence all related that they only had friendships with non-disabled peers. While Carlotta had friendships with disabled children, they seemed to recede in importance to her in her striving to be accepted in the non-disabled world, by her non-disabled peers. Lena's circle of social acceptance "treated her like everybody else" and seemed to function separately from her school world, which may explain her diminished self-confidence when she encountered the hostile attitudes of non-disabled students at school.

Lauren became disabled at eighteen with an already established sense of a viable self she had constructed out of her own stubbornness. During her five years of hospitalization she was virtually abandoned by her family and friends, though her mother did come see her for fifteen minutes most days during that time. It was the nurses who cared for her during those years who were able to affirm her worth as a human being, eventually honoring her "risk taking" personality by sneaking her out of the hospital for social events despite hospital policy. Initially, after coming home from the hospital, her

changed physical appearance was a source of shame for her, as her family and social circle had always highly valued a “well put together” appearance. In the end, though, it was Lauren’s “indomitable will” to have a life on her own terms that carried her through the many years of rebuilding her life.

Fiona, Ray, Garth, George and Frank all acquired their disabilities as young adults. For Ray, his family’s capacity for collective support and their involvement in the civil rights movement before he was injured predisposed him to understand his disability experience within that same light. He never experienced shame, a lack of self-confidence or conviction of the rightness of his perception or actions. Likewise, Fiona’s European American family’s culture beliefs and values of social justice and questioning of authority enabled her to understand the psychiatric system within that critical theoretical framework. They were able to support her refusal to subject herself to such a system, even though often uncertain of how to help her in crafting her own means of managing her psychiatric disability. For Garth and George, the culture of the rehabilitation centers in which they recovered played an important role in fortifying them to envision living life on their own terms, despite the cultural beliefs, values and assumptions each of them had internalized from their families. They were both empowered by the psychological and emotional nurturance they received in those environments to believe in themselves and their ability to go out and build a life of their own choosing. Frank, similar to Clyde’s experience, first experienced his disability within an affirming multigenerational cross-disability setting that enabled him to virtually immediately embrace his disability within a cultural context that honored him as a whole person. Conversely, his relations with his family have been strained because of his openness about his psychiatric disability.

All non-disabled families, at one point or another and to one degree or another, required that their children deny, hide, mask or minimize the full extent of their

disabilities, so as not to disturb the families' view of them as not that much different from them, as having achieved some semblance of normalcy, as having overcoming their disability, or that they truly were "the exception" to the stigmatized rule (French, 2001). Gail parents were unable to grasp how beneficial a power wheelchair would be to her, because they were unaware of how much energy it took for her to manipulate her manual chair. Karla's family was unaware that their expectation of her walking was, in fact, misery for her. Phyllis' family has never made their houses fully accessible to her, requiring she deny how much energy it takes for her to get in them. Don's family is unaware of how the difficult access to their pool area affects his sense of self in social situations. Frank's father was furious when he became so open about a disability he could have actually hidden from potential employers. Lucy spoke of always trying to limit the obviousness of the spasticity of her muscles and speech patterns. Claudia's family accepted school officials' recommendations to not let her use a cane, so as not to appear blind. Garth spoke of his family never being able to deal with the difficult realities of his life, so he would only be cheerful and upbeat with them

Education: Getting a good education was another important factor, for participants in this study, which led to their developing skills that built a sense of self-confidence to take on increasingly more complex roles in their adult lives. The process of getting a good education was one fraught with many obstacles and barriers. The resistance encountered at every level of education was based on society's negative beliefs, values and assumptions held that to be disabled was to be globally unable, leading to universal underestimation of their abilities of disabled people. Because there was no legal mandate requiring an "appropriate education" for all disabled children as exists now, educators were free to make their decisions based on prevailing cultural prejudice of the time and were validated in doing so by the society around them (Gliedman & Roth, 1980). Neither were there laws, such as exist today, requiring

colleges and university provide equal access to education for disabled students. And yet, in successfully prevailing against the cultural educational prejudice, at whatever historical time participants encountered it, they and/or their families played important roles in creating larger cultural changes that have unfolded over the years because of their efforts. Every one of the participants in this study used their education to professionally move the cause of the disability community forward, whether they acquired degrees of higher learning or not. And it was, in fact, the professional work their education prepared them to do that furthered their own disability identity development, at different points in their careers.

For those participants who had significant disabilities as children before any disability rights laws existed - Lucy, Karla, Phyllis, Florence, Clyde, and Gail - getting a quality education required their families engage in ongoing battles with school officials throughout their school years. The struggle for a quality education for Claudia and her sister required moving the family to another state where mainstreaming was just being implemented. Interestingly enough, the struggle for an equal education that both Gail and Karla's parents engaged in, both sets of parents who held cultural beliefs about collective responsibility and action, ultimately benefited all the disabled children and black children their respective larger communities. The others' parents' struggles were only focused on benefiting their child. Clyde's parents' chose to send him to hearing neighborhood schools, because the segregated deaf education was not of a level that could challenge him intellectually. Yet, it was only through Clyde's prodigious intellectual abilities and drive that he was able to make that work for him, as the school system was not legally required to, and did not, provide him with any significant accommodations. Carlotta and Don, who did not speak of their families having educational battles, may very well have benefited from other parents' struggles that had opened the door for them already. Lena and Florence both spoke of personal struggles with self-esteem and self-

confidence because of the active rejection by non-disabled classmates who mercilessly teased them – Lena because of her label of special education and Florence for the physical realities of her disability, which neither European American family seemed culturally prepared to counter or challenge. Lennie and Leslie's limited disabilities did not seem to engender resistance from school officials, as neither of them mentioned it as an issue.

Garth, George, Lucy, Florence and Lauren experienced resistance, in varying levels and degrees, from college and university officials that they had to overcome themselves in their pursuit of a degree. Lauren was forced to get a degree in a field she despised, because rehabilitation professionals funding her education considered it the only appropriate option for her to pursue as a disabled person. Only in pursuing a second degree of her own choosing did she encounter the disability community and the new paradigm of disability. Garth and George, both for reasons of independence, chose to go to colleges that would "let them in, in their wheelchairs," because neither was willing to participate in segregated disabled student programs at universities that were purportedly more welcoming. Lucy, Clyde and Florence encountered discrimination in their professional training, which they made a part of their own professional development.

For Leslie, Phyllis, and Frank, their education seemed a relatively unfettered path to connecting with the disability community intellectually and professionally, rather than a process in which unnecessary obstacles factored highly in their memories .

Age at disability onset: Acquiring one's disability at an older age, such as Fiona, Ray, Garth, George, Frank and Lauren did, meant the starting point of their disability identity development was from the viewpoint of someone who had already developed a sense of self in the world as a non-disabled person. For these participants, the timeframe it took for them to actively reject society's negative cultural beliefs, values

and assumptions about disability was generally shorter, than for those who had internalized those negative messages since childhood. For Fiona and Lauren, the inadequacies of the medical system's response to their needs, plus their awareness of the larger culture's devaluing beliefs, values and assumptions about their disability, enraged them both and became the catalyst for crafting their own rejection of it. George simply paid no attention to social perceptions of himself, before or after his disability, which his economic and gender status had always enabled him to do. Ray returned from Vietnam the same confident man he had gone there as and his maturity enabled him to immediately see his next course of action was fighting for disability rights. Frank was already working in the disability rights movement, as a seemingly non-disabled professional, when his psychiatric disability manifested itself. He, too, almost immediately perceived that being "out" about his disability was the only honest choice to make, as he himself was benefiting by his professional involvement in the movement. Lennie acquired his disability right at the point of entering puberty "with all the hormones raging," in which he already had a "bad boy" sense of self that he shared with his friends who were also engaged in constructing their own rights of passage into male adulthood. Because these friends were committed to their collective journey, Lennie was able to integrate both transitions – to manhood and to being disabled – with their support.

Gender identity/sexual orientation: Gender identity and sexuality were interrelated with the disability identity development of many of the participants in this study. For Garth, his homosexuality was something that he denied along with the full extent of his disability because he was so driven to succeed in politics. He said he "couldn't be disabled and queer at the same time," so he "passed" as heterosexual in order to be viable professionally. It was only after his physical and emotional collapse that he was able to begin to claim both identities, which required being willing to risk being publicly and personally involved with other gays and disabled people he had been

leery of identifying with for twenty years. Having a “delayed adolescence” was a theme that emerged for some participants, although they did not all talk about it in those terms, a reality similar to that of the delayed adolescence of gay and lesbian youth who have had no role models for their own sexual development (Minton & McDonald, 1984). Lucy, Carlota, Phyllis, Florence, and Lauren all related that their families communicated to them, in different ways, that they had no expectations of them fulfilling society’s traditional female role expectations of marriage or parenting. For Carlota, Lucy, Phyllis and Florence, disabled female role models were instrumental in their beginning to embrace themselves as “real” women. Lauren defied that lack of expectation by marrying a man who was quite comfortable with her physicality and need for support with activities of daily living. And yet, when his caring support exact the price of a fuller development of her capabilities, she again set out on her own to chart an independent course of self-definition as a disabled woman. These reports reflect Rousso’s (1988) study that the majority of parents of disabled girls viewed their disabled daughters as “defective women,” unable to fulfill traditional female roles. These women all had to encounter the new paradigm of disability, before they felt entitled to claim their own self-defined sexuality, with its more inclusive standards of beauty (Wendell, 1992). While Leslie did fulfill her family’s traditional gender role of “marrying well,” her delight at finding a circle of “disabled girls” to hang out and share with completed her sense of herself as a disabled woman.

Clyde was the one heterosexual male who spoke of having a delayed adolescence, because he had been unable to fully communicate with his hearing classmates. It was only in the company of Deaf peer role models, with whom he could fully communicate, was he finally able to fully begin to explore his whole self and have his adolescence. Interestingly, four of the heterosexual men - George, Ray, Frank, and Lennie – did not relate that their gender/sexual identity was an issue in their disability

identity development, which could be partially explained by the age at which their disabilities. But it also reflects the reality that disabled men are inherently, as a function of being male in this society, are more likely to be in relationships or married than disabled women, even if their disability occurs before the relationships began (Asch & Fine, 1988). In dealing with his later loss of physical abilities, Don mentioned that his sexuality was becoming an issue, but also mentioned that disabled women he met in the disability community were far more accepting of him as a disabled man, than non-disabled women. That same comfortableness of shared experiences with disabled women echoes Carlota's comfortableness at now being in a long-term relationship with a disabled man, a relationship that was filled with the meaningfulness of understanding each other at a deeper level.

