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# Living as subject : the stories of five women with disabilities

Lois M. Symington

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To the Graduate Council:

I am submitting herewith a dissertation written by Lois M. Symington entitled "Living as subject : the stories of five women with disabilities." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Education.

Laurence J. Coleman, Major Professor

We have read this dissertation and recommend its acceptance:

Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

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We have read this dissertation
and recommend its acceptance:

Susan M Benner

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Olga Welch

Accepted for the Council:

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Associate Vice Chancellor and
Dean of The Graduate School

# Living as Subject:
## The Stories of Five Women With Disabilities

A Dissertation
Presented for the
Doctor of Philosophy Degree
The University of Tennessee, Knoxville

Lois M. Symington
December 1999

# DEDICATION

This study is dedicated to the five women with disabilities who so willingly gave of their time and energies to participate and who have given me the gift of their friendship.

It is also dedicated to other women with disabilities whom I have met personally; with whom I work; and those who have shared their lives through their books, stories, and poetry.

Their lives have had a significant impact on me and have shown me new ways of living, thinking, and relating.

This study is also dedicated to Larry Coleman, chair of my dissertation committee. I am deeply grateful for his kindness, sensitivity, and patience and for listening.

Finally, my love and appreciation go to my family and co-workers who have so patiently put up with me for the past six years. Now we can clean off the kitchen table.

Tomorrow I am going to rewrite the English Language.
I will discard all those striving ambulist metaphors of power and success
And construct new ways to describe my strength.
My new, different strength.

Yes, tomorrow I am going to rewrite the English language
Creating the world in my own image
Mine will be a gentler, more womanly way
To describe my progress.
I will wheel, cover and encircle.
Somehow I will learn to say it all.
—Lois Keith, 1996, p. 57—

# ABSTRACT

The purpose of this study is to increase our understanding of the processes by which a select group of women with disabilities have reached a position of subjectivity. Subjectivity is defined as a process of *becoming*—a process in which women placed on the margin of society define themselves and use power and agency to effect personal change as well as change in others. Women with disabilities are oppressed, perceived and portrayed as roleless, and considered objects of pity and sympathy.

The five women participating in this study have developed critical consciousness about their status in our society, and in so doing have been able to move beyond internalization of society's beliefs and perceptions about them. In order to contradict these perceptions as well as prevalent research methodology, considered "alienated research" by many women with disabilities, this study was constructed with the researcher as co-participant. The use of first-person narrative provides a position from which I can hear their voices and enter their struggles rather than take the position of the "Other."

Three theories inform this study: the sociopolitical—or minority group model—of disability, critical theory, and feminist theory. A fourth theory, chaos theory, helped me understand the contradictions in the participants' lives. These theories have roots in critical theory and have caused me to examine the social, economic, and political barriers that force people with disabilities into marginal roles.

The five women with disabilities participating in this study were purposefully selected on the basis of existing mutuality and a perception of subjectivity. Mutuality was developed over years of personal and professional experiences. Qualitative research methods, including participant observation, in-depth interviews, and analysis of artifacts, were used to increase my understanding of the processes by which these women have reached a position of subjectivity. For the purposes of this study, I spent an additional three years with them in their homes and in other activities in order to develop a deeper understanding of how living on the margin is a source of strength as well as a place of resistance.

Each woman experienced shame and stigma in her youth because of perceived differences and developed strategies for coping, surviving, and negotiating boundaries. She also had an experience, described as a "catalyst," that caused her to become more aware of the power she has on the margin to resist. In the process of becoming subject, each has experienced *communitas,* or being part of a nonjudgmental sharing community. Each woman has also learned to use anger and power in new ways as she names the sources of her oppression and rejects words and actions that do not affirm her identity and pride.

This study provides new insight into notions of subjectivity, particularly for women with disabilities. It demonstrates that living with a disability from a position of subjectivity is not about "overcoming." Nor is it about using anger destructively, to exert power over others, or to live independently. Rather, it is learning about the power of interdependence, of living with an obligation to others, of learning to trust others and become vulnerable to their influence, and of learning how to be "constantly and forever adaptive." These women have learned skills for living that can be used by all of us as we learn to live in a world of increasing diversity and decreasing resources.

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# CHAPTER 1—INTRODUCTION

*We cannot enter the struggle as objects in order to later become subjects.*
*—Paulo Freire, 1970—*

For the last 24 years I have been personally involved with disability through the experiences of my son, my husband, and to some degree, myself. On a professional level, I have worked with people of all ages with disabilities in many different settings, from their homes to places where they learn and work. In particular, I have had very close personal and professional association with women with disabilities, both as friends and coworkers.

On another level, as a woman in America, I have had to deal with conforming to the images and roles of women that are shaped and fashioned by media and culture. My life experiences have led me to form certain impressions about the lives of other women, in particular, women with disabilities. Many of these women, because of their disability, may be roleless, being denied traditional women's roles of wife, mother, and sexual being. Some seem to be more affected than others by their disabilities. Some are defiant and angry, and others have an attitude of entitlement or resignation. A few seem to have incorporated disability into the fabric of their lives. I wondered why some women have gained social and personal integrity or have resolved the internal and external conflict between what our society expects of them as women with disabilities and the reality of their experiences. At the outset of this study, I called this a position of subjectivity, based on readings of Paulo Freire. In this position, these women challenge existing perceptions about them.

## *Purpose of the Study*

The purpose of this study is to increase our understanding of the processes by which a select group of women with disabilities have reached a position of subjectivity. Subjectivity is defined as a process of *becoming,* in which women who have been placed on the margin of society define themselves and use power and agency to effect personal change as well as change in others. Through the telling of their life stories and experiences, they describe how they have become subjects rather than objects of pity.

## *Justification for the Study*

Little research has been done *with* women with disabilities. The few studies that have been done to date focus primarily on issues of rehabilitation, health or psychological well-being (Cottone & Cottone, 1992; Gatens-Robinson & Tarvydas, 1992; Wang, 1993) or on statistical differences in the status of men and women with disabilities (Danek, 1992). Other studies, while providing enlightenment about the social construction of disability do not include in-depth personal, lived experiences of women with disabilities (Fine & Asch, 1988; Oliver, 1989; Pobl & Brown, 1992; Hillyer, 1993; Ingstad & Whyte, 1995). Most of these studies recognize the minority group status of women with disabilities, focusing on what women with disabilities *need,* such as "empowerment," or the development of "autonomy" or "self-esteem." Other studies about living with disability (Murphy,1990; Krefting & Groce, 1992; Hahn, 1993; Groce & Zola, 1993) do not specifically include women, so the reader is left with one of two impressions: that the authors assume that women's experiences with disability are the same as men's; or that women were not included in the study.

I wanted to know *how* some women with disabilities have become subject, how they have been able to incorporate disability into their life, into their sense of who they are, and use their knowledge and awareness to influence others. Theorists such as Marx, Freire, hooks, and Butler who discuss subjectivity start in the middle or at the end of the topic. They talk about being in a position of subjectivity, or acting as subjects rather than objects. What they have not talked about is how a person *becomes* subject.

Most disability research focuses on people with disabilities as objects, not subjects, and distances research from experience (Fine & Asch, 1988). This study is centered in the lived experiences of five women with disabilities placed within a personal, social, economic and political milieu in order to gain some understanding of the processes through which they have become subject. These women have been marginalized from society yet have learned to "survive and grow through crisis and change" (Pearpoint, 1992).

This study has the potential for wide-ranging benefits. It may provide new insight into living with a disability. It may also lead to a greater understanding of living on the margin and how marginal living shapes a person. In addition, as our population becomes older and more diverse, more and more people may be forced into devalued social roles. Since the margin is a site of potential growth and points to the direction in which society is going, we may all benefit from a deeper understanding of the dynamics and interactions required to maintain the margins.

Another benefit of this study is contributions to the fields of disability and feminist theories, showing the connection between the two. It may help break the assumption of a metanarrative about women, namely that women have an additive, universal experience, and that the same is true for women with disabilities. Some disabled authors are concerned that disability issues have not been included in feminist theory, methodology, research and politics (J. Morris, 1991). On the other hand, we may also demonstrate that the strategies for coping and surviving used by women with disabilities may benefit all women. As the participants discuss the need for mutuality, support, and interdependence, we may hear in their narratives lessons that can transform our society's emphasis on "rugged individualism" into new definitions of power and new ways of relating to each other.

This study attempts to place the subjective reality of the participants' lives and experiences at its core. Disability is a social problem because of attending prejudices and assumptions. Therefore, I as the researcher, must be very careful to not use words that foster existing stereotypes and perceptions about women "suffering" from a disability. Instead, I have been challenged to use words that affirm the disability experience as a source of strength for these five women. This is not a study about denying disability but rather of embracing it.

In order to recognize and honor the position of subjectivity of the five participating women, I have been very conscious of not objectifying them. Rather, I have entered into their lives and they into mine. I have chosen to write this study in the form of a first-person narrative because it provides a way of showing the meaning that emerges out of each participant's personal experiences as well as those shared with others. Each woman's experiences express a range of attitudes, values, beliefs, and behaviors which might be otherwise overlooked or silenced by an imposed voice. The use of first-person narrative provides a position from which a document such as this one can be held accountable to the realities of the participants (Warren, 1995). In addition, the "I" lets us hear each other's voice, strengthening the position of subjectivity held by each participant, of which I am one. I have chosen to engage in social struggle *with* these five women in order to avoid the position of the Other. In the position of the Other, "no need to hear your voice when I can talk about you better than you can speak about yourself," (Fine, in Denzin & Lincoln, 1994). As part of speaking from the position of the "I," I must reveal the relationship between the participants and me and how we have negotiated those relationships.

## *Theories Informing the Study*

Three theories inform this study: the sociopolitical model of disability, feminist theory, and critical theory. I also delved briefly into a fourth theory, chaos theory, used by one of the participants to help her understand how to cope with ongoing change. It will be discussed later in the context of her story and data analysis. Together these theories have helped shape my thoughts about development of self-hood, agency, and subjectivity in women with disabilities.