Personality traits: Many of the participants described personal characteristics they attributed to their personality that they thought playing an important role in how they personally responded to the conditions in the environments around them. Lauren described herself as stubborn and having an indomitable will that enabled her to devise strategies to get out of the hospital environment where she felt they were content, along with her family, to let her lie in on a back ward for the rest of her life. Lennie and Clyde both described themselves as fighters that enabled them to move through sub-optimal realities in their life without internalizing their negativity. Don, too, views himself as a fighter, which has enabled him to accomplish much "despite his challenges." Phyllis described herself as an "aggressive" personality who, like Lucy, Don and Florence, used her intellect in academic, professional and social environments to counter under estimations of her abilities. Leslie described herself as "fiercely analytical," a quality she imagines developing from her awareness of other's reaction to her disability. Frank described himself as "highly intelligent, bordering on arrogant," whose disability has now humbled him to use his intellect to work for social justice in constant awareness of his

capacity to hurt people. George, too, described himself as a spoiled, obnoxious, wealthy juvenile delinquent whose disability “salvaged” his life and transformed his anti-social behavior into a rebel for the cause of civil rights. Garth described himself as creative and sensitive, with enormous will power; the latter carrying him through the initial years of his living with a disability, while the former sustained him in the years after his collapse. Ray spoke of always feeling good about himself and self-confident, prior to going to Vietnam, and those qualities enabled him to single handedly begin to work for change.

New paradigm of disability: The reframing of disability as a civil rights issue enabled the participants to view their personal disability outside of the medical model that had shaped their understanding of themselves and their place in the world. The “new paradigm of disability” was the single most important factor in transforming every participant’s view of themselves as a disabled person. It enabled them to reframe their disability experiences from being their “personal problem” into a positive, collective identity as a “marginalized group” uniting for a political identity about empowerment with all other disabled people. The new paradigm also laid the foundation for disabled people to build a community on shared beliefs, values and assumptions that honored differences and commonalities. For some people it was like religious conversion experience, a collective way of living life on disability community terms, of “having people around you who will support you, no matter what.” For others, it was an intellectual construct that enabled them to make meaning of their disabilities in their lives and a critical framework that helped them deconstruct the role the social system of disability had played in how they had constructed their sense of self.

Disability community: Being a part a community and culture that can honor who one is builds a sense of self that is whole (Erikson, 1968). Living in community, with people who are like oneself, profoundly influences one’s sense of self on a level that can

remain virtually unconscious; until one is without it or until one must regularly engage with people with worldview that cannot fully honor who you are. Living in a society dominated by cultural values that do not honor who you are can make one deeply appreciate being with members of one's own community who share your understanding of the world, because of common experiences and shared values. The experience of growing up in a family, community and culture with people who are unlike yourself, who cannot fully honor who you are and may require that you diminish your difference, can leave one feeling like an alien who doesn't really belong. To be taught that you are not acceptable, as you are, teaches you that others who are different like you are also not acceptable and so you learn to avoid them, giving one the sense there is no place to search for belonging (Gill, 2001; French, 2001).

When disabled people finally do encounter other disabled people who fully accept themselves and other disabled people, it is like finding a "home place" you did not even know you were missing. Experiencing a sense of connectedness with other disabled people was made possible by the reframing the experience as a civil rights issue and a positive collective experience with a developing culture. Participants found others who shared common experiences and validated feelings and perceptions about the world around them be "truthful...share experiences...talk and compare notes...know they are not singling me out"... "a kinship right away...a familiarity ...we all had something in common...the emotional part that was so good was simply not being the only! Meeting other disabled people They found role models for roles and activities they had wanted to participate in, but did not know if it was possible. With other disabled people they could Don developed a sense of collective pride with the disability community, because he finally had a place to belong - "like everyone else!" Leslie's instant bonding with other disabled intellectuals gave her first profound experience of emotionally being a part of a community, of not being the only one! Claudia and Karla, both, had conversion

experiences when they encountered disabled people were engaged in the struggle for rights and empowerment they were already involved with. Lauren's first encounter with the disability community blew her mind, she knew instantly these were her kind of people, because they were collectively doing what she had done alone. Phyllis' immediate bonding was strictly political, yet her later bonding with disabled friends was in shared understanding of common experiences. Lucy's strong need for real disability community came after experiencing professional discrimination, turning to other disabled professionals for validation of her evaluation of the situation and to hear of their own similar experiences. Florence's first taste of disability community, through disability activism in her privileged college setting, deepened into a broader emotional understanding and bonding with the whole disability community when she was later immersed in the community at the independent living center. George and Clyde became a part of the disability community when they found common ground with other disabled people who shared their vision of justice for all humanity. Carlota initially found validation for her choice to value herself as she is from the disability activist she bonded with around disability rights. Gail and Clyde both grew up surrounded by disability/Deaf community from childhood on, always nurtured by their "change agent" role models to have a sense of belonging within their communities and in the large community.

Role models, disabled or non-disabled: Bronfenbrenner (1979) understood that people learned the socially expected roles and activities for adult life from people like oneself and the validity of that assessment is no more clear than when looking at the lives of disabled people who can live the majority of their lives completely surrounded by people who are unlike themselves. For Florence, after being introduced to the new paradigm of disability during an internship, her first disabled role models were fellow disabled students who took collective action and successfully sued their university for inaccessibility. Working with these intellectual peers increased her comfortableness in

being with other disabled people, because their collective civic action was integrating their professional training with their emerging disability identity. Florence's later need to find a disabled role model for being a mother and wife underscores the fact that disabled people need to have multiple disabled role models that enable them to envision taking on a wide variety of roles and activities in adult life. Phyllis' first encounter with disabled professional peers, who introduced her to the new paradigm of disability, was also her first encounter with role models who were also exploring themselves as sexual beings. Having never envisioned herself as capable of winning in that activity, she had foreclosed that part of her identity. Gail's first role models were her parents, whose "change agent" role modeling had a profound effect on her and her community of disabled kids who grew up to be change agents themselves, because of the lessons they had learned from their parents' fights for their education. She also spoke of the children being role models for each other as they grew up, exploring their adolescent development together, imagining the world they wanted, and ultimately making those changes happen through the political actions of their disability rights organization. Lucy's first disabled role model was a boss who enabled her to envision herself being successful in a meaningful job and in a relationship with a man. The disabled professionals she organized later in life were also personal role models who, in turn, served as disabled role models for disabled girls and young women in a mentoring program subsequently organized. Leslie found a disabled professional role model at the time she was first beginning to explore her disability as a member of a devalued social class, a mentor who introduced her to the disability community itself. Carlota had had disabled friends starting as a teenager, but it was not until she began viewing disabled women as role models of a standard of beauty that honored who she was, that she was able to incorporate her disability positively into her sense of self as a woman. Lennie did not have disabled role models until later in life, when he began working in the disability

community and was himself one for disabled people who came to the independent living center he directed. His role models became the national leaders of the disability community who, by the very scope of their work, challenged and eventually recruited him to take on a larger role at a national level. Karla did not have disabled role models until she was a professional, but her family had modeled for her how to live her life with dignity in the midst of discrimination. For Fiona, her initial role models and community were other psychiatric survivors who were struggling together to address the injustices in the psychiatric system which later expanded to include leaders of the disability rights movement who are also struggling with issues of injustice, nationally and internationally. Clyde grew up with Deaf role models and in a Deaf community, as well as civil rights leaders who taught him how to understand his experience through a civil rights lens. Ray's role models were also his African American family and his bonding with the disability community came through the effort to train disabled people about disability rights and local efforts to build a local disability community.

Given that all of the preceding interrelated external and personal factors do influence an individual's disability identity development, one can begin to appreciate the complexity and fluidity of the disability identity development process. For some of the leaders in this study, disability was always a part of their life; it was always a part of how they experienced themselves in the world. For others, who acquired their disability later in life, either in childhood or older, theirs was an identity development process that required incorporating their disability into a sense of self that had already been constructed on a foundation of a non-disabled lived experience. It is at the juncture of the interaction between who disabled individuals understand themselves to be and how the world around them perceives them to be that is the grist for their disability identity development mill. As Lauren and Lennie so beautifully and painfully put it, the process of disability identity development may, first, be about not letting others define you

negatively and limit who you imagine you can be. Or, it may be about co-constructing a positive sense of self with others who can honor who you are, whether they share the disability experience or not. What we now know is true, at whatever point one begins one's journey of disability identity development, is that the process of integrating one's disability into a whole sense of self can only be achieved if one has found a place of belonging in the disability community. It must be a sustained place of belonging that is more than intellectualized, with relational, mutual-responsibility networks that bring role models into your life who can both nurture and challenge your emotional, psychological, spiritual and political growth; sisters and brothers who can both encourage you and kick you in the butt, because they understand; and heroes and sheroes whose examples both inspire you to follow your dreams and push you out of your comfort zones so that you, too, can make the world a better place for the next generation.

The following table (Table 1) is a matrix charting the disability identity development journeys of the eighteen leaders in this study. Over the course of their own disability identity development process, all of these leaders have taken on one or all of these relational adult roles mentioned above; roles that are needed in any community to further its development, but most especially needed in a community that is still in the process of consciously defining and growing itself. They are, or have been, the heroes and sheroes who had the dream of a disability community and set about building it for themselves and others. They are, or have been, role models to others who have found their way home to this new community and share the desire to strengthen it and ensure its future as part of the larger human project. And they are, and have been, the very best brothers or sisters a disabled person could ever hope to have to talk about everything with, to get different insights from, to share battle stories and triumphs with and to cry over pain and loss with. The table demonstrates that individual leaders' disability identities begin at different "positions" and progress to more complex

“positions,” depending on their personal and/or environmental contexts. It also indicates the disability identity “position” each leader has occupied during the course of their lives with disabilities, as well as “positions” they may yet achieve over the course of the rest of their lives, given the opportunities and resources they may yet encounter on their journeys.

Table 1
Disability Identity Development Matrix

Particip- ant Name	Age of Onset	Gen der	Race/ Ethni city	Posi tion #1	Posi tion #2	Posi tion #3	Posi tion #4	Posi tion #5	Posi tion #6
Phyllis	18 MO.	F	EA	X	X		X		
Lauren	17	F	EA	X	X		X	X	X
Leslie	birth	F	EA	X	X		X		
Lena	birth	F	EA	X	X	X	X		
Clyde	birth	M	AA			X	X	X	X
Lennie	14	M	EA		X		X	X	
George	20	M	EA		X		X	X	X
Garth	19	M	EA	X	X	X	X	X	X
Ray	19	M	AA				X	X	
Florence	birth	F	EA	X	X	X	X		
Lucy	birth	F	EA	X	X		X		
Claudia	birth	F	L/NA	X	X		X	X	
Gail	18 MO	F	EA				X	X	X
Carlota	infant	F	Italian	X	X	X			
Don	birth	M	AA	X	X		X		
Frank	24	M	EA		X			X	X
Fiona	21	F	EA	X	X	X		X	
Karla	9	F	AA		X		X	X	X

Legend:

AA: African American

NA: Native American

L: Latina

EA: European America

X: Indicates leader articulated some or all of the qualities that characterize this identity “position.” The time period “occupying” marked position varies and the last “X” to the right represents the identity position leaders articulated at time of interview.

Summary

In this chapter, I have generated a “working model” of cross-disability identity development from the synthesized contents of the interviews with the eighteen individual disability community leaders in this study. I have discussed the eight factors in the lives of these leaders that have positively or negatively influenced their identity development process over time. And finally, I have presented a chart that represents a composite picture of the identity development of each of the leaders and the various disability identity “positions” they articulated in their interview. Chapter Six will be a discussion of the patterns that emerged during the process of synthesizing individual identity development models into the “working model.

Chapter 6

To be liberated from the stigma of blackness
by embracing it, is to cease, forever, one's
interior argument and collaboration with the
authors of one's degradation.

J. Baldwin

Just so's you're sure, sweetheart,
And ready to be healed,
Cause wholeness is not trifling matter.
A lot of weight when you are well.

Toni Cade Bambara

Patterns, Limitation, and Directions for Future Research

In this chapter, I will discuss some patterns that have emerged about the disability community itself, about the disability experience and about the process of disability identity development itself. I will also discuss the limitations of this study and avenues of future research that will need to be areas of inquiry the disability community should internally be addressing as it matures and develops in the future.

Patterns

This study has begun to reveal that the process of disability identity development can be as fluid as the disability experience itself. The fluidity of one's disability identity development will be influenced by the very nature of one's disability and that disability could be episodic or progressive, such as Fiona's psychiatric disability that causes her to withdraw when she's depressed, because it takes too much energy to deal with people while her reservoir of energy is depleted. Or, Don's disability identity is influenced by his progressive neuromuscular condition is creating greater social and work limitations for him to manage emotionally and psychologically. One's sense of self can also be fluid depending on the level of usability and accessibility of communications, the built environment, or the consumer goods created to be used in those built environments. Bronfenbrenner (1979) mentioned that being able to function in and move between environmental spheres is an essential building block for development of the roles and activities expected of adults in society. So, it

is not just the response of people in one's environment that can determine the saliency of one's disability at any given point, but it can also be the very design of the environment itself that exaggerates one's limits and influences the interpersonal dynamics of a given situation. The usability or accessibility of one's world can either enable one's ability to fully be oneself or decrease one's ability in any given situation. Again, it is another environmental factor that influences one's sense of self and also one's real ability to fully express that self rather than disability itself, just as cultural and social environments influence disability identity development independent of one's disability. George, Garth, Don, Ray, Lauren, Claudia, Karla, Carlota, Gail and Phyllis all made mention of the important role their "concrete" environments play in their being able to function in their environment, a reality that ultimately influences one's own sense of self, as well as one's sense of having a place in the world in which to make one's contribution.

Another pattern of fluidity in the disability identity development process that began to emerge in these interviews involves the realities of aging with a disability. This form of fluidity is not so much situational, as it is on the order of Teutonic plate shifting that is requiring a revisiting and reworking of the role of impairment in the disability identity development process. The disability community has succeeded in shifting the cultural dialogue about disability for itself from the reductive, medical models' view of disability as defect to be cured, overcome or irradiated from the face of the earth to a social model of disability in which it is oppression and discrimination that needs to be overcome and irradiated from the place of the earth. Yet, what has happened to the impaired embodied experience of disability is precisely what happened to the body in Freud and Erikson's conceptualization of psychosocial development – it has disappeared! That is not to say that disabilities themselves have disappeared - how could you demonstrate your belonging to the community without it? But rather, that in focusing the rhetoric and action of the disability community strictly on the basis of rights and social participation the community has created

yet another false binary that is taking its toll on the psychosocial and physical health and well-being of members of the disability community. The very real limitations that arise from having a disability – an impairment of functioning of one kind or another, be it psychiatric, intellectual, or physical - is consigned to the back porch of community's consciousness because it is a challenge to the new prevailing notion that disability is all about in the interaction between the disabled person and society (Hughes & Paterson, 1997).

What is beginning to be discussed within the disability community is a self-imposed social process of the silencing body, or the energetic "body," that physically registers the daily realities of managing both our disabilities and our lives in an ableist culture, no matter what the disability. It is a silencing that can mask the very real consequences of a life lived having to prove one is as good as "able-bodied people," as Garth so eloquently put it. The new "poster child" rhetoric used by some disabled people and manufacturers of technology disabled people use is what I call the tyranny of "without limits," the representation that once the social barriers have been removed and the proper technology acquired to support our lives, disabled people are either "just like everybody else" or the sky's the limit, both false notions that deny the true physicality of our embodiment, and echoes the superhero overcomer of years gone by – except it is now being perpetrated by disabled people themselves. Hughes & Paterson (1997) posit that both the medical model and the social model of disability treat the body as "a pre-social, inert, physical object, as discrete, palpable and separate from the self," a position that helps explain how Don and Phyllis can embrace the disability rights movement and still envision being the same person, even if their disability disappeared. Their disability is discrete from who they conceive themselves to be and, therefore, excisable with no consequence to the self; it is another variation on the same view of the body that exists in "old" medical model, which posits that surgically altering or removing some part of a disabled body will also have no impact on the sense of self of the disabled child. Conceiving of one's disability as separate from oneself would also explain

the shock and dismay of George and Garth when their bodies finally reasserted themselves, after years of being subsumed under both of their prodigious minds and wills, and began to manifest “real limitations” they could not ignore any longer.

bell hooks (1993), in *Sisters of the Yam: Black Women and Self-Recovery*, teaches about how essential it is for people who live in oppressive societies to “de-colonialize” their minds of and liberate their bodies from cultural values, beliefs and assumptions that dishonor who they are. There is a strong parallel between the embodied lived experience of disability and hooks’ description of how black women’s unconscious internalizing of negative messages from the patriarchal and racist society then generate equally unconscious and reactive “strategies of resistance for survival,” (Baldwin, 1962; Robinson & Ward, 1991) that are inextricably locked in with that cultural belief it purports to be resisting. The fact that such reactive strategies are undermining the well-being of black women can also be seen in the lives of disabled people as they age. Those who have not yet liberated themselves and their bodies from their own internalized shame of having limits are inexorably, and by degree, slowly killing their body, mind and soul. There is hardly a week goes by in which the news of yet another disability rights warrior’s death is sent out over the internet. Or you see that the stress of living in anger and rage or pushing one’s body beyond its honorable limits causes another person to suffer a collapse such as Garth’s.

Aging with a disability brings all of these issues back to the front porch where the neighbors can see them and disabled people must finally deal with them...or not, depending on whether the community itself supports the task of addressing the issues of emotional liberation, a change Garth questioned would ever occur. George spoke of his new disabilities near the end of his life as “the real deal,” and his earlier disability experience as a “symbolic” disability; that symbolic disability enabled his wild macho man to avoid the emotional issues of reciprocity and dependency that he was currently dealing with every day near the end of his life. And as the life and death cycle would have it, both George and

Garth died before this dissertation was completed, having both lived rich, long lives of public service for the disability community and both having come to a place of understanding themselves and their disabilities within a much larger spiritual context.

Karla, too, was given pause when she realized how her disability consciousness had shifted from her earlier concern about others' perceptions of her with a disability to an increasing need to be aware of her physicality, which was not necessary in her younger years. Don confessed to contemplating the desirability of a cure, because life would be easier; while Lucy contemplated a career change because of the toll activist fatigue was taking on her body. Ray and Florence both alluded to needing to slow down and, in the end experienced such physical health issues that they both had to withdraw from their public involvement in disability community life. In discussing her profile on the phone, even Leslie confessed that emailing was beginning to take a physical toll on her and she was needing to contemplate using an alternative means to write, a prospect she seemed difficult for her, as up to this point her disability has not involved any significant limitations for her. The drive that all of these leaders possess has required a certain "mind over matter" approach, as they have worked to break new cultural ground, challenges that require an external focus. And as their aging process speeds up, they find themselves needing to slow down and be more aware of self-care.

Another unexpected pattern that emerged while analyzing these interviews was how many of these leaders related that they had been in counseling for many years. None of them identified their counselor as a disabled therapist, of course, or even one who had been trained to look at disability from a multicultural counseling framework, but they all attested to the usefulness of counseling in helping them deal with the fundamental human issues everyone struggles with. From my current perspective, and one that Lucy affirmed in a recent article on this topic in the disability press, that it is important for disabled people to have access to disabled counselors who have done their own work. It is possible that if some

of these leaders had been in counseling with a disabled therapist, some of their current self-understanding and unresolved issues may have been examined in very different ways and resolved in more integrative manner into a whole sense of self.

Another pattern that emerged is one that validated the concerns of the four leaders of color about the unconscious racism that exists in the disability community and how that unconscious white privilege functions in concert with “physical disability privilege” in influencing who become leaders in the disability community. Two of the eleven European American leaders alluded to their race, though “pasty white” and “WASP” do not qualify in my mind as serious acknowledgement, much less an acknowledgement of the inherent privileges that accompany being white. Clyde did acknowledge racism, both within the disability and the Deaf communities, and expressed his concern that his privileged, suburban-dwelling, white, hearing children learn about the horrors of racism and prejudice, so they can understand why appreciating diversity is important. But the rest of the European American leaders did not even allude to their race. Given this lack of significant racial awareness by the majority of the European American leaders in this study, it seems that George had grounds for his deep concern about the community maintaining its close ties with the larger civil rights movement. And even though most European American leaders spoke of being involved in other liberation struggles, the lack of any racial awareness carries with it both cause for concern and a hope for the future. Clyde understood that it is only when we are aware of the horrors of racism and unearned privileges that we can truly understand why disabled people’s issues are so inextricably linked to the struggle for civil and human rights. But as disabled European Americans, we must first learn to be aware of our own unconscious white and possible non-disabled privileges that have influenced how we view the world and, in so doing, begin to be aware of our own unconscious racist actions and practices.