### *Sociopolitical Model of Disability*

The sociopolitical, or minority group model of disability began after World War II and flourished in the 1960s with the beginning of the independent living movement that began with Ed Roberts in Berkeley, California (Shapiro, 1993). People with disabilities who were leaders in disability studies like Longmore (1984), Hahn (1988), and Gill (1996), have helped develop and define this perspective on disability. They refute the notion that disability means biological inferiority (Hahn, 1988). Rather, disability is defined as a socially constructed identity and role triggered by a stigmatized biological trait. The low self-esteem experienced by many people with disabilities is not a personal response to disability but the internalization of social bias (Longmore, 1984). In order to change social practices and public policies, a minority group analysis must be applied to the historical experience of people with disabilities, including portrayal in literature, films, and the media, and the language used to describe the disability experience.

Those who espouse the sociopolitical model of disability actively focus on the language used to describe people with disabilities, because we know that the debate is really about power and who does the defining. Words like “confined to a wheelchair,” “suffers from Down Syndrome,” “the mentally retarded,” and “the blind,” describe people in terms of their disabilities and help foster beliefs in their helplessness and dependency. Social identity is swallowed up or subsumed by disability. Other medical labels such as “patients,” “cases,” or “victims,” are equally objectionable because they also imply that people with disabilities are primarily objects of medical treatment. Words like “special” and “exceptional” were created with good intentions by parents and advocates of people with disabilities in an attempt to get around the effects of prejudicial labeling; however, these words still have the unintended effect of reinforcing the essential differentness of people with disabilities. Underlying the attempts by people with disabilities and their advocates to change the language that describes the disability experience is a refusal to accept a stigmatized social identity, an assertion of pride in oneself as fully human whatever one's disability, and an effort to break out of a limiting and subordinate social role (Longmore, 1985). Insistence on a "people first" approach to describing people with disabilities has become part of the fabric of the sociopolitical model of disability with our focus on a person's abilities and potential rather than on the *dis*-ability.

The effect of embracing the sociopolitical model of disability for me and others can be seen in the activities and actions in which we involve ourselves. We feel that we have an obligation to change society's perceptions about people with disabilities. We feel that segregation and exclusion is wrong, whether for children in schools, for adults in institutions, or for a person who cannot get on an inaccessible bus. We work to change the systems that deny people with disabilities the right to self-determination and self-directed lives. Through the words we use as well as our actions, we attempt to address cultural devaluation. All of us, parents, advocates, and adults with disabilities, know that economic, political, and social conditions must change before people with disabilities have access to adequate or available education, transportation, jobs, and supports. In this model of disability, the value of a person's life is not measured by a doctor but rather by internal self-respect, pride, and having control over one's personhood that is gained by being given equal opportunities in society.

### *Feminist Theory*

My way of thinking has also been influenced by feminist theory, mostly in the past twelve years. Although I have had strong female role models in my family, including my grandmother, mother and aunts, their influence was primarily directed toward passing on lessons they learned about being dependent on men. Aspects of feminist theory learned in university classes were not internalized until the late 1980s. At that time, I acquired administrative responsibilities that included considerable travel across the United States. Additional duties included public speaking, fundraising, and financial responsibilities. These experiences changed my awareness of how women are treated in our society. Daily experiences included being ignored in a restaurant, denied lodging in a rural motel, and having to address an audience primarily of men (usually in suits, with crossed arms and dour faces). Assumptions continue to be made, because I have a title of "Executive Director," that I am a man. These experiences make me angry. In response, I sought a balance between the fire-brand, bra-burning feminists of the 1960s and the more moderate feminists of the 1990s. I developed my own definition of feminism, which includes recognizing and valuing feminist characteristics in me and others. Feminist authors that have been of particular influence to me include Bettina Aptheker, Jean Baker Miller, and Carol Gilligan. It was perhaps in Aptheker's work that I first came across the notions of subjectivity and a seeking for balance in a system that institutionalizes class, race, gender and disability. She says, "What we have not known is how to begin from our own centre, how to begin from our own experiences, how to make ourselves as women the subjects of the act of knowing," (p. 8). Her writing helped me understand that each of us has a different center, depending on class, geography, age, sex, race, physical ability, nature of work, and personal relationships. Women's emphasis on daily activities, our need for relationships, and the act of creating are characteristics to be valued. Much as in quilt-making, we have to take the pieces of our lives and arrange them into meaningful and useful patterns. Also in quilt-making, we arrange our patterns within the context of *communitas,* a community of support and obligation (Kirp, 1995).

Miller's and Jordan's work from the Stone Center in Wellesley, Massachusetts focused my attention on mutuality and power, and how the use of each of these attributes affects our relationships with other women. In a mutual exchange, a person is both affecting another and being affected by the other. Core to notions of mutuality is the willingness to have an impact on the other and being willing to have others influence us, which has not been easy for me to learn to do. When mutuality exists, your experiences and others' experiences are validated and accepted, leading to a process of growth for both (Jordan, 1986).

Many women acculturated in the United States reject the male notion of power derived from personal experiences as well as the media, that of domination and control. We fear using power in ways that hurt others or build ourselves up at the expense of others. Our notions of power are more about using it to foster the growth of others than about controlling and destroying relationships (Miller, 1982). In the past, many women have had to manipulate men by playing the role of a helpless, hapless female in order to get what they wanted. Some still do, or think they have to. Somewhere in between is a new definition of power that is acceptable to me and many other women, in which we are learning to negotiate and use power constructively and critically to address society's inequities. We have become increasingly aware of the need to be informed of laws, policies and practices that regulate our lives, and we have learned about the power of the vote and the press.

### *Critical Theory*

I came into this study with a critical theory perspective based on years of studies in economics. Through reading works such as *Blaming the Victim* (Ryan, 1976) and *Learning Capitalist Culture* (Foley, 1990), I became increasingly aware of the economic bases of the decisions made about people and the manipulation of people and their needs for economic, political and social reasons. In our society, as in most democratic capitalist nations, our economic system requires the presence and identification of surplus, or exploited, people. Laissez-faire capitalism does not foster socioeconomic equality. Power brokers in our society, mostly men, determine who and what is of value and define who is to be devalued.

Because critical theory, like feminist theory, is emancipatory, I also hold to the belief that we can change a society that defines good in terms of profit rather than human need. Feminist emancipatory writers like Audre Lorde and bell hooks have heightened my awareness of the potential of people who have been marginalized by society to change it and to demonstrate new models of relating. They and others have also called for new models of representation for marginalized people, in which those on the margins have a formative place in the constitution of social and political life where they can critically interrogate issues of subjectivity and power (Grossberg, 1994).

These three theoretical perspectives, the sociopolitical model of disability, feminist theory, and critical theory, are overlapping and complementary theories. Although those who have developed the sociopolitical, or minority group model, of disability do not explicitly admit their critical theory roots, they are there nevertheless. The sociopolitical model of disability, however, extends notions of critical theory because it focuses on issues broader than class. Feminist theory also expands critical theory because of its focus on women's issues. A woman who believes in mutuality and the power of relationships is not comfortable in a society occupied with consumption to the neglect of building community. Together these three theoretical perspectives have influenced my notions of how to survive as a woman, with a disability, in America. They have given me hope that we can develop new ways of thinking and relating that will be emancipatory for all of us. E., a participant in this study, wrote in an unpublished manuscript, "The greatest energy is expended holding to the extremes rather than balanced in between reactive extremes. New models of thinking, that turn notions of power upside down in less threatening ways, accommodate a variety of extremes or opposites" (1997).

## *Design of Study*

The following chapters are designed to guide the reader through the steps I took in uncovering the processes by which five women with disabilities have become subject. I had to first position this study within the boundaries of my own experience, assumptions and theoretical perspective, with the awareness of how a critical-feminist theory perspective would affect key components such as data analysis and interpretations.

This study, therefore, is designed to reveal the lived experiences of a select group of women with disabilities that "asserts and stresses real differences and combats false and oppressive explanations of the origin and nature of those differences" (Abberley, 1987). These experiences are placed within the framework of a minority group model embraced by people with disabilities that recognizes the socioeconomic basis of oppression. I use Qualitative research methods which allow me to explore interactions and contradictions in notions of subjectivity, power, and language. This design was influenced by readings of experiences of other people with disabilities, in particular Irving Zola. He cautioned about studying disability in such a way that rendered people “emotionally and cognitively inaccessible” or that portrayed them as “successfully adapting and overcoming” (Zola, 1982). Feminist researchers with disabilities echo Zola, calling it “alienated research” because it does not include their definitions of oppression or their subjective reality (J. Morris, 1991).

In an attempt to go beyond “representation” of the disability experience, which is an anathema to these women, I deliberately selected women with disabilities that I had known long enough to realize that they had reached a position of subjectivity. In addition, their selection was based on the presence of mutuality, in which we have been emotionally available to each other. The need for emotional accessibility, “unalienated research,” and the requests of these women caused me to include my own story about disability experience, something I had not planned to do. This story has been included in the Methodology section since it supports the research methods used.

Chapter 4, entitled “Phase 1: Women’s Stories” includes a section about our shared experiences and substantiates each woman’s selection based on mutuality. Each woman’s story about her disability experiences is also included in Chapter 4. Chapter 5, called “Phase 2: Data Analysis” examines the processes by which these women have reached a position of subjectivity. The final chapter focuses on results and questions raised by doing this type of research as well as considerations for future research.

# CHAPTER 2—REVIEW OF THE LITERATURE

In this section I will briefly review the history of disability, focusing in particular on women with disabilities in our culture so that readers will have some notion about the reality of living as a woman with a disability in America today. I will also review literature about women's development of agency and subjectivity in order to situate this study within existing knowledge about these topics.