Education was such an important element in these leaders’ disability identity

development, which indicates it is an important element in any disabled person's ability to take on the adult roles and activities in this society. It was the quality education that these parents fought for, before there was any mainstreaming or special education, which prepared these leaders to take on the role of leadership they now have in the disability community. Lena's negative experience with the "special education" system is indicative of a "solution" that has been devised for a "problem" defined by non-disabled cultural values, beliefs and assumptions. Special Education defines the disabled children as having the "problem" of not learning like other children and its segregated educational "solution" communicates the stigma society attaches to people who are different. Rather than requiring that all teacher training programs expand their scope of education to include learning to teach all kinds of learners, a segregated training system has been established that only trains a fraction of teachers to teach "problem" learners. The power dynamics of professional privilege has created yet another colonized experience based on the medical model of disability, locating the problem within the disabled individual rather than educational systems that are ill prepared to support all kinds of learners. The same medicalized approach has now been instituted by universities in fulfilling their legal obligations to provide equal access to education for all disabled college students. The predominance of non-disabled professionals who staff such disabled students service offices embody the same cultural beliefs, values, and assumptions of the special education system in how they conduct themselves, *vis a vis* disabled students. And many of the young disabled students view these services and the non-disabled service providers as extensions of the stigmatized special education system they do not want to be identified with. Both disabled students and non-disabled professionals view their disability as requiring an external and concrete response to provide individualized support services, like therapy or surgery. Such an individualized approach is far easier than working to change the limitations in the educational process of the university itself by instituting. A "universal"

pedagogical approach to educating all university students is being developed by disabled university professionals, which also includes addressing the psychosocial identity development needs of disabled university students; a need that is as ignored by non-disabled university service providers as it is by non-disabled family members. The young disabled university students I encountered during my Master's program, who could not identify positively with other disabled people, would have benefited from such educational programming directed at their unacknowledged need to be with others like themselves.

Another interesting pattern that emerged, which I'm not sure what to make of it, if not a sign of progress, was that the women in the sample did not identify their being female as another "minority status." Since many of these women have been involved in one way or another in the women's movement, perhaps such an involvement reduces one's sense of isolation and being invisible and devalued or they do not view their female experience that way. On the other hand, it could also mean that disability simply was the salient aspect of themselves they were focusing on at the time of the interview, though their thorough discussion of being women, as well as disabled, would not lend itself to that simplistic an explanation.

Another pattern that contributed to the psychosocial development of the leaders who grew up in homes culturally fortified to teach them resistance skills, was that these children also grew up intimately involved in multiple social environments learning to relate to different kinds of people who are collective and mutually working on the same kinds of activities and skills – music, Girl/Boy Scouts, school musicals, student government, religious instruction, with disabled and non-disabled children, etc. In keeping with Bronfenbrenner's model, the fact that these children were supported in their transitioning between home and community settings by their sense of having inherent of belonging at home, as they were, and that sense of belonging ensured their success both in those transitions and in the more complex transitions later in life. My theorizing on this point is that without the internal fortification of

experiencing a sense of belonging within a collective that values you as a person, such transitions would not be successful and probably only serve to underscore ones difference rather that incorporate it into a group or setting.

Limitations of the Study

This study has limitations in its sampling, methodology and data analysis.

Sample. The single most important limitation of this study is its limited transferability to the disability community as a whole. There are several factors that contribute to this reality: limited range and number of participants, the educational level of participants, the employment status of the participants, and their access to resources other disabled people may not have, such as counseling.

The fact that this sample was limited to the disability identity development of leaders of the disability community may limit its transferability in describing the disability identity development of non-leaders in the disability community. By virtue of that fact that all of the participants are all leaders means they possessed of personal qualities that the average disabled person may not be, in addition to the greater access to resources. The fact that not every participant “occupied” or yet achieved all of the six identifiable identity positions could ameliorate some concerns about the sample being view as completely homogenous in its representation of a privileged group.

The levels of higher education, and subsequent employment and career development opportunities, played such an important role in the disability identity development of these leaders may limit this model of disability identity development from being transferable to the general population of the disability community. Fifteen of the eighteen participants had at least one degree of higher education, while eleven of the participants had two or more degrees, which is much higher degree of education than the typical disabled person.

The racial/ethnic diversity of the sample is also a limitation. Thirteen of the leaders

are European Americans and five of the leaders are people of color - one Latina/Native American and four African Americans. Although this sample does not reflect the racial and ethnic make-up of the entire disability community, it does reflect the historical profile of the racial make-up of disability community leaders, which has traditionally been European Americans.

Only one participant identified as gay and none of the women leaders identified as lesbian, which does not reflect the estimated 10% lesbians found in the general population (Finley, 1997).

Although not all of the participants reported degrees of higher learning, they all were or had been working full time, which is another factor that limits the transferability of this model to the disability community as a whole. Only 35% of disabled people polled in the 2004 Harris Poll reported full or part time employment, while 100% of this sample in this study reported being or having been employed full time over the course of their employment and careers.

Method. Qualitative research methodology can create limitations in the consistency of information gathered and only doing one interview can exacerbate that limitation. I see this issue of one interview as a distinct limitation on, both in my ability to gather information over a life span in one setting and in consistency of information. I did do some short follow-up conversations with a couple of people who requested it, because of their own time constraints. Even as a member of the disability community, establishing trust in inquiring about some of the more personal aspects of participants' disability identity development presented some challenges. Given the fact that these leaders lives were so focused on their external work of social change, it was sometimes necessary to ask such questions in multiple ways to try to elicit more personal information about emotional and psychological realities of their lives. Such attempts led to very mixed results, as mentioned in some of my theoretical notes. Relying on individual self-report has led to some limitations in the

consistency of information reported. We did not gather specific information on participants' level of educational achievement, sexual identity or sexual orientation, so relied on participants sharing whatever information they considered relevant to their disability identity development.

Analysis. I had an external coder who coded each transcript for the qualitatively different identity development positions he could identify. Of the five different disability identity development positions that he identified, we had 72% agreement on the statements that he quoted as examples of each position. In examining the statements we were not in agreement on, I concluded that our different conclusions were the result of our different understandings about the qualitative difference in the scope between the third and fourth positions, as well as the expanding scope of awareness and commitment beyond the disability community in the fifth and sixth positions. The qualitative differences between the third and fourth positions involved participants developing the capacity to identify with an increasing larger variety of disabled people, with different kinds of disabilities other than one's own. The qualitative differences in the fifth and sixth positions that were not identified in either the coding or positions were the expanding commitment to the civil rights struggle of groups beyond the disability community and the United States. Some of the participants also expressed an increasingly spiritual view of disability, viewing disability as one element of being human that is no more important than other elements in the struggle to be fully human.

Achieving coder agreement, given the dearth of local disability scholars, presented a challenge. By its very nature, coding will always be more art, than science, as any coder will read life stories, such as these interviews, and attend to different factors that will be salient to them in the "story line." Such selective attending is always and simply the product of a specific coders' worldview, theoretical framework, personal life history, and personal identity development. And so it was with working my external coder. We did share similar

theoretical frameworks, we had different worldviews, were at different places in our own identity development and our personal histories were quite different.

Directions for Future Research

In discussing possible directions of future research, I can actually say that the next phase of research arising from this particular study is *currently* being conducted by our research team. One research finding from the disability identity development data analyzed thus far was that families play one of the more important roles, positive and negative, in nurturing the identity development of their disabled family member. To investigate this factor further, we proposed a “best practices” study and received our second National Institute of Disability and Rehabilitation Research field initiated research grant. The project is heuristic research with families that have culturally fortified their children to successfully take on the adult roles required of adults in this society (Akbar, 1991). The purpose of the study is to uncover the approaches and strategies families have developed and used to fortify their children through doing intensive family case studies with as many family members as possible. We will then analyze that data and structure that knowledge into a strengths-based community training program to be offered to families of disabled people who are themselves not culturally fortified to support their disabled family member in a way that is affirmative and properly supportive. We will then offer the training to be made available to families through rehabilitation centers in the United States.

Another avenue of research that was almost funded for this fall as a post-doctoral study was a proposed U made to the University of California Berkeley, for a study that I feel sure quite will be funded in the near future. The proposed study was a quasi-experimental study based on the deliberate psychological educational design approach of N. A. Sprinthall (1994) will, in actuality, be also an extension of this current study. The team is developing an operationalized model of disability identity development, constructed for the whole sample of disabled people in the national study, including the leaders included in this study,

as an instrument for assessing disability identity development. The proposal is to collaborate with the Cal Berkeley campus Disabled Students' Center and the CA Vocational Rehabilitation Administration to work with the disabled students in their residential training program. Students with significant disabilities attending Cal Berkeley have the option live on campus and participate in a structured training program for taking on the role of living independently and be in charge of every facet of their adult lives. It is a highly structured program that not only supports the students academically, but also supports them in learning the roles required of a person who is a quadriplegic or paraplegic, etc. in how to manage the personal care assistants they will require services from throughout the course of their lives. My proposal was to add a structured weekly group to this process, complete with reflection activities that could serve as another collective means of support, as well as a means of further the psychosocial development they are in the midst of experiencing with the many new roles they are taking on. Given the findings from this current study about how little families of disabled people actually discuss such topics within their family, this group would be an opportunity to develop the language and emotional skills to talk about their inner experience of disability with their peers. It would also give these students the opportunity to experience supportive disability community and meet potential role models who could support their dreams.

We also plan to do larger studies to validate the disability identity instrument, with larger groups of people in multiple settings around the country, such as independent living centers, national gatherings of disabled people, such as ADAPT actions, annual conferences of various disability organizations, disabled student centers on university campuses, etc.

Implications for the Field of Counselor Education

As disabled people become an integral part of our communities, educational systems, transportation systems, housing markets, schools and universities, neighborhood

grocers and theaters, etc. we are increasingly present in all community settings, including mental health centers and private counseling offices. Despite all of the recent progress in legislation, communities continue to function within traditional ableist beliefs and assumptions, so it would be safe to conclude that disabled people will be part of every counselor's potential client base, needing counseling services near where we live and work in order to manage the stress of "multiple world" living. For this reason, introducing disability into the multicultural counseling paradigm is essential in order to train future counselors to be prepared to provide culturally appropriate counseling services to those disabled people who will come through the doors of their offices.

Currently, the field of counseling, in its very professional structure and training, still segregates the issues of disabled clients to the purview of rehabilitation counselor training programs, which perpetuates the cultural misperception of disabled clients needs "special" designation of that society uses distance itself from the disability experience and the reality that disability is a normal part of the human experience. This specialization perpetuates the notion that disabled people issues are different from other counseling clients' issues, yet as we have seen in this study participants in more complex identity positions have a growing awareness that disability issues as basically fundamental human issues, and as such require the same counseling approach in resolving them.

As this study demonstrates, disability identity development does indeed unfold in a fashion similar to that of other diverse cultures and communities, and therefore requires that counselors learn about disability within the perspective of multicultural counseling training and demonstrated competencies. Being able to assess where a disabled client may be in their own disability identity development would enable a counselor to provide developmentally and culturally appropriate resources for that person to support their identity development. Counselors would also need to demonstrate their understanding of their own unconsciously held beliefs, values and assumptions about the disability experience and

worked to resolve them. Counselors must demonstrate a working knowledge of the actual lived experience of disabled people as articulated by members of the disability community and they must be prepared to share culturally, and developmentally, appropriate resources for disabled clients who seek their service, particularly those disabled people who claim multiple identities, including their disability (Atchinson, et al., 1983; Robinson & Howard-Hamilton, 2000).

The life stories told in this dissertation are so powerful in their portrayal of resiliency, strength, wisdom, courage, kick-ass attitude, passion, vision, commitment, love, hope – all capacities of the self that have been forged on the anvil of the disability experience in an ableist world. Non-disabled counseling professional would benefit from reading about these heroes and sheroes of the disability community. The stories, in and of themselves, would make an instructional tool for exposing the fallacies of the beliefs, values and assumptions everyone in the culture has been taught to believe about disability. To that end, I am in discussion with multiple people in the disability community about the possibility of developing these interviews share their stories in fuller form in a book that could be used in multiple educational settings and for personal biographical reading. Many of the participants wanted their names used, as they know the power of story telling in building a community and the reason for all of them participating in the story was to help create change in others' understanding about disability. Lennie commented after he had read his profile that he now realized how important it was to say those things that he had never said before and how important it was that others were going to read it.

Concluding Remarks

One last pattern I must address in closing. Only upon nearing the end of this analysis process did I realized that if had I completed my analysis of this data several years ago, when folks expected me to, I would have missed or possibly not even grasped the larger disability community issues, such as racism, white privilege and non-disabled

privilege, that were evident to me in my later analysis. It seems that I, too, have grown while working on this process, which should not be construed as a flip justification for the length of time it has taken to complete this task. But rather, it is an acknowledgement that my seeming lack of progress during these years has, in fact, been my practicing *wei-wu-wei* – the Taoist notion of doing without doing, of letting things reveal their true nature and all is accomplished without effort. My “stuckness,” which confused and puzzled even me, actually caused me to withdraw from the distracting political activity of disability community politics and from the draining dramas of those professional colonizers of the disability experience in North Carolina. Reading the life stories of these national leaders and mourning those who died, while and recalling their legacies, pulled my vision beyond the voices fighting for entitlements and rights to the voices of those who have grounded their actions and their larger visions in spiritual places. Their repeated concern for nurturing or mentoring the next generation of young people, preparing those young people to take on the challenges of the disability community in their adults lives, confirmed my growing sense that the future work of the community is addressing the nurturance needs of disabled young people. This experiential encounter with the Tao of working on this dissertation, the years of seeming inactivity have changed me and that process has grounded me more strongly in my community and its needs.

References

- Admi, H. (1996). Growing up with a chronic health condition: A model of an ordinary lifestyle. *Qualitative Health Research*, 6 (2), 163-183.
- Aisenburg, N. & Harrington, M. (1988). *Women of academe: Outsiders in the sacred grove*. Amherst, MA: The University of Massachusetts Press.
- Akbar, N. (1989). Nigrescence and identity: Some limitations. *The Counseling Psychologist*, 17(2), 258-263.
- Akbar, N. (1991). Paradigms of African American research. In R. L. Jones (Ed) *Black psychology* (3rd ed.) (pp. 709-726). Berkeley, CA: Cobb & Henry Publishers.
- Anspach, R.R. (1979). From stigma to identity politics: Political activism among the physically disabled and former mental patients. *Social Science and Medicine*, 13(A), 765-773.
- Atchinson, D.R., Morten, G., & Sue, D.W. (1983). *Counseling American Minorities: A Cross-Cultural Perspective* (3rd ed.). Dubuque, IA: William C. Brown.
- Baldwin, J. (1972). *No name in the street*. New York: Doubleday.
- Bat-Chava, Y. (1994). Group identification and self-esteem of deaf adults. *Personality and Social Psychology Bulletin*, 20(5), 494-502.
- Baynton, D. C. (2001). Disability and the justification of inequality in American history. In P. Longmore and L. Umansky (Eds.). *The New Disability History: American Perspectives*. (pp. 33-57). New York: New York University Press.
- Becker, G. (1981). Coping with stigma: Lifelong adaptation of deaf people. *Social Science and Medicine*, 15(B), 21-24.
- Becker, H. S. (1990). Generalized from case studies. In E. Eisner and A. Peshkin (Eds.), *Qualitative Inquiry in Education: The Continuing Debate*. (pp. 233-242). New York: Teachers College Press.

- Becker, G. & Jauregui, J.K. (1985). The invisible isolation of deaf women: Its effect on social awareness. In M.J. Deegan and N.A. Brooks (Eds.), *Women and Disability: The Double Handicap* (pp. 23-36). New Brunswick, NJ: Transition, Inc.
- Bennett, E.L. (1992). *The psychological and developmental process of maintaining a positive lesbian identity*. Unpublished doctoral dissertation, Boston University, Boston, Massachusetts.
- Blackford, K. (1990). A different parent. *Healthsharing*. Summer.
- Bloland, S. E. (1999). Fame: The power and cost of a fantasy. *The Atlantic Monthly*, November, 51-62.
- Bogdan, R. (1988). *Freak show: Presenting human oddities for amusement and profit*. Chicago: The University of Chicago Press.
- Bogdan, R. and Taylor, S. (1975). *Introduction to research methods*. NY: Wiley & Sons.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments in nature and design*. Cambridge, MA: Harvard University Press.
- Brown, L.S. (1995). New voices, new visions: Toward a lesbian/gay paradigm for psychology. In N.R. Goldberger & J.B. Veroff (Eds.) *The Psychology and Culture Reader*. (pp. 558-574). New York: New York University Press.
- Bryan, W.V. (1996). *In Search of freedom: How persons with disabilities have been disenfranchised from the mainstream of American society*. Springfield, IL: Charles C. Thomas Publisher.
- Cass, V. C. (1979). Homosexual identity formation: A theoretical model. *Journal of Homosexuality*, 4, 219-235.
- Cass, V. C. (1984). Homosexual identity: A concept in need of definition. *Journal of Homosexuality*, 4, 219-235.
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. *Sociological Quarterly*, 35,(2), 269-288.

- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly*, 36(4), 657-680.
- Claire, E. (1999). *Exile & Pride: Disability, Queerness, and Liberation*. Cambridge, MA: South End Press.
- Coles, R. (1973). *Erik H. Erikson, the growth of his work*. London: Souvenir Press.
- Conte, L.E. (1983). Vocational development of persons with disabilities. *The Career Development Quarterly*, 37, 269-278.
- Corbett, J. (1994). A proud label: Exploring the relationship between disability politics and gay pride. *Disability & Society*, 9(3), 343-357.
- Crewe, J. & Zola, I.K. (1983). Introduction. In J. Crewe & I.K. Zola (Eds.) *Independent Living for Physically Disabled People: Developing, Implementing and Evaluating Self-Help Rehabilitation Programs* (pp. 4-5). San Francisco: Jossey-Bass Inc. Publishers.
- Cross, W.E. (1971). The Negro to Black experience: Towards a psychology of Black liberation. *Black World*, 20(9), 13-27.
- Cross, W. E. (1991). *_Shades of Black: Diversity in African-American identity*. Philadelphia, PA: Temple University Press.
- Cross, W.E., Strauss, L. & Fhagen-Smith, P. (1999). African American identity development across the life span: Educational Implications. In R. Hernandez-Smith and E.R. Hollins (Eds.). (pp.29-47). *Racial and Ethnic Identity in School Practices: Aspects of Human Development*. Mahwah, NJ: L. Erlbaum Associates.
- Czuczka, T. (2003). Nazis used hospitals for killing. The Associated Press, September 30, 2003).
- Davis, L.J. (1995). *Enforcing normalcy: Disability, deafness, and the body*. London: Verso.

- Davis, L.J. (1997). Constructing normalcy: The bell curve, the novel and the invention of the disabled body in the nineteenth century. In L.J. Davis (Ed.), *The Disability Studies Reader* (pp. 9-28). London: Routledge.
- Deegan, M.J. (1985). Multiple minority status: A case study of physically disabled women. In M.J. Deegan and N.A. Brooks (Eds.), *Women and disability: The double handicap* (pp.37-55). New Brunswick, NJ: Transaction Books.
- Deegan, M. J. and Brooks, N.A. (1985). Introduction - Women and disability: The double handicap. In M.J. Deegan and N.A. Brooks (Eds.). *Women and disability: The double handicap* (pp. 1-22). New Brunswick, NJ: Transaction Books.
- DeLois, K.A. (1993). *How women come to identify as lesbian: A grounded theory study*. Unpublished doctoral dissertation, University of Washington, Seattle.
- Denzin, N.K. (1970). *The research act*. Chicago: Aldine Publishing.
- Dolnick, E. (1993). Deafness as culture. *Atlantic Monthly*, September, 37-53.
- Donmeyer, R. (1990). Generalizability and the single-case study. In E. Eisner and A. Peshkin (Eds.). *Qualitative Inquiry in education: The continuing debate*. (pp.175-200). New York: New York University Press.
- Duffy, Y. (1981). *...All things are possible*. Ann Arbor: A.J. Garvin & Associates.
- Erikson, E.H. (1964). *Insight and responsibility*. New York: W.W. Norton & Co.
- Erikson, E.H. (1950). *Childhood and society*. New York: W.W. Norton & Co.
- Erikson, E.H. (1968). *Youth: Identity and crisis*. New York: W.W. Norton & Co.
- Feng, G.F. & English, J. (1973). *Tao te ching*. New York: Vintage Books.
- Finger, A. (1990). *Past due: A story of disability, pregnancy, and birth*. Seattle, WA: Seal Press.
- Fine, M. & Asch, A. (1988). Disability beyond sigma: Social interaction, discrimination and activism. *Journal of Social Issues*, 44(1), 3-22.