On the outset, I want to state that discussing any group in the aggregate tends to obscure differences that exist among sub-groups and individuals within that group. Women with disabilities may be a group, but they are a group composed of *individuals* with many differences including ethnicity, type of disability, class, status, age, and environmental characteristics.

In our society, people with disabilities are defined almost entirely by their disability. They are not usually described as young or old, man or woman, African, Latino, Indian, Christian, pagan, rich, or poor. They have a disability, therefore, the ramifications of what they can or cannot do is related to their disability. The word "disability," however, does not describe what a person is. Every person is different in 100,000 ways from every other person. Walking is a gift, but so is not walking (Snow, 1994). By not labeling something as an asset or a deficit, as perfect or imperfect, beautiful or ugly, we can reflect, without polarizing conclusions, about new possibilities. I hope this study reflects that perspective.

## ***Selected History of Disability***

Disability as a social phenomenon was first institutionalized with the enactment of England's Elizabethan Poor Laws in 1598. Since the old feudal order had given away to a form of capitalism with the arrival of a mercantile class, wandering unemployed vagabonds were creating social unrest. People that could work were expected to do so or be punished. This was perhaps the first time that a society drew lines between those "deserving" and "not deserving" charity. Poverty and unemployment were viewed as personal problems and defects of character, and the receipt of charity was cause for humiliation. The blind, old, lame, and others with "diverse maladies" were given licenses to beg. Almshouses were established for the care and incarceration of "invalids." These persons were defined as social dependents, incapable of self-care and in need of governance (Browne, connors, & Stern, 1985).

The English Poor Laws were imported to the North American colonies, with few changes until the 1920s. The Smith-Fess Act of 1920 established the first national vocational rehabilitation program. In the 1930s, the Social Security Administration and other New Deal measures were introduced to address the high unemployment and social unrest of that time. Although its purpose was to provide for the vocational rehabilitation of people disabled in industry, it was significant because it established a national vocational rehabilitation program for civilians in the form of grants to states to develop and deliver vocational rehabilitation services to people with disabilities. At the same time, disability continued to be defined as the inability to pursue an occupation because of physical impairment. Even as American society became increasingly industrialized, people with disabilities were considered unemployable because of the perception that they were negative profit makers (Ryan, 1976).

One other significant event happened in this time period, that of a change in the design of wheelchairs. An engineer, Harvey Jennings, responding to the needs of a friend, Herbert Everest, who became paralyzed in a mining accident in 1918, designed the first lightweight wheelchair in 1932. Although it made little difference in public perceptions about disability in the 1930s, it was the first step in lightweight, aerodynamic wheelchair design that liberates people with disabilities today.

World War II greatly increased the number of people who had disabilities because of lives saved by advancements in medical and surgical technology. Groups such as the Paralyzed Veterans of America, the President's Committee on Employment of the Handicapped, and the National Federation of the Blind were formed in the 1940s to promote medical care for veterans. For the first time, a group of people indicated interest in the process of adjustment to disability and how change in physical condition affects human behavior. Wright, Barer, Meyerson, and Gonick, in their report to the Social Science Research Center in 1946 and again in 1953, first drew attention to the parallels between the lives of people with disabilities (defined as men) and those of other minority groups (Meyerson, 1988). Wright also suggested that a difference might exist in the perceptions of people with disabilities about themselves, which she called an "insider perspective," and those without disabilities, or "outsiders" (Wright, 1983). Rehabilitation efforts treated disability as a condition to be eliminated or corrected at the individual level.

The polio epidemic of the late 1940s and 1950s was one of the first major epidemics in America that reached across lines of age, class, race, and geography. It has been called the greatest force in American history in bringing the plight of people with disabilities to the public consciousness (Byrom, 1993). Many of today's outspoken activists and leaders in the disability movement, including Judy Heumann, Justin Dart, and Irving Zola, had polio as children.

A new era for people with disabilities started in the 1960s with the birth of the independent living movement in Berkeley, California. Influenced by the Free Speech Movement, the anti-Vietnam war protests, and women's movement, a group of adults with disabilities came together as a political force that targeted discrimination. They rejected the notion, as women had, that "anatomy was destiny," and asked for control of their own bodies. Through their efforts, the California Department of Rehabilitation was forced to provide them with adequate housing out of a hospital and supports so that they could lead self-directed lives. The newly formed group took to the streets and asked the city of Berkeley to add curbcuts to its sidewalks (Shapiro, 1993).

The 1970s was the beginning of the disability rights movement. Adults with disabilities as well as parents of disabled children organized into a vocal political movement. These groups saw the locus of disability problems in political, social, and legal systems rather than within individuals. They fought against systems that denied equal protection of the law, equal rights, and equal opportunities. Again the public was reminded that separate is not equal.

Significant laws affecting people with disabilities were passed beginning in the 1970s. The Rehabilitation Act of 1973 was the first civil rights legislation protecting the right of people with disabilities to equal employment opportunities and providing an egress to discrimination. In 1975 Congress passed the Individuals With Disabilities Education Act (originally titled The Education of All Handicapped Children Act), which was the first legislation that provided free public education in the least restrictive environment to children with disabilities. In 1990, the Americans with Disabilities Act became law, which gave people with disabilities the same protection against discrimination that had been given to women and other minority groups in the Civil Rights Act of 1964. For the first time, people with disabilities had a law to force the removal of architectural barriers and prohibit discrimination in programs and services on the basis of disability. In 1990, two-thirds of people with disabilities, or about 28,000,000 Americans, had never been to a theater, seventeen percent had never eaten in a restaurant, thirteen percent had never been in a grocery store, and sixty-six percent were unemployed (Louis Harris & Associates poll, 1988). One of the findings of a Presidential task force is that "...people with disabilities, as a group, occupy an inferior status in our society and are severely disadvantaged socially, vocationally, economically, and educationally" (*Re-Charting the Course,* 1998).

Along with changes in legislation has come a more subtle attitudinal change in society. More students with disabilities are being included in general education classes. Politically active disability groups such as Not Dead Yet are focusing public attention on issues like assisted suicide that are broader than disability. They are helping us see that issues facing people with disabilities affect all of us, particularly as we get older. President Clinton placed people with obvious physical disabilities in important places in his cabinet, such as Judy Heumann who became Undersecretary of Education, and Bob

Williams, who was head of the Commission on Developmental Disabilities. We see more people with disabilities on the streets and in the stores because they can now get *on* the sidewalks. Attitudes toward women with disabilities, however, have not changed much since the creation of the Poor Laws in the 1500's.

## *Women with Disabilities in America*

In many ways, the history of women with disabilities has paralleled that of men. In a 1942 study of over 100 women with disabilities, only 17 were married (Byrom, 1993). This same study stated that "…the handicapped form fewer attachments to men…and feel little or no desire for closer contacts" (p. 26). Women were not supposed to "overcome" their disability, but rather were expected to subsume it so that it did not get in the way of being a woman or feminine. They were also expected to appreciate the pity and charity handed out to them by society's well-intentioned people and remain roleless. Twenty-five years ago, most women with severe disabilities would have died or would have been institutionalized. Those with less significant or less visible disabilities may have continued to live at home, although as dependents. Those who took care of them were considered self-sacrificing and selfless (Kennedy, 1964). Murphy's quote that "we represent a fearsome possibility" has been doubly true for women with disabilities, as society perceived that disabled women could pass on personal "defects" to their children. Many of these attitudes are still with us. When talk-show host Bree Walker Lampley got pregnant a few years ago, many in her listening audience were aghast at the possibility that her children would inherit their mother's disability, a condition that causes fusing of the bones in the fingers and toes. One woman said, "I would rather die than live with something like that, and I would hate my mother if she had brought me into the world."

The eugenics movement that started in the late 1890s and continued until after World War II attempted to document the hereditary nature of disabilities and shaped the domestic life of women with disabilities until the 1990s. Women with disabilities were perceived as asexual, unmarriageable and unfit to be mothers (Shapiro, 1993). Women with disabilities are still less likely to be married or in a significant relationship, perhaps because of perceptions of their physical and emotional care-taking abilities (Hanna & Rogovsky, 1991).

Carol Gill, director of the Chicago Institute of Disability Research, reflects the position held by many women with disabilities.

> Keeping us genderless by discounting us as women and as sexual beings helps to prevent us from reproducing, which keeps us harmless to society. And, once we are categorized as nonbreeders, we are discarded as socially useless. (Gill, quoted in Fiduccia & Saxton, 1997)

Women with disabilities face double discrimination or stigmatization in the workplace. Women in general historically have been "disabled" from participation in skilled industrial, policy making, and business spheres of society. Medical or psychiatric theories of biological inferiority, such as hormonally induced hysteria, have been used to justify discrimination based on sex. Domestic work and child-rearing have been considered natural, instinctual occupations. Women with disabilities, however, have been disqualified from both domestic and wage work, a double bind (Browne et al., 1985; Hanna & Rogovsky, 1991). The Social Security legislation of the 1930s, shaped by attitudes about women and work, further exacerbated the marginal position of women by restricting benefits to those who were single mothers or on relief. The result has been that women with disabilities must remain single to get financial support or they get no financial support at all because they have been restricted to occupations that may not participate in Social Security (Reisine & Fifield, 1992).

Women with disabilities also experience institutional sexism, particularly in vocational rehabilitation (VR) programs. VR counselors, who have the authority to determine appropriate placements for people with disabilities, often channel women into traditional "women's work." If women can sew, type, or cook, they are considered rehabilitated. Women's cases are more likely to be closed in a non-wage earning capacity, and they are more likely to be denied services entirely. In addition, they are less likely to be referred to vocational or on-the-job training (Fine & Asch, 1988).

Women with disabilities continue to remain unemployed or underemployed. Disincentives to employment are built into the Social Security Act. For example, most Supplemental Security Income (SSI) or Medicaid beneficiaries who marry partners who are not on SSI or Medicaid lose their eligibility for health and personal assistance benefits. Once their earned income has reached the poverty level, they may be determined ineligible for any services at all. Welfare benefits are below the minimum wage in order to provide incentives for employment. Frequently, women with disabilities have to choose between having access to food or medical care. "Our survival is an act of resistance in a society which would just as soon eliminate us and is also a testament to our resourcefulness" (connors, 1985, p. 105).

Since the 1980s, more women with disabilities have found adequate employment, live in accessible communities and homes, and have reciprocal and rewarding relationships. Many, however, still live in institutions or nursing homes, in poverty, and in isolation. Funding for social programs on a national and state level is in jeopardy or has been cut. Most disabled women are still underemployed. Only 33 percent are in the labor market compared to 69 percent of men with disabilities. Thirteen percent are employed full-time, and their earnings are $3,100 less than women without disabilities and $8,200 less than men with disabilities. In addition, they are restricted to a narrower range of occupations (U.S. Bureau of the Census, 1989).

Two critical values of 20th-century America that particularly influence the perception of women with disabilities are personal appearance and individual autonomy. Women who fail to meet prescribed standards of physical attractiveness and functional independence are not only assumed to be biologically inferior, but they are also exposed to stigma that depicts them as not quite human (Hahn, 1988). All women have to contend with the message "keep young and beautiful if you want to be loved" (quote taken from A Century of Women Video Series, 1994). Women with disabilities may contradict all the values held by able-bodied women and men with and without disabilities, such as youth, virility, activity, and physical beauty. In her book *The Body's Memory,* Jean Stewart (1989), a woman with a disability who lost her ability to walk because of cancer in one hip, talks about her journey from being an able-bodied attractive woman to a disabled attractive woman. She worried what others, particularly men, would think about her if she started using a wheelchair.

> I clanked around on crutches for almost three years in intolerable daily pain before it dawned on me that: (1) crutches were the wrong apparatus for me; (2) life didn't have to consist of nothing but pain; and (3) I deserved better. I deserved a wheelchair. Sweet freedom! If not from architectural barriers, at least from physical hurt. *My disability was not my fault, and did not merit punishment.* (p. 262)

## ***Development of Agency and Subjectivity***

Karl Marx was perhaps one of the first to use the term "subject" in his treatise on the role of labor in production. For Marx, labor was essential for human's self-realization and self-creation. He conceived humans as subjects who are active productive beings, constituted historically by his or her own interaction with nature. History is not a process without a subject. Part of his theories addressed the need for workers to have control over their own destiny. He believed that history is an open process and that contradiction is a component of social reality and an ongoing dialectic. His writing reflected the belief that every human has the potential for autonomous, self-determining activity. "Marx envisaged a society where institutions were under the control of the individuals who compromised them…where humans could freely express their species-being…which would facilitate the full and free development of every individual" (B. Morris, 1991, pp. 191–214).

Paulo Freire (1970), many years later, echoed Marx's words in his book *Pedagogy of the Oppressed.* He believed that every person, no matter how ignorant or submerged in the "culture of silence" he may be, is capable of looking critically at his world in a dialogical encounter with others. With the proper tools, which for Freire included education, a person can perceive his personal and social reality as well the contradictions in it, become conscious of his own perceptions of that reality, and deal critically with it (p. 12). He defined people who were "subjects" as those who know and act, in contrast to "objects," who are known and acted upon. Those people who recognize themselves as oppressed must be among the developers of a liberating pedagogy in a process Freire called "reflective action" or "praxis." His quote, "We cannot enter the struggle as objects in order to later become subjects," was the starting point for this study (Freire).

Subsequent authors have elaborated on notions of subjectivity, including Bettina Aptheker, Judith Butler, and bell hooks. Aptheker uses the word "autonomy" rather than subjectivity. She defines autonomy as the right to self-determination, with emphasis on the collective. It does not mean separation. Autonomy is a political concept in a social setting rather than a personal concept in a psychological setting. Aptheker speaks of things that "corrode and subjugate the mind," like political domination, racial superiority, poverty of material resources, loss of esteem, and an inability to give expression to experience. Aptheker writes of "affirming the self," and provides a poem by Kate Rushin from the book, *This Bridge Called My Back: Writings by Radical Women of Color* (1989) that illustrates the connection between self and a collective identity.

I must translate
My own fears
Mediate my own weaknesses
I must be the bridge to nowhere
But my true Self
And then
I will be useful

Judith Butler adds a dimension to the discussion about subjectivity as she examines the position of the "I." According to her, we come to a position of subjectivity through a set of selective and exclusionary procedures which must be examined in order to position us historically. The "I" is not just positioned; it is *constituted* by its position by matrices of power and discourse that produce me as a viable subject. She says, "Indeed, this 'I' would not be a thinking, speaking 'I' if it were not for the very positions that I oppose" (p. 42). Discourse is a part of what constitutes the subject. Butler highlights the connection between use of power and the constitution of the subject. Butler makes one other point that is relevant to this topic. She suggests that subjectivity is a precondition for agency. She states that agency belongs to a way of thinking about people as instrumental actors who confront an external political field. "*Agency is always and only a political prerogative,*" (her emphasis; p. 47). The subject is always a permanent possibility, fully political, and constituted through exclusion (Butler, 1995).

hooks reflects on how people who are dominated, oppressed and exploited make themselves subject, creating an oppositional world view. She suggests that opposition is not enough. In the space after one has opposed, there is a necessity to *become,* to make oneself again or anew. That space is called resistance, where we begin to understand how structures of domination work in our lives, where we develop critical thinking and critical consciousness and invent new ways of being. That space of resistance that we have defined is also called the margin. Marginal locations are spaces where we can best become whatever we want to be while remaining committed to liberatory struggle. She also makes a distinction between marginality that is imposed by the Other and marginality that is chosen as a site of resistance and a place of possibility. In this space, marginality is *seen,* not overseen by an authoritative Other (hooks, 1990).

One final set of authors have contributed to my understanding of the subject, putting the concept more into a psychological perspective than social and political. Belenky, Clinchy, Goldberger, and Tarule (1986) consider subjectivism one of the stages of development in women. In this stage, a woman begins to rely on her inner resources for knowing and valuing, and through listening to this "inner voice" she experiences growth in strength and self-esteem. This is a shift from dependence on external definitions of truth to an adherence to the authority within us. This perspective on becoming subject implies that it is a developmental process. The authors suggest that there is usually a catalyst or traumatic event that takes a woman to this stage in development, and it is usually a crisis of trust in male authority (p. 58). Women in this stage of development have a high tolerance for internal contradiction and ambiguity and rely on personal experiences as the test of what is true (Belenky, et al.).

Notions of agency and subjectivity are contrary to how Americans perceive people with social problems should act. A measure of success for any group that has a social problem (race, gender, religion, disability) in America has traditionally been adaptation to and acceptance into the mainstream (Hahn, 1993). Some people with disabilities have internalized the beliefs and attitudes about them and act in expected ways, pitiful, helpless and hopeless. Others have developed and adopted an alternative set of values, those of self-determination, interdependence, and human community. They have learned the power of resistance from the margin. These values reflect a growing sense of autonomy and agency that refute the mainstream notion that a person who is dependent cannot be autonomous.

# CHAPTER 3—METHODOLOGY

This study used qualitative research methods, including participant observation, in-depth interviews, and analysis of artifacts such as photographs, conference proceedings, and articles from newspapers or magazines. Five women with disabilities were key participants, and these five women ranged in age from about 35 to 65 years old (Table 1). They now live in different parts of the country, although when they were being interviewed they lived in the southeastern part of the United States. Formal interviews started in April, 1996 and were completed in August, 1999.

Table 1: Demographics of the Five Women Interviewed

| Participant | Age | Race | Married | Children | Employed |
|---|---|---|---|---|---|
| S. | 40s | White | Yes | 2–young | No |
| K. | 30s | White | No | 2–young | No |
| D. | 40s | White | No | 0 | Yes |
| C. | 60s | Black | No | 2–grown | No (retired) |
| E. | 40s | White | No | 0 | Yes |

## *Selection of Participants*

In my quest for understanding the meaning of disability, I had many opportunities to get to know women with disabilities. Some of them I met at conferences, and others were people with whom I worked on a regular basis. I also read literature written by women with disabilities. For over eight years, I studied women with disabilities and began to recognize a difference in them that had nothing to do with their physical appearance. Some women had an entitlement attitude, or the attitude of "You owe it to me because I have a disability." Other women were angry about their disability. One woman in particular, who acquired multiple sclerosis in her 30s, was so angry that she painted her house red as a flag to the world about how she felt, unable to turn loose of her anger. Younger women who lived with protective parents seemed to be inhibited in their process of self-identification. As a contrast, other women seemed to incorporate disability into their being, not by denying it, but by embracing it. They had strong notions of agency and autonomy. Three women whom I met that exemplified this attitude were Judith Snow, Carol Gill, and Jean Stewart. Each of these women are also prolific writers, so I had access to their written and spoken words. Other women that I met, such as Kate Gainer, became examples to me of how any women should strive to live, with dignity, pride, and humor.

The poem "Dignity" in Lois Keith's book, *What Happened to You?*, seemed to identify characteristics of subjectivity.

> i accept myself as i am…
> i am all these thing…
> whole, complete and beautiful.
> i want to plant my own garden,
> decorate my own soul. (Duffy, 1996, p. 31)

I did not understand fully what she meant, but it was important for me to know why and how some women with disabilities have become subject and others have not. I also believed, because of my theoretical perspectives and personal experiences, that outside forces contributed to or caused the development of subjectivity. Finally, I believed women with disabilities who had reached a position of subjectivity could, through the telling of their stories, contribute to the literature about the power of living with a disability. Feminist literature, in particular, tends to ignore issues of disability and old age, and both of these human experiences need to be integrated into feminism's political and theoretical challenges.