- Finley, H.C. (1998). Women with multiple identities: A qualitative search for patterns of identity development among complex differences. Dissertation Abstracts International, 58(7-B), 3921.
- Fowler, C., O'Rourke, B., Wadsworth, J., and Harper, D. (1992). Disability and feminism: Models for counselor exploration of personal values and beliefs. *Journal of applied rehabilitation counseling*, 23(4), 14-19.
- Frank, G. (1988). On embodiment: A case study of congenital limb deficiency in American culture. In M. Fine and A. Asch (Eds.) *Women with Disabilities: Essays in psychology, culture, and politics* (pp. 41-71). Philadelphia, PA: Temple University Press.
- Franz, C.E. & White, K.M. (1985). Individuation and attachment in personality development: Extending Erikson's Theory. *Journal of Personality*, 53(2), 224-256.
- Freidson, E. (1965). Disability as social deviance. In M. B. Sussman (Ed.), *Sociology & Rehabilitation*. American Sociological Association.
- French, S. (1992). Researching disability: The way forward. *Disability and Rehabilitation*, 14(4), 183-186.
- French, S. (1993). "Can you see the rainbow?": The roots of denial. Pp. 69-77. In J. Swain, V. Finklestein, S. French, and M. Oliver (Eds.), *Disabling Barriers – Enabling Environments*.
- Friere, P. (1970). *Pedagogy of the oppressed*. New York: Continuum.
- Fries, K. (1997). *Body, Remember: A Memoir*. New York: Dutton Books.
- Gallagher, H.G. (1995). *By trust betrayed: Patients, physicians, and the license to kill in the third reich*. Arlington, VA: Vandamere Press.
- Gallagher, H.G. (1998). *Blackbird Fly Away: Disabled in an able-bodied world*. Arlington, VA: Vandermere Press.

- Gerschick, T.J. & Miller, A. S. (1994). Gender identities at the crossroads of masculinity and physical disability. *Masculinities*, 2(1), 34-55.
- Gill, C. J. (1985). The family/professional alliance in rehabilitation viewed from a minority perspective. *American Behavior Scientist*, 28, 424-428.
- Gill, C.J. (1987). A new social perspective on disability and its implications for rehabilitation. *Occupational Therapy in Health Care*, 7(1), 49-55.
- Gill, C.J. (1994). A bicultural framework for understanding disability and family. *Family Psychologist*, 10, (4). 13-16.
- Gill, C.J. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation*, 9, 39-46.
- Gill, C. J. (1998). Re-Defining wholeness: Formulating a minority group model of disability identity development. *Field Initiated Research Proposal*. Chicago: University of Illinois at Chicago.
- Gill, C.J. (2001). Divided understandings: The social experience of disability. In G.L. Albrecht, K.D. Seelman, M. Bury (Eds.) *Handbook of Disability Studies*. (pp. 351-372). Thousand Oaks, CA: Sage Publications.
- Gilligan, C. (1982). *In a different voice: Psychological theory and women's psychological development*. Boston: Harvard University Press.
- Gilson, S., Tusler, A., & Gill, C. J. (1997). Ethnographic research in disability identity development: Self-determination and community. *Journal of Vocational Rehabilitation*, 2. 7-17.
- Glaser, B. and Strauss, A (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Glesne, C. & Peshkin, A. (1992). *Becoming qualitative researchers: An introduction*. White Plains, NY: Longman.

- Goffman, E. (1963). *Stigma, notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall, Inc.
- Goodstein, L. (2003). As if we didn't know. *New York Times*. October, 8, 2003.
- Grotevant, H. D. (1992). Assigned and chosen identity components: A process perspective on their integration. In G.R. Adams, T.P. Gullotta and R. Montemayor (Eds.), *Adolescent Identity Formation* (pp.). Newbury Park, CA: Sage Publications.
- Guba, E. G. (1978). *Toward a methodology of naturalistic inquiry in educational research*. CSE monograph series in evaluation no. 8. Los Angeles: University of California, Los Angeles, Center for the Study of Evaluation.
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic research. *ECTI*, 29(2), 75-91.
- Guba, E. G. and Lincoln, Y. S. (1989). Judging the quality of fourth generation evaluation. In *Fourth Generation Evaluation* (pp.228-279). Newbury Park, CA: Sage Publications.
- Guba, E. G. and Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In Y. S. Lincoln and K. Denzin (Eds.) *Qualitative Research Handbook* (pp. 105-117). Newbury Park, CA. Sage Publications.
- Hahn, H. (1982). Disability and rehabilitation policy: Is paternalistic neglect benign? *Public Administration Review*, *42*(4), 385-389.
- Hahn, H. (1985). Towards a politics of disability: Definition, disciplines, and policies. *The Social Science Journal*, *22*(4), 87-105.
- Hahn, H. (1988). Can disability be beautiful? *Social Policy*, Winter, 26-32.
- Haggins, K.L. (1995). An investigation of optimal theory applied to identity development. (Doctoral dissertation, 1995). *Dissertation Abstracts International*, *55*(12-B), 5553.
- Herman, N.J. and Miall, C.E. (1990). The positive consequences of stigma: Two case studies in mental and physical disability. *Qualitative Sociology*, *13*(3), 251-269.

- Hillyer, B. (1992). *Feminism and Disability*. Norman, OK: University of Oklahoma Press.
- hooks, b. (1993). *Sisters of the Yam: Black women and self recovery*. Cambridge, MA: South End Press.
- hooks, b. (1989). *Talking back: Thinking feminist, thinking black*. Boston: South End Press.
- Hubbard, R. (1997). Abortion and disability: Who should and who should not inhabit the world. In L. J. Davis (Ed.) *Disability Studies Reader*. (pp. 187-202). New York: Routledge.
- Hughes, B. & Paterson, K. (1997). The social model of disability and the disappearing body: towards a sociology of impairment. *Disability & Society*, 12(3), 325-340.
- Jackson, B. (1975). Black identity development. *Journal of Educational Diversity*, 2, 19-25.
- Johnson, M. (2000). Sandusky and Dillery: What do they mean to the disability movement? *New Mobility*, 11(76), 26-33.
- Josselson, R. (1987). *Finding herself: Pathways to identity development in women*. San Francisco: Jossey-Bass Publishers.
- Kerwin, C., Ponterotto, C.J., Jackson, B.L. and Harris, A. (1993). A racial identity in biracial children: A qualitative investigation. *Journal of Counseling and Development*, 40, (2). 221-231.
- Kirschbaum, H. (1991). Disability and humiliation. *Journal of Primary Prevention*, 12, 169-181.
- Kirschbaum, M. (1988). Parenting with disabilities and their babies. Zero to three. Washington, D.C.: National Center for Clinical Infant Programs.
- Kitzinger, C. (1990). *The social construction of lesbianism*. Newbury Park, CA: Sage Publications.
- Klein, B. S. (1997). *Slow Dance: A Story of Stroke, Love, and Disability*. Toronto: Page Mill Press.
- Kubler-Ross, E. (1968). *On death and dying*. New York: The Macmillan Company.

- Ladd, P. (1994). Deaf culture: Finding it and nurturing it. In C. J. Erting, R. C. Johnson, D. L. Smith, and B. D. Snider (Eds.), *The Deaf Way: Perspective fro the International Conference on Deaf Culture*. (pp.5-15). Washington, DC: Galludet University Press.
- Lee, J.D. (1977). Going public: A study of homosexual liberation. *Journal of Homosexuality*, 3, 49-78.
- Lerner, H.G. (1985). *The dance of anger: A woman's guide to changing the patterns of intimate relationships*. New York: Harper & Row, Publishers Inc.
- Lemer, M. J.(1980).*The belief in a just world: A fundamental delusion*. New York: Plenum.
- Lincoln, Y. S. & Guba, E. G. (1989). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: New York University Press.
- Livneh, H. (1986). A unified approach to existing models of adaptation to disability. *Journal of Applied Rehabilitation Counseling*, 2.
- Longmore, P.K. (1987). Uncovering the hidden history of people with disabilities. *Reviews in American History*, September, 355-364.
- Longmore, P.K. (1985). A note on language and the social identity of disabled people. *American behaviorial scientist* 28(3), 419-423.
- Longmore, P.K (1993). What is disability? Revolutions in ideology and consciousness. Speech made at "Disabled and Proud: 1993 National Gathering of College Student Leaders with Disabilities" University of Minnesota – Minneapolis.
- Longmore, P.K. (1995). The second phase: From disability rights to disability culture. *The Disability Rag and ReSource*, 16, 4-11.
- Mairs, N. (1996). *Waist-high in the world: A life among the non-disabled*. Boston: Beacon Press.

- Marcia, J.E. (1987). The identity status approach to ego identity development. In T. Holness & K. Yardley (Eds.), *Self-Identity: Perspectives across the lifespan* (pp. 161-171). London: Routledge & Kegan Paul.
- Mayer, E.L. (1988). Erik H. Erikson on bodies, gender and development. In R.S. Wallerstein and L. Goldberger (Eds.) *Ideas and identities: The life and work of Eric Erikson*. Madison, CT: International Universities Press. 79-98.
- Maxwell, J.A. (1996). *Qualitative research design: An interactive approach*. Thousand Oaks, CA: Sage Publications.
- McIntosh, P. (1989). Unpacking the invisible knapsack of white privilege. *Race and Freedom*, July/August, 10-12.
- McIntosh, P. (1990). *Interactive phases of curricular and personal re-vision with regard to race*. Wellesley, MA: Wellesley Center for Women.
- Merchant, B.M. (2001). Negotiating the boundaries and sometimes missing the mark: A white researcher and a Mexican American research assistant. *Multiple and intersecting identities in qualitative research*. Mahwah, NJ: Lawrence Erlbaum Associates. 1-18.
- Minsky, R. (1996). *Psychoanalysis and gender: An introductory reader*. London: Routledge.
- Minton H. L. & McDonald, G.J. (1997). Homosexual identity formation as a developmental process. In J. P. De Cecco (Ed.), *Bisexual and Homosexual Identities : Critical Clinical Issues*. (pp. 91-104). New York : Harrington Park Press.
- Mphandre, L. & Myers, L.J. (1993). Traditional African medicine and the optimal theory: Universal insights for health and healing. *Journal of black psychology*, 19(1),25-47.
- Montgomery, D.E., Fine, M.A., Myers, L.J. (1990). The development and validation of an instrument to assess an optimal Afrocentric world View. *The journal of black psychology*, 17(1), 37-54.