I actively looked for women with disabilities that were speaking from a position of subjectivity and selected five through purposeful sampling (Huberman & Miles, 1994; Kuzel, 1992). In the beginning of this study, I defined subjectivity as speaking from a position of control and anger. These were "in your face" women. They were active in disability politics and activities in their communities, and they were recognized by their peers as leaders in the disability field. Purposeful sampling was selected because of its potential to give an added dimension to the study, namely the aspect of subjectivity. A shortcoming of this sampling procedure is that the persons selected may not represent the general population of women with disabilities. In addition to the perceived presence of subjectivity, these five women were selected with some regard to age, socioeconomic status, race, and onset of disability, although these factors in themselves were not primary criteria for selection. None of the women selected were customers of the nonprofit agency where I worked.

More significantly, these women were selected because of the existence between us of a relationship of trust, friendship, and the existence of mutuality. I had worked professionally with these women for at least five years, and their selection was based on the fact that I had more than a superficial knowledge of their lives. Our experiences together included presenting at local and state conferences, providing training to parents of disabled children and other disability groups, and socializing before and after work.

We knew of each other's families and personal struggles and triumphs. Through their prodding and influence, I finally realized that I had to share my life with them as much as they did with me. In order to identify with them, I had to enter their struggle.

## *Procedures*

Recognizing that reality is "a multiple set of contextually-bound constructions," I entered into the settings in which these five women create and enact meaning (Bogdan & Biklen, 1992). As part of this study, I spent from eight to 20 hours with each woman, including time in her home, at work (when appropriate), and in community and social settings for over three years. Data sources included field notes from observations, tapes and transcripts from formal and informal interviews, notes from meetings and conversations, and copies of articles from newspapers, conference proceedings, and other publications. Each participant was interviewed formally at least twice and informally up to six times. Since three of the participants moved after the initial interviews, we have continued to communicate via telephone and e-mail on questions related to this study.

The first interview question was open-ended and nondirected in order to encourage these women to speak freely about their lives. Given that I knew something about them before this study started, the question, "What experiences have you had in your life that have resulted in what you think about yourself today?" was significant because of what they chose to talk about.

Questions for the second interview were more directed (Figure 1). These questions came from readings in feminist literature and from experiences with other women with disabilities, including those I had met as well as books written by disabled women. Underlying these questions was my theoretical perspective about disability, namely that it is the outside world that disables and oppresses a person. I was very sensitive to the fact that most research done about women with disabilities results in objectifying them, thereby alienating them from their experience. In order to take on the subjective reality of their experience, I had to enter that experience and identify myself with these women. During our formal and informal interviews, they asked me as many questions as I asked them. They also sometimes changed my questions to them or reframed the question. For example, the question, "How do you go about changing things in your life?" became for one woman, "Do you mean, how do I deal with change in my life?" They chose where and when the interviews were to take place and who else would be present (such as children, friends, or spouse). In one interview in a community coffee house, the participant deliberately chose to remain where others could hear what she was saying.

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1. What choices have you had in your life?
2. What things are you able/unable to do that you want to do? Why do you think you're able/unable to do those things?
3. How do you go about changing things in your life that you don't like or want to change?
4. What do you feel you can control in your life, or what do you want to control?
5. How do you handle/deal with unpleasant tasks?
6. What are your challenges?
7. What brings you pleasure?
8. How do you make yourself heard and understood?
9. How would you describe your life?
10. What image do you have of yourself, as a woman with a disability? As a woman?
11. How do you compare the experiences you have had with women without disabilities? With other women with disabilities?
12. What other people do you feel can represent you, or speak for you? Why?

*Figure 1.* Structured questions used for the second interview.

## *Data Analysis*

The data was analyzed with a high level of personal self-awareness and reflection, taking into consideration my interaction with the participant at the moment as well as events in our relationship that might affect data analysis. Reflection included the meaning I was gaining from the analysis process. Information is created every time people come together in new ways, and the participants and I reflected on information created by our coming together to do this research project. We found opportunities to probe and process the information and to confirm or disconfirm the meaning gained from its processing.

I read and re-read collected material, making notes about recurring themes within each woman's story, consistent with qualitative research methodology (Bogdan & Taylor, 1982; Bogdan & Biklen, 1992; Denzin & Lincoln, 1994). I listened to tapes of interview repeatedly in order to capture in writing the main thoughts each woman was expressing. In the margins of my notes I placed the tape counter number so that I could go back, if necessary, and review what the participant had said. As described by Lincoln and Guba (1985), I developed coding systems for content analysis as well as content cards based on themes within each story. These cards were identified by each woman's first initial and then by topic, such as anger, power, or control. The cards were then grouped by themes across stories. At each point in the process, the participants had an opportunity to confirm the themes or findings to date.

## *Emergence of Themes*

The themes that emerged from data analysis came from the participants' words. These included patterns of thought and behavior, their use of language, how they maintain stability in the face of constant change, their experiences of shame, the choices and decisions they have made, and their relationships with others. Their "stories," which took almost two years to write, came from the "first data analysis" and gave me a deeper understanding of their daily lives and experiences. Each woman had a chance to edit her story and make changes. For example, one participant, E., changed the phrase describing her experiences from "never deny" and "discount" to "accept" and "affirm." Their comments gave me greater insight into what was of importance to them and how aware they are of critically interrogating words used to describe them.

These stories are the foundation for the "second data analysis" located in Chapter 5 of this study. I had to lay aside the themes that created the five stories in order to begin to understand the process of becoming subject. I also had to lay aside preconceived notions of subjectivity and assumptions about uses of power and control. I had to study the patterns of becoming subject in each woman and look for the parallels across all five women. I examined the content and patterns of their quotes. For example, three women spoke more about daily living in their families and communities. Two were more global in outreach, and their words were more philosophical and political. The content cards were shuffled into many configurations in order to reveal the patterns underlying the process of becoming subject.

## *Data Credibility Procedures*

Efforts to achieve credibility of the themes presented included both qualitative triangulation (Bogdan & Taylor, 1982; Denzin, 1978; Janesick, 1994) and meeting criteria of data trustworthiness (Kincheloe & McLaren, 1994; Lincoln & Guba, 1985). According to their guidelines, triangulation leads to trustworthiness when what is written is descriptively credible to both the study's participants and the research audience. In this study, the following data checks were employed to assure credibility:

- I consistently coded content cards with cross-references to transcripts' page numbers and tape counter numbers; card content was based on participants' exact words and actions (Huberman & Miles, 1994: Strauss & Corbin, 1994);
- I observed and interviewed these women for over three years and kept field notes, e-mail messages, and a journal of notes from visits and telephone calls (Bogdan & Biklen, 1992);
- At each stage of the study, the participants were asked to provide their interpretations of the observations and interviews ( Janesick, 1994);
- I used multiple data gathering techniques and sources including participant observation, in-depth interviews, unstructured interviews, e-mail, and document analysis (pictures, news articles, conference proceedings; Bogdan & Biklen, 1992); and,
- An external experienced researcher confirmed the process.

Interviewing, observation, and analysis of artifacts such as photographs, articles in publications, and conference proceedings provided opportunities to balance what participants said about themselves or a particular event with what others said about them, a process referred to as triangulating multiple perspectives (Lincoln & Guba, 1985). It also provided opportunities to compare what these women said with observations of what they, in fact, did. Observations of participants in interactions with others and comments by participants to me after interactions with other people, provide substantiation of their words.

## *Summary*

Five women with disabilities were selected to participate in this study because of perceptions of subjectivity and because of the existence of mutuality between us. Qualitative research methods were used to probe the meanings of their words and actions in order to uncover the processes by which they have become subjects, rather than objects. In structured and unstructured interviews, these women asked as many questions of me as I did of them. They requested that my story be included along with theirs, in order to give readers an understanding of the ways in which I identify with them. The following section is simply called "My Story."

### *My Story*

I agree with one of the participants, K., in that I do not like to talk about myself. Coming to an understanding of the need for this section, as well as the ability to write it, is recognition of the growth and change I have gone through. Understanding the need, however, does not make it any the less painful.

Another participant, E., described me. She says that if we were to describe ourselves as if we were a breed of dog, she would describe me as a little rat terrier: fierce, loyal, thorough, giving close attention to details, faithful to friends, funny, fast, and small.

I am a white woman, born in the southeastern part of the United States, to parents who were both from the north. My father came to the South after World War II looking for college and work. He settled there with his family of three children and a wife.

We were a middle class family, living in a big, old house on a few acres. We always had a few animals, a big barn and a garden. Our summers were filled with helping around the house and yard, playing, sleeping, reading, and traveling. Part of my father's ethos was that for us to know the world we had to see it. It wasn't good enough to read in a geography book that the Mississippi River was narrow in Minnesota and wide in Louisiana. We had to cross it on a ferry or a bridge. Likewise, we had to see the homes of all the presidents to believe they really lived. Education, reading, and work were valued and stressed. We grew up without television because my parents didn't believe it was good for us. We had books, music, friends, paper and pens for writing, and our own ingenuity and inventiveness for pastimes. My father, coming from the Midwest, had what Garrison Keiler calls the "work for the night is coming mentality." If I was deprived I didn't know it.

We also had church. Both of my parents were conservative Christians, and my father was a Navy chaplain. We were expected to go to church on Sundays and to other services through the week. I deeply resented being made to go to church and used the time to my best advantage, such as studying my French vocabulary instead of paying attention to the service. If anyone told me to do something and couldn't come up with a good reason why I should, I generally didn't do it.

I didn't think of myself as attractive when I was growing up. Living in the shadow of an elegant, tall, older sister, I felt short, fat, and dumpy. I had buck teeth that were corrected by the time I was in eighth grade, and I wore glasses from the time I was in the second grade because I liked to read in bed with a flashlight (which was forbidden). It's always been easy for me to put on weight.

Looking back, I see that rebellion was a pattern in my life. My father, who helped develop in me a questioning, inquisitive mind, may be partly to blame. I didn't understand all of his books I read, like the *Dead Sea Scrolls,* when I couldn't get to the library, but I suspect they have a lot to do with how I think. He decided when I was 16 that I needed to learn to fly, perhaps in the belief that I needed to be involved in constructive activities. I flew two years before I drove a car, and wrecked his new Rambler within 30 minutes of driving it the first time.

I love to travel, whether it's down a dirt road in my community that I've never been down before or on a bus in northern France. The thought has occasionally crossed my mind that I could disappear without anyone knowing what happened to me. I love to sit in public places and watch people, and I love it when they approach me and start talking. I often wonder what is on my face that encourages total strangers to ask me which blouse to buy or just to comment on current news.

### *My Experience with Disability*

Three years ago, when I started this dissertation, I would not have identified myself as a woman with a disability. I'm not sure I would today, either. However, through the sharing of our lives, the women who have participated in this study have helped me understand myself and my experiences and have given me tremendous insight into how past events have shaped my way of thinking and doing—not in the sense of "walking in someone else's shoes," or even in the sense of "being thankful for what I have; it could be worse." What I have come to realize is that I have experienced disability on a very personal level, with my family, through the lives of friends, and in my work.

### *History*

Some of the things that happened to me happened before I can remember them completely. My family has filled in some of the blanks. My mother tells me that I nearly died as a baby from asthma. Through careful nursing, chiropractic care, and homeopathic medicine I was 'cured' of asthma by the time I was three. Apparently I was sick for most of the time until then.

I have one vivid memory when I was four. I was outside swinging in the yard with my sister, standing on the swing seat. I remember falling, pain, and my mother's horrified face. That is the last memory I have of my youth until I started to school. I did significant damage to my back, legs, and some internal organs. Through forced bed rest, more chiropractic, and infinite patience on the part of my mother, I got better.

When I was in the third grade, I fell again. This time I was playing in the hay loft of our barn with my brother and sister. On the way down the ladder I slipped and fell the rest of the way to the ground. My memories again are of pain, spending time in bed, and someone shuttling lessons between school and home. I had many visitors, some of whom brought books for me to read. I don't know how long I spent in bed or was away from school, except that I do not remember anything about the third grade after my fall.

I had routine falls during the rest of my elementary school days and into high school: down stairs, on ice, from step ladders. Height of any kind seemed to encourage a misstep. Through the process of falling I developed a fear of activities that might cause more falls, such as skiing. I also feared that some day I would fall and never walk again, and I learned to hate chiropractors.

When I was 19 I had the worst fall of all. I was with a group of young people, having a good time, playing outside games like badminton and volley ball. As the last game of the evening, we decided to divide into two teams and play a game made famous in one of Winslow Homer's paintings, called "Snap the Whip." It just so happened that the people on either side of me let go of my hands at the same time, and I fell down hard, hitting the base of my spine onto a sharp rock. I did not sit down again on anything but a doughnut cushion for over a year. The base of my spine was crushed, and from that day to this I have not lived without pain. With age, the pain has gotten worse because of arthritis and simple wear and tear on my back and legs.

Now, the question is: Does that make me disabled? I don't know. I do know what it means to not be able to do some things by myself, what it means to have to ask others, or wait for others, to do things for me. And for a person as independent as I am, that hurts as much as the pain. I know what it means to be left out of events because of pain or fear of causing more pain or because I simply cannot do certain things. Those closest to me know how frustrated I get when things are out of reach or I have to wait on someone to lift or carry something for me. I have learned to live with a high tolerance for pain, because I refuse to live on pain medicine or take a chance that surgery on the base of my spine could cause more damage than there already is. I have learned to live with a dusty house on days or weeks I can't vacuum. In my home, my couches and chairs are filled with cushions so that I can sit erect, and I keep cushions in my car for days when I have to prop myself into a more comfortable position.

In addition to my experience, I have two members of my immediate family who have experienced disability. Through their experiences, I have learned how disability affects those closest to us as well as ourselves.

About 25 years ago, my husband, who is a contractor, was sawing or cutting a piece of metal when a very small piece flew into his eye. He immediately went to an ophthalmologist, who removed the piece of steel and predicted that his eye would be healed in a few days. It was not. In fact, it did not heal for almost a year. Instead of healing, the hole left by the steel actually ulcerated. Various doctors tried different strategies to heal the eye: eye patches, new medicines, contact lenses, more surgery, keeping both eyes blindfolded, and other procedures. One doctor suggested prayer, another alcohol. My husband could not see to drive, work, read, sit outside, or go for a walk. I would prepare a meal, set it on the table, and turn off the lights so that he could come into the room and eat. He pleaded with the doctors to remove the eye because of pain. Finally, an experimental procedure was tried in which a part of the white part of his eye was cut away and pulled down over the hole, which was in the center of his pupil. The hope was that the hole would fill, and the eye start to heal. What we know is that six months after the surgery, we drove to the ocean, and after a week in the salt water, he was able to remove two sets of sunglasses and start living again.

So what was the effect of this experience on me? I did what had to be done. We did not have children at the time, so I was able to work full time and do outside work as well, since we lived on a small farm. We made very little money, drove an old VW because it got good gas mileage, and had weeks where we literally didn't have money for a postage stamp between us. I learned that hardship is shared. I learned that it's okay to ask for help and depend on others to help. I learned to value friends. I learned that there are things and events beyond our control and to have faith that our needs would be met. We learned to live very simply, live to a large extent off what we could grow, and to depend on inner resources during the darkest days and nights. We, my husband and I, often talked about "what if." What if his eye didn't get better? He openly discussed suicide because of the pain and frustration at not getting any relief.

During that year I often thought of the difference in men and women's tolerance to pain and even how individuals handle crises. Perhaps it is harder for men to face loss of independence and have control of their lives placed in the hands of others, particularly women. At that time, my thinking was very general. What I know is that we survived. My friends tell me I never complained. Perhaps it is the stoic coming out in me, or the New England genes: You don't show your feelings to strangers in particular, you do what has to be done, you make do with what you have, and you don't complain. I also know that the VW had several dents by the front door where I kicked it regularly.

Twenty years ago, or about five years after "the year of the eye," my husband and I decided to adopt a little boy. The circumstances were somewhat unusual, in that we knew this little boy's family and background. Through unfortunate circumstances, his birth mother had become addicted to prescription drugs. She had two daughters already, and the stress of raising them as a single mother, plus other inherited emotional problems, took her to the brink. The event of another child pushed her over, and our son's birth came after she attempted to abort through a drug overdose. His first four years were marked by neglect. If his older sisters had not given him some care and attention, he would not have survived.

When he was four, his sisters were in their early teens and beginning to get in trouble themselves. Social service agencies stepped in to remove all the children from the home for their health and safety's sake, and we asked for our son to be placed in our home on a temporary basis at first, then permanent.

Many friends and acquaintances tried to talk us out of it. He had a label of autism, they said. He was considered out of control, unable to talk intelligibly, had not been taught to even use the bathroom, would or could not eat anything but baby food, and on and on. He would wreck our home, our lives, and our marriage. We listened, and then brought this little boy to our home for a weekend. We agreed that if we could live with him and with each other at the end of the weekend, we would take him in to our homes and lives as we would a son of our own birthing.

I don't remember much about that weekend, except pity and fury: fury at his birth mother for her neglect and pity for our son because of four lost years. Our son remembers that weekend, however. He remembers being in a peaceful, clean and safe place. He remembers having warm food and cats that slept on his bed. He remembers the tire swing in the back yard and having his own record player.

Our son, now 24, has what would most likely be labeled developmental disabilities. He had a terrible time in school learning in traditional ways. He has very poor auditory processing and short-term memory skills. When he was 13 he had his first grand mal seizure, and since then has been on seizure medication. His seizures, although infrequent, are getting more severe with age. He has many autistic-like tendencies: He requires precision, order, and structure in all parts of his life, from his work schedule to his bedroom shelves.

Our lives have been tremendously changed by our son and his experiences, and we have learned much about valuing people for what they are rather than what they do. In our culture, usually the second question asked about or to a person is, "So, what do they/you do for work?" Your value as a person seems to be directly related to the type of work you do. If you can't or don't work, then you are perceived as of lesser value. We have become very sensitive to the fact that people are of value and can contribute regardless of whether or not they work or what kind of work they do.

We have learned more about living from our son than he will ever learn from us. Living with disability, for us, is not a narrowing of our lives but a widening. It has led us to increased awareness of the needs of others, as well as tolerance for difference. We are still learning to live life more in the present than in the future. Happiness is measured in small things: a day or week without seizures, a raise at work, a new friend.

Our son has a full-time job at a local fast-food restaurant and drives a car at this time. We don't know how long either will be possible. He hopes to get married in the near future, which will be another new experience. Having lived through supported education and employment, we suspect that we're also going to learn about supported marriage.

When he was in school, I learned how to negotiate with his teachers about making modifications for him. Another parent was a mentor and went with me for the first year or so, when we realized that he had significant learning problems. I blamed him, the teachers, and God, sometimes all at the same time. I learned what to ask for and how to make sure that teachers did their jobs. Over the years his teachers and I became friends and partners, but I never let them forget their responsibilities in teaching or their liabilities in abiding by the laws set up to protect our son and other children with disabilities. Mostly I learned to value and accept small successes. The favorite phrase on report-card day was, "Well, at least it isn't an F."

My experience as a parent led me into the work I currently do as well as advocate for other parents. Because I refused to look just at his disabilities, but rather looked also at our son's abilities and gifts as well as at the learning environment, I started a search for new ways of teaching and learning. That search took me to the United Kingdom as well as to many parts of the U.S., and it has influenced the way I now teach other teachers as well as work with individual students. I pass on what I have learned to other parents in the hope that they will gain strength and wisdom for their own battles and struggles as well as faith in their children.