- Murphy, R. F. (1990). *The body silent*. New York: W.W. Norton.
- Murphy, R.F., Scheer, J., Murphy, Y., and Mack, R. (1988). Physical disability and social liminality: A study in the ritual of adversity. *Social Science & Medicine*, 26, 235-242.
- Myers, L.J. (1988). *Understanding an Afrocentric worldview: Introduction to an optimal psychology*. Dubuque, IA: Kendall/Hunt Publishing Company.
- Myers, L.J. (1991). Exploring the psychology of knowledge optimally: The importance of worldview revisited. In R. L. Jones (Ed.), *Black psychology*. Berkeley, CA: Cobb and Henry Publishers.
- Myers, L.J. (1998). Optimal theory and human diversity psychology. *Human diversity: Perspectives on people in context*. San Francisco: Jossey-Bass Publisher.
- Myers, L.J., Speight, S.L., Highlen, P.S., Cox, C.I., Reynolds, A.L., Adams, E.M., & Hanley, C.P. (1991). Identity development and worldview: Toward an optimal conceptualization. *Journal of counseling & development*, 70, 157-166.
- Minton, H.L. & McDonald, G.J. (1984). Homosexual identity formation as a developmental process. *Journal of Homosexuality*, 9(2/3), 91-104.
- Morris, J. (1992). Personal and political: A feminist perspective on researching physical disability. *Disability, Handicap & Society*, 7(2), 157-166.
- Nafziger, K.L. (1992). Pre- and post-disability congruence, life satisfaction, and career development of collegiate wheelchair athletes and non-athletes. Unpublished master's thesis, University of Illinois, Urbana-Champaign.
- Neal, A. M. & Wilson, M. (1989). The role of skin color and features in the black community: Implications for black women in therapy. *Clinical Psychology Review*, 9, 323-333.
- Neimeyer, G. & Resnikoff, A. (1982). Qualitative strategies in counseling research. *Counseling Psychologist*, 10(4), 75-85.
- Nobles, W. W. (1989). Psychological nigrescence: An afrocentric review. *The Counseling Psychologist*, 17(2), 253-257.

- Oberman, C.F. (1965). *A history of vocational rehabilitation in America*. Minneapolis, MN: Denison.
- Oliver, M. (1990). *The politics of disablement*. London: Macmillan.
- Oliver, M. (1993). Re-defining disability: A challenge to research. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.) *Disabling Barriers – Enabling Environments* (pp. 61-67). London: Sage Publications in association with The Open University.
- Onken, S.J. & Slaten, E. (2000). Disability identity formation and affirmation: The experience of persons with severe mental illness. *Sociological Practice: A Journal of Clinical and Applied Sociology*, 2(2). (99-111).
- Ossana, S.M., Helms, J.E., and Leonard, Mary M. (1992). Do womanist identity attitudes influence college women's self-esteem and perceptions of environmental bias? *Journal of counseling & development*. 70, January/February, 402-408.
- Parham, T.A. (1989). Cycles of psychological nigrescence. *The Counseling Psychologist*, 17(2), 187-226.
- Parham, T.A. & Helms, J.E. (1985). Attitudes of racial identity and self-esteem of Black students: An exploratory investigation. *Journal of College Student Personnel*, 26, 143-147.
- Parson, T.A. (1948). *The social system*. New York: Free Press of Glencoe.
- Patton, M.Q. (1990). *Qualitative valuation and research methods*. Newbury Park, CA: Sage Publications.
- Phillips, M.J. (1985). "Try harder": The experience of disability and the dilemma of normalization. *Social Science Journal*, 22(4), 35-57.
- Phillips, M.J. (1990). Damaged goods: Oral narratives of the experience of disability in American culture. *Social Science and Medicine*, 30(8), 849-857.

- Phillips, M.J. (1993). Straight talk from "crooked" women. In S.T. Hollis, L. Pershing & M.J. Young (Eds.), *Feminist Theory and the Study of Folklore* (pp. 396-410). Chicago: University of Illinois Press.
- Phinney, J.S. and Rosenthal, D.A. (1992). Ethnic identity in adolescence: Process, context, and outcome. In G.R. Adams, T.P. Gullotta and R. Montemayor (Eds.), *Adolescent Identity Formation* (pp. 145-172). Newbury Park, CA: Sage Publications.
- Priestly, M., Corker, M., & Watson, N. (1999). Unfinished business: Disabled children and disability identity. *Disability Studies Quarterly*, 19(2), 90-97.
- Rappaport, J. (1977). *Community Psychology: Values, Research, and Action*. New York: Holt, Rinehart and Wilson.
- Robertson, B. (1994). Disability culture, community, and pride. Unpublished paper. University of Minnesota – Minneapolis.
- Robinson, T. L. (1993). The intersections of gender, class, race, and culture: On seeing our clients whole. *Journal of Multicultural Counseling and Development*, 21(January), 50-58.
- Robinson, T. L. (2000). *The Convergence of race, ethnicity, and gender: Multiple identities and Gender*. Up Saddle River, NJ: Merrill Prentice Hall.
- Robinson, T. L. & Ward, J.V. (1991). "A belief in the self far greater than anyone's disbelief": Cultivating resistance among African-American female adolescents. *Women & Therapy*, 11, 87-103.
- Roman, L. & Apple, M. (1990). Is naturalism a move away from positivism?" Materialist and feminist approaches to subjectivity in ethnographic research. In E. Eisner and A. Peshkin (Eds.), *Qualitative Inquiry in Education: Continuing the Debate*. New York: Teachers College Press. 38-73.
- Rothman, D.J. (1990). *The Discovery of the asylum: Social order and disorder in the new republic*. Boston: Little, Brown and Company.

- Rouso, H. (1984). Fostering healthy self-esteem. *The Exceptional Parent*, December, 9-14.
- Rouso, H. (1988). Daughters with disabilities: Defective women or minority women? In A. Asch and M. Fine (Eds.) *Women with disabilities: Essays in psychology, culture, politics* (pp.139-171). Philadelphia: Temple University Press.
- Safilios-Rothschild, C. (1976). Disabled persons' self definition and their implications for rehabilitation. In G. L. Albrecht (Ed.), *The sociology of physical disability and rehabilitation* (pp.39-56). Pittsburgh, PA: University of Pittsburgh Press.
- Seligman, S. & Shanok, R.S. (1998). Erikson, our contemporary: His anticipation of an intersubjective perspective. In R.S. Wallerstein and L. Goldberger (Eds.) *Ideas and identities: The life and work of Eric Erikson*. Madison, CT: International Universities Press. 325-351.
- Sevig, T.D. (1994). Development and validation of the Self-Identity Inventory (SII): A pan-cultural instrument. *Dissertation Abstracts International*, 54(8-A), 2999.
- Shapiro, J. P. (1993). *No Pity: People With Disabilities forging a new civil rights movement*. New York: Random House, Inc.
- Speight, S.L., Myers, L.J., Cox, C.L., & Highlen, P.S. (1991). A redefinition of multicultural counseling. *Journal of counseling & development*, 70, 29-36.
- Sprinthall, N.A., Sprinthall, R. C., Oja, S. N. (1994). *Educational psychology: A developmental approach*.
- Stevens, R. (1983). *Erik Erikson*. New York: St. Martin's Press.
- Thompson, S. (1995). *Going all the way: Teenage girls' tales of sex, romance, and pregnancy*. New York: Hill & Wang.
- Thomson, R. G. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. New York: Columbia University Press.

- Tooms, S.K. (1994). Disability and the self. In T.M. Brinthaupt and R. P. Lipka (Eds.) *Changing the Self: Philosophies, Techniques, and Experiences*. (pp. 337-357
Albany: State University of New York Press.
- Treanor, R.B. (1996). *We Overcame: The Story of Civil Rights for Disabled People*. Falls
Church, VA: Regal Direct Publishing.
- Vash, C.L. (1994). *Personality and adversity: Psychospiritual aspects of rehabilitation*.
New York: Springer Publishing Company.
- Walters, K.L. & Simoni, J.M. (1993). Lesbian and gay male group identity attitudes and
self-esteem: Implications for counseling. *Journal of counseling psychology*, 40(1),
94-99.
- Weeber, J.E. (1996). Career development for disabled people: The need for an ecological
approach. Unpublished paper. North Carolina State University.
- Weeber, J.E. (1999). Belonging and understanding: Disability identity grounded in the
disability community. *Disability Studies Quarterly*, 19(2), 107-112.
- Weinberg, T.S. (1985). Biology, ideology, and the reification of developmental stages in the
study of homosexual identities. *Journal of Homosexuality*, 10(3/4), 77-84.
- Wendell, S. (1992). Toward a feminist theory of disability. In H.B. Holmes and L.M. Purdy
(Eds.) *Feminist Perspectives in Medical Ethics* (pp. 63-81). Bloomington: Indiana
University Press.
- Winzer, M.A. (1997). Disability and society before the eighteenth century. In L.J. Davis
(Eds.) *Disability Studies Reader*. New York: Routledge.
- Wolfensberger, W. (1969). The origin and nature of our institutional models. In R.B. Kogel
and W. Wolfensberger (Eds.) *Changing Patterns in Residential Services for the
Human Services*. Washington, DC: President's Committee on Mental Retardation.
- Wright, B. A. (1983). *Physical disability-A psychosocial approach*. New York: Harper &
Row, Publishers.