These personal and family experiences have given me a deep affinity for the daily experiences of women who have disabilities and for parents who have children with disabilities. You dare not act impulsively, and you live with the knowledge that your plans might be changed in a second. You walk through life as if on broken glass.

### *Change in Perception*

Three years ago, if asked to write about who I am, I would not have written the above. In my journal for April 1996, I wrote things about myself relating more to personality than to events that have shaped the way I think. The process of writing this dissertation and getting to know and work with these five women on a very personal level has helped me understand the similarities in our experiences and perspectives. It has given me the courage to write about myself and has helped me understand that I am part of their lives and experiences.

Some changes in me, I suspect, are common to many women. We learn as we get older about the value of friends, of the need for interdependence and community, of the value of the present, and of the need to prioritize our time and resources. We realize that most of life is neither black nor white and that extremes, although sometimes necessary, are not the most desirable place to live.

On a deeper level, I have had to ask myself to what degree my upbringing—white, middle-class Protestant—has affected the way I think and believe. I can't remove myself from my culture or even suspend or separate myself from cultural influences, but I can interrogate how those influences affect my thinking and actions. A more than healthy dose of skepticism has caused me to question very deeply what I believe and why. It has caused me to question deeply ingrained cultural beliefs in faith and God. I refuse to believe, as some still do, that disability is a sign of God's disfavor or punishment and that faith can heal.

Growing up in the Vietnam era had some effect on my social consciousness. Perhaps for the first time in American history, we openly and abrasively questioned those in authority and got away with it. We developed skepticism and cynicism about our government, our culture, our parents, our education, our faith, and any thing else that seemed to be traditional and the status quo. Although not aware of it then, I am now very aware of how that time shaped my future thoughts and actions.

Where I am now in my quest for understanding is awareness of a tension or dialectic in the universe. In all things there is a balance and imbalance that is neither good nor bad. Both states are temporary, resulting in feelings ranging from thrilling to frightening. Many things cause imbalance and tension: death, accident, injury, disability, new jobs, marriage, divorce, having or losing children, vacations, new homes, moving, dissertations. These events do not reduce the quality of our lives; contrarily, our lives are richer because of them.

In the reflective state caused by this dissertation, I have had to finally ponder the route I took to becoming an ardent feminist. The roots were certainly not in my upbringing, at least that I saw growing up. My mother worked as a social worker and nurse, but she was most certainly subservient to my father. Friends were the first to acquaint me with feminism, and I remember being shocked the first time one particular friend left to go to a meeting without her husband. Perhaps when I had to shoulder the burden of living during my husband's trials I began to realize that I could act independently. One older neighbor voiced her concern for our marriage when she learned that we actually voted on opposite sides in a local election. College classes helped somewhat, although I still didn't grasp what feminism really meant. As a closet critical theorist, I had some notion that the meaning of feminism was to improve the lot of women and that men were to blame for all the bad things that had happened to women, but that line of thinking didn't seem to take me too far or too deep. I certainly became more aware of how many aspects of women's lives are controlled by men, and I rebelled against "suits" making decisions for me that affected my life.

Readings in philosophy and religion gave me a deeper understanding of the issues with which I had been grappling and an understanding of how our western Protestant culture has been shaped by Biblical teaching. The writings of an Episcopal priest, John Shelby Spong, in particular have helped me through the process of understanding how our society has arrived at its treatment of and attitude towards women. My understanding has led me to want to make others more aware of how their attitudes affect me and other women. As a last step in my feminist evolution, I have been deeply influenced by people I have met and books I have read. One ardent feminist, a woman who also has multiple sclerosis, showed me how anger that is not directed and focused on a common good can eat up your soul and destroy you. A native American shaman helped me understand that our actions can change our culture. It doesn't all "just happen to us." Martin Luther King and Gandhi's writings showed me the power of passive and quiet resistance.

The participants in this study have shown me what it means to live as a woman in this society. From them I have garnered strength and pride in who and what I am, and to them I am deeply grateful for showing me how to direct anger and frustration into constructive thoughts and actions. One day driving home I heard a comment from a person being interviewed on our local public radio station. She said, "When I let someone else define my reality, then they have power over me." (WUOT, "Sound and Spirit," February 1, 1998). Like the women in this study, I have learned that you can control who defines your reality, but that you can also give up control, and that in either condition you gain strength to face what life brings. Joan Chittister says, "It may be that those who are powerless by choice can best demonstrate the power that comes from not having power" (p. 9).

# CHAPTER 4—FIRST DATA ANALYSIS

## *Introduction to Women's Stories*

The five women participating in this study tell their stories in this section. They have had an opportunity to read their narratives, to comment on them, and to edit them. These stories are not all of their lives but rather are a part they have selected to tell. In the telling, they have shown how they have been shaped by their experiences. They are speaking from the core of their experiences as women, as well as women with disabilities, without apology. Their stories represent, a least partially, the process of becoming subject.

These stories are less linear than repetitive, cumulative, and cyclical. Living daily with a disability is a process. These stories reveal that these five women do not see themselves as victims, nor do accept titles such as "inspiration" or "brave." They do not reject the aspect of disability in their lives, because in the rejecting they would repudiate their lives and deny who and what they are. Because of the presence of disability, they have learned to live with integrity and meaning, with a sense of wholeness. Telling these stories is an attempt to affirm their way of experiencing disability.

Each of the sections has a specific purpose and reflects the broad categories derived from the data. To the greatest extent possible, their words have been used in these sections. The first section, Setting for Interviews, gives the reader a window on where each woman lives. The next section, My Experience, is intended to help readers understand mutuality, which was one of the requirements for participant selection. Each woman gave personal history, such as when and where she was born and how her upbringing influenced who and what she is today. The section, “Who She Is,” is interpretive as well as factual. Each woman was asked to describe herself. In addition, I observed some things that they did not necessarily talk about as they discussed who they are. They each spent the greatest amount of time talking about the reality of living with a disability. The section called Daily Experiences with Disability includes examples that reflect how ordinary experiences, like shopping, are complicated because of the presence of disability and society’s attitudes. This section also provides readers with a view of their reflections about other’s attitudes, society’s barriers, personal feelings, and on-going challenges.

Together, the five sections in each of the five stories are intended to demonstrate, using each woman’s words, her position of subjectivity and some of the experiences that have been instrumental in making that happen.

Chapter 5 provides the reader with a different kind of analysis. In this section, called “Second Data Analysis,” I have retold these women’s stories based on themes that represent the processes by which they have become subject. The reader may wish to read Chapter 5 before the women’s stories in Chapter 4 in order to get a feeling for the gestalt of this study.

## *C.’s Story*

### Setting for Interviews With C.

Most of my interviews with C. took place in her apartment, which is part of a large multi-unit complex on the outskirts of a large city. The apartment itself is on the second floor, and at the time of the interviews C. could still climb stairs. Each apartment in the four-unit building in this complex has a balcony, and many of the balconies are filled with pots of flowers and hanging plants.

C.'s apartment has a combination living room and dining room, a small kitchen, two small bedrooms, and a bathroom. Her furnishings are nice but simple. Pictures on the walls are mostly of her children and grandchildren. Books, such as mysteries and biographies, and magazines that she is reading are on the end tables by the couch, and a few are stacked on the floor by her recliner. A large stereo system is in a prominent place in the living room close to her recliner, and there are many tapes, records, and CDs of classical and contemporary music close by. A well-worn Bible is on the table by her recliner.

Her apartment is neat and mostly uncluttered, with restful colors and plain furnishings that are nice but not extravagant. Simplicity and functionality seem to be the criteria for selection and placement of items in her home, since things she uses frequently are placed where they can be reached from a sitting position. In two corners of the dining room are stacks of puzzles and other craft projects, which C. enjoys.

Our interviews took place in the living room or dining room, depending on what supports C. needed for her body. Some days she needed to rest her arm on the table while we were talking. Follow-up questions were done via telephone or by briefer visits, when I was in the neighborhood. Since C. travels frequently, several days elapsed between the time I left her a message and the time we actually could meet.

During some of our visits we looked at things she had found in her boxes of collectibles: notices of special dances she had gone to as a young woman, announcements of events such as Open House at the day-care center where she worked when she first moved to New York, and letters she received from young men in the armed services. We also talked about and looked at things we both had saved, such as flyers from workshops or conferences in which we had both been involved.

C.'s life is calm and peaceful, and her home reflects her life. She is a gracious hostess, seeing to the comfort of her guests. During the time I was with her, she did not let the telephone interrupt our conversation. Her comments were, "Oh, we'll just let the answering machine get that. Whoever it is can wait a little while longer."

## My Experience With C.

My first meeting with C. was when she joined an advisory group on disability issues for the city in which we both were living. I wondered who the tall, stately Black woman was who slowly limped into the room, carefully watching where she was going. When she spoke, she enunciated each word with precision, speaking slowly and deliberately. Besides her gait, the only other obvious sign of disability was the fact that she was holding her right arm close to her side as she walked. Her hair was gray and closely cut to her head. She was dressed simply and sensibly, including her shoes. As she walked into the room, many members of the advisory group greeted her with questions about her health.

For almost five years we worked together, meeting at least once a month for our regular advisory group meeting as well as other times for work related to the advisory group. The work we did was both business and pleasure, since we sometimes went out to eat after the meetings, and other times we worked together on specific projects. Some of those projects included planning an annual conference related to employment of people with disabilities, working on a committee that looked at access to public buildings, and planning a Speaker's Bureau.

As chair of the planning committee for the annual conference, I recruited C. to present at the employment conference several times. Her perspective on the disability experience, as a person who acquired a disability later in life, made her a valued contributor to this event. She could relate to other people in the audience who also had disabilities and faced work-related problems. C. said that the conference was one of the times when "I felt I really made a difference."

C. was a reliable and punctual member of the advisory committee. In almost three years of regular monthly meetings, she missed only two meetings. She contributed valuable information and advice and was never afraid to disagree with the group, although her concerns were always voiced with kindness and wisdom.