- Yoshido, K. K. (1993). Reshaping of self: A pendular reconstruction of self and identity among adults with traumatic spinal injury. *Sociology of Health & Illness*, 15(2), 217-245.
- Zola, I.K. (1981). Communication barriers between 'The Abled-Bodied' and 'The Handicapped'. *Archives of Physical Medicine and Rehabilitation*, 62(August), 355-359.
- Zola, I.K. (1982). *Missing Pieces: A Chronicle of Living with a Disability*. Philadelphia: Temple University Press.
- Zola, I.K. (1991). Bringing our bodies and ourselves back in: Reflections on a past, present , and future "Medical Sociology." *Journal of Health and Social Behavior*, 32(March), 1-16.
- Zola, I.K. (1993a). Self, identity, and the naming question: Reflections on the language of disability. *Social Science and Medicine*, 36(2), 167-173.
- Zola, I.K. (1993b). Disability statistics, what we count and what it tells us: A personal and political analysis. *Journal of Disability Policy Studies*, 4(2), 10-39

APPENDICES

Appendix A

On-line Leaders Focus Group Announcement

I am holding an online “focus group” to identify leaders of the disability community today. The purpose for gathering this information is to include some of those leaders in a larger study of disability identity development. It is assumed that such leaders will be found in many different endeavors, i.e. the arts, education, politics, community organizing, government policy, law, etc. I would be most grateful for your sending the names of people you consider to be leaders of the disability community to: jweeber@ncsu.edu

Appendix B

Demographic Description

1. Age:
2. Sex:
3. Race/ethnicity:
4. Other minority group membership:
5. Type of disability:
6. Age at which disability was acquired:

Appendix C

North Carolina State University INFORMED CONSENT FORM

Title of Study: Redefining Wholeness: Formulating a Minority Model of Disability Identity Development

Principal Investigator: Joy E. Weeber Faculty Sponsor: Dr. Herbert Exum

You are invited to participate in a research study. The purpose of this study is to find how people with disabilities from various backgrounds and social groups develop a sense of identity.

INFORMATION

If you agree to be in this research, you will be asked to do the following things:

1. Participate in an interview about your experiences that asks for information about you and some of feelings and beliefs about yourself.
2. Your participation may take about 2 hours and your spoken answers will be audio-taped.

RISKS

This research is not expected to present any risks beyond the discomfort or inconveniences of any psychological test and possible psychological discomfort of discussing personal issues related to disability identity. If you are uncomfortable with any aspect of the research procedure, just let the researcher know and you may bypass it or withdraw from the entire project at any time.

BENEFITS

By participating in this study, you may help the investigator discover information about disability identity development that may be helpful to people with disabilities, their families, and professionals. Otherwise, there is no direct benefit to you from participation.

CONFIDENTIALITY

The information in the study records will be kept strictly confidential. Data will be stored securely and will be made available only to persons conducting the study unless you specifically give permission in writing to do otherwise. No reference will be made in oral or written reports which could link you to the study.

COMPENSATION

For participating in this study you will receive \$40. If you withdraw from the study prior to its completion, you will not be penalized, but you will not receive any payment either.

CONTACT

If you have questions at any time about the study or the procedures, you may contact the researcher, Joy. E. Weeber, at 530 N. East St., or 919-832-7162. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact the Dr. Matt Zingraff, Chair, NCSU IRB for the Use of Human Subjects in Research Committee, Sponsored Program and Regulatory Compliance Services, Box 7514, NCSU Campus, Raleigh, NC 27695.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed.

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Subject's signature _____ Date _____

Investigator's signature _____ Date _____

Appendix D

Interview Transcript Review Email Cover

Hi [name],

Thank you again for participating in this study on disability identity development. I have transcribed our interview and “cleaned” it of any identifying information and am returning it to you, in Word format, for your review. Because I am concerned that I am analyzing the most accurate and anonymous transcription of our recorded conversation, I would like to ask you to read the transcript for any inaccuracies or identifying information I may have missed.

Thanks again for your time and interest in this project,

Joy Weeber

Appendix E

Member Checking Cover Email

Hi [name].

I'm writing again with a request that I hope is not as daunting as reading a lengthy interview – although reading this profile may drive you to check the transcript! I can tell you that its hugely daunting to me to ask your approval of my attempt at your-story-telling, because I feel a great responsibility to you to maintain your anonymity and tell your story as I heard it without editorializing on the facts...and still be able look you in the eye when next we meet. In the world of qualitative research, one way to ensure the strength (alternative form of reliability) of one's findings is to do "member checking" and ask for feedback on conclusions drawn or profiles written. Hence, this email asking you to read the profile I have written of you.

I have tried to construct your profile with the sole purpose of describing your identity development process – events, family/others' perspectives, environmental influences, changes in self-concept, things/people who influenced changes, changes in views of disability, etc. My hope is that the results reflect not only the words you spoke in our interview, but also the spirit in which you conveyed it. I have tried to use the very words you spoke, placing them in "quotes." Many are short quotes that have been "spliced" together from various parts of the interview to describe your view of a particular event, perspective, pattern, influence, etc. There are some long quotes that are so rich and complete that I simply could not condense or splice them and remain true to your voice. So if, in my splicing, I have misrepresented anything at all, I would welcome feedback and correction on it!!!

I have tried to limit the facts that I used to things that were salient to you in your identity development process or because you mentioned it in response to a given question. I have deliberately not included elements of your story that I think would make it easy to guess your identity, such as agencies, etc where you have worked and I have tried to mask personal particulars of your story that seemed irrelevant, such as where you grew up/lived, colleges, degrees, etc. that could be used as identifying markers. BUT, you may not see it that way and so I hope you will tell me if I have crossed the line and revealed too much.

If you want to make any changes, hit reply and [bracket] any additions or deletions.

I am deeply indebted to you for giving me so much of your time for the interview and hope this "member checking" request is not one thing too many!

All my gratitude,
Joy E. Weeber

PROFILE

Appendix F

Individual Interview Questions

1. How would describe yourself to someone who doesn't know you, in a sentence or two?
If no, would you mention your disability in this description?
2. How would you describe what its like to be disabled?
How important or unimportant is disability in making you the person you are?
3. How do you feel about talking about your disability to others?
4. Are there times or situations when you are more aware of your disability than others?
5. Think about when you were growing up (first became disabled). How have your views of having your disability changed over time?
6. What has helped you feel good about being a person with a disability?
What has made it difficult?
7. On the whole, how do you feel about being a person with a disability?

We've talked about your views of your disability, now I'd like to ask you about how others view your disability.

8. How about your family? Your friends? What about professionals?
How, if at all, do their views differ from yours?
9. How did their view of your disability influence their expectations of you?
How have you been affected by their views of disability?
10. How do you feel about hanging out with other people with disabilities?
11. How much do you feel you have in common with other people with disabilities?
12. In the beginning of our interview, you described yourself as having various identities, like x, x.
How do those other identities relate to your identity as a person with a disability?
13. We've been talking about how people with disabilities develop a positive sense of self. Is there anything that I have not asked you about that you feel has been important to you in developing your sense of self as a person with a disability?

Appendix G *Atlas ti Codes*

1. Others' attitudes, beliefs, assumptions

- 1a work to be "normal"
- 1b focus on practical/medical
- 1c denial - like everyone else
- 1d no/low expectations
- 1e hero/inspiration
- 1f disability as negative
- 1g sick/never get well
- 1h resistance of medicalizing life
- 1i viewed as unattractive/asexual

2. Negative environmental influences

- 2a negative school administrators
- 2b inaccessible environments
- 2c under-estimation of abilities
- 2d treated as different
- 2e limit use of assistive devices
- 2f discrimination/devalued social status
- 2g domination of medical model
- 2h aloneness
- 2i choice-limiting "helping" systems
- 2j deny/unaware of emotional/psych
- 2k silence about disability w/ others
- 2l no disabled role models
- 2m delayed development

3. Positive environmental influences

- 3c identifying w/ disability community
- 3d disability as civil rights
- 3e disabled professional peers
- 3f experiences w/ disabled children
- 3g fully integrated in neighborhood
- 3h family's/others' high expectations
- 3i others acceptance of difference
- 3j shared values, culture & history
- 3k "change agent" parents/self
- 3l accessible environments
- 3m personal accomplishments

4. Early self-perceptions

- 4a denial/hide limitations
- 4b disability source of pain
- 4c avoidance of disabled people
- 4d "exceptional" one
- 4e adopt non-disabled identity/passing
- 4f "victim of X"

- 4g blow to sense of self/self worth
- 4h sexuality denied/delayed
- 4i no self consciousness of difference
- 4j 4j a non-negative difference

5. DP's attitudes, beliefs, assumptions

- 5a disability hierarchy
- 5b commonality in oppression & discrimination
- 5c anger at injustice/devaluation
- 5d life is all struggle
- 5e disability "Master Status"
- 5f identify w/ limited # of disabilities
- 5g my personal problem
- 5h isolated aspect of self
- 5i disability integral part of self
- 5j identify w/ all disabled people
- 5k disability litmus test

6. Spirituality

7. Current perceptions of disability

- 7a natural part of self/life
- 7b comfortable in my own skin
- 7c little concern w/ other's perceptions
- 7d openness about disability realities
- 7e commonality w/ diverse communities
- 7f part of whole self

Aging

- 8a reworking old lessons
- 8b new limitations
- 8c revisit unresolved issues

Strategic responses

- 9a years of psychotherapy
- 9c accept slowness of social change
- 9d positively juggle multiple worlds
- 9e accept educating on-going reality
- 9f intergenerational responsibility
- 9g imagine & fight for life you want
- 9h insistence on self-definition
- 9i willingness to take risks
- 9j belief in own abilities
- 9k disability identity/career integration
- 9l focus on strengths
- 9m be better prepared than others

10. Positive aspects of disability

- 10a forges creativity, flexibility, wisdom, strength
- 10b focuses career & purpose
- 10c clarifies values & friendships
- 10d greater compassion/sensitivity for others

11 Sexuality**12 Innate characteristics**

- 12a indomitable will
- 12b stubborn
- 12c aggressive
- 12d risk-taker
- 12e never saw self as "victim"
- 12f drive
- 12g fighter
- 12h intelligent

13 Multiple identities

- 13a couldn't be gay and disabled
- 13b racism in disability community
- 13c ableism in AA community
- 13d better woman, as disabled woman

14 Transition points

- 14a internship
- 14b blatant discrimination
- 14c physical/emotional collapse
- 14d one too many surgeries