C.'s and my relationship during the five years on the advisory group was more professional than personal; however, our friendship has deepened since we both retired from that group. As we have gotten to know each other better, we realize that we share many friends and causes in common. For example, as part of her church she worked on providing hot meals for homeless people that lived close to her church. I was simultaneously working with a group a block down the street on the same issues and for the same organization. We both have worked on other inner city projects, such as the need for low-cost accessible housing.

This study has allowed both of us to get to know each other better and to realize that we have many commonalities, not the least being experiences with disability. C. has added a dimension to my notions of subjectivity, demonstrating that uses of control and power can be quiet and dignified.

## C.'s History

C. was born in a mid-size town Virginia in 1931, the youngest of nine children. Her father died when she was three years old, and her mother remarried when she was seven. C. says that these were years of struggle. Her mother worked at a local college as a maid and supplemented her income by doing laundry for individual students.

Even though her mother worked long hours, C. also recollects that her family always had plenty to eat and adequate clothes to wear. Her mother owned the house in which they lived, had a vegetable garden, fruit trees, and a few chickens and a hog. She sewed most of the clothes that C. wore. C. looked forward to trips to the store for coats and shoes or very occasionally for a loaf of bread or candy.

> Mother always had a job. It didn't bother me that she did laundry for others. Servitude was the only jobs Blacks could have. But mother wanted better for her kids.

Looking back, C. remembers these years as times of poverty that were rich in relationships that shaped her attitudes as an adult. People helped one another. Her family, she reported, didn't seem to be touched much by events beyond their immediate community. They lived in an insular and segregated world. Few people could afford cars except for the undertaker, preacher, or insurance man, who were very generous taking C. and her mother to various events.

C.'s mother instilled in her feelings of pride, in spite of doing what appeared to be menial labor, wearing home-made clothes, and lacking luxuries such as cars. She helped C. understand the importance of pride in who she is as a person rather than what she has or does for a living. From her mother, C. learned that it was acceptable and perhaps even necessary to protect dignity and pride at the risk of losing a job.

> I also cleaned for a woman when I was in high school. I wouldn't say, "Yes, ma'am'" to the woman for whom I was cleaning, and she complained to my mother. My mother told me and my employer that I would address her as Mrs. So and So, and that it was no sign of disrespect that I wouldn't call her "ma'am." This was the first experience I had with people wanting to be treated in a different way.

C. was part of a close family and was raised with love and discipline by a strict and wise mother who instilled in her notions of equality and fairness. In a time when the males of the household were not required to do inside chores, C.'s brothers were learning to do laundry and ironing and had to help with the dishes. They also had to accompany C. to socials in the community. Her mother allowed her children to have parties at home as long as they could play cards, drink, or dance quietly (which was not entirely acceptable for Baptists). For a Black family in the 1930s, recreational and social opportunities apart from home, school, or church were limited.

Although C.'s mother did not have much formal education she was well-read and very religious, depending on the Bible for guidance. Her life was centered around the church, which was accepted by her children as part of their family life. On Sundays and Wednesdays, as well as other times when needed, they were in church or involved in church-related activities. Her mother worked in several women's and youth organizations as part of the church, and she traveled regularly to area, regional and national conventions, taking some of her children with her. She was known among many in Virginia for her dedication and example as a woman of character.

> My mother set a good example for us. She didn't smoke or drink, but she enjoyed being with people and having a good time. She looked for and expressed in many ways the good she saw in people, and young people were drawn to her because of this quality.

These are qualities that C. has today, she believes, because of her mother's influence and example. Their experiences together as C. was growing up instilled in her notions of fairness and responsibility for and belief in others.

Her mother's model for living inspired C. to want to be a missionary from the time she was a little girl. She was encouraged and supported in her goal of working in Christian education. To that end she majored in philosophy and education at a time when very few churches had paying positions in that field, especially for women.

Because of the possibility of finding work in a church in a large city, C. moved to New York in 1951. For C., it was like a dream come true.

> For a young girl not yet 21, it was like a fairy tale to move to New York to live. Since I was living in the home of a family friend, it was like going from one home to another. There were four or five other young women in the house, and we became very close to each other. We had many good times. We would travel together, visit places, and see the sights. On Fridays we'd visit the clubs, not getting home until 2 or 3 a.m. I loved to dance and especially loved going to the Savoy.

C. did volunteer work at a church for about six months before getting her first paying job as an assistant teacher in a nursery school in the Bronx, where she worked for eight years. Many hours were spent working with children of low-income and working parents, observing and teaching them, intervening on their behalf if they had problems. The school was the first accredited nursery that opened in New York for minority children, especially Blacks, and as such it received a considerable amount of attention and prestige. Prominent entertainers came to help with its fundraisers, and from its staff came the woman who founded Hale House.

In 1958 she became a social worker in Queens, New York, a job that had never been handled by a woman. "It seems like I'm always looking for challenges, and that was a challenge." She felt very secure in the neighborhood once she got to know the street people. "They looked after me." The social work was good preparation for her future life and was filled with wonderful, exciting, sad experiences. "I really looked for those children who needed that extra bit of support or encouragement." She also gave extra assistance to single mothers that she met who needed more help than they were getting from existing social services. C. recognized that the decisions these mothers made were not always reflective of their true nature, and that single mothers in particular sometimes had to make decisions that, to outsiders, looked uncaring. In one such instance, a mother lost her children because of perceptions that she was unfit. C. let her know she had faith in her, but that she also held her to a high standard of behavior.

> She was a good mother. The children went to school and were clean. I told her that I would work with her to get her children back, but that she had to promise that she would never again leave the home without someone looking after the children. She did, and she called and stayed in touch with me for several years.

She held the job in New York for 11 years until she married. At that time she moved to upstate New York, where her husband had a job. They soon had two daughters, and she didn't work outside of the home while they were young. She preferred to care for her family and involve herself in church and community activities. Even though these were the years of the Civil Rights Movement, she didn't "get caught up in it." The events swirling around her in the rest of the country had little effect in the town where she and her family were living.

> Having grown up in the South, I didn't feel segregation as such. We had our schools and the Whites had theirs. We lived and played together, and

> we had white families living on the same street. I never encountered prejudice. I was raised to believe that if you treat people nice, they will treat you nice.

In 1972 C. and her family returned to the mid-South. Her daughters were still young, and she wanted to be with her girls as they became part of a new community. The city to which she moved was her husband's home, and although they knew a few people, it was mostly a strange place for C. It was also her girls' first experience in going to an integrated school, and C. wanted to be available to them as they made the adjustment. "They stood out more because of their New York accent than because of their color."

Over the next ten years C. became very involved in her church, taught Sunday school, and served on church committees. As she was a member of the Board of the Lutheran Church Women, C. had the responsibility of helping to plan an annual regional convention as well as guiding local women's groups. One church activity she was responsible for initiating in the early 1970s was feeding the homeless in her town. She and others also tried to get other area churches interested in building homes for the elderly.

During this time C. was also an assistant teacher and reading tutor for college freshmen with reading difficulties. Friends and mentors encouraged her to get her teaching credentials, and as a result of their encouragement she started working on her master's degree in education in 1981.

1983 was a milestone in C.'s life because of the occurrence of two major events. First, a teaching position became available, which was a realization of a dream for her. Secondly, she had a stroke three months after starting the new job.

> I had no headaches, no dizziness. Nothing. One night, in bed, I felt something was happening in my back, like a pounding on my back. I felt numbness in my legs. I just got my second degree [in teaching] when my disability occurred. It was a painful thing to deal with. I had gotten to where I wanted to be in life, with a career I enjoyed, working with children in the classroom, when the stroke came, leaving me paralyzed on my whole right side. I was *determined* I was going to overcome that and get back in the classroom. It took a lot of work and supportive people. It involved a lot of adjustments. I had to learn how to use my left hand to write, to do anything I normally did with my right hand.

C. was in in-patient rehabilitation for four months. During this time she continued to receive therapy, learning to write with her left hand. She also continued to work on completing her master's degree, which was so important to her.

In June of 1984 she learned that her mother had cancer, and she returned to Virginia to take care of her.

> It was my time to help her, with my limited abilities. This was something I could do—sit with my mother. I was with her every day, all day, until she

> passed away in November. It met a need she had for caring and emotional support, and it was helpful for me, too.

In September of 1985, C. reached her goal of getting back into the classroom. She starting by teaching first grade, then moving to fourth at her insistence. She spent five happy and fulfilling years as an elementary teacher.

In December, 1990 doctors found tumors on the left side of her brain. Surgery was required to remove them, resulting in paralysis on her left side and related problems in walking and using her left hand. Tumors were back in 1995, and this time her doctors opted for radiation rather than more surgery. Each episode resulted in loss of balance, difficulty in walking, and increased overall weakness. In January, 1996, C. learned that the tumors had returned but were not big enough for removal by surgery.

Having to deal with the tumors contributed to her decision to take an early retirement from teaching in 1996. Since that time, C. spends her time reading, working on jigsaw puzzles, and involving herself in church and community activities such as her sorority and groups that address issues faced by people with disabilities. She travels when she feels like it, looking for opportunities that are fun as well as mentally or spiritually uplifting and challenging.

How she chooses to spend her time depends on her physical condition. She and her daughters are very close and enjoy time together, such as their family vacation each year. Her daughters do not live in the same city as she does, which is an arrangement that is to C.'s liking. "I haven't thought of moving closer to them. I want to live here by myself, as long as I'm able, and be independent and lead my own life. I'd have my own place even if I were closer to them."

## Who C. Is

C. leaves the impression that she is unshakable, that because of inner resources or life experiences, nothing can happen to her for which she is unprepared. When C. was asked what she wanted people to know about her, she said, "I want people to know that I am a very happy person, despite my disabilities and setbacks." She feels blessed by the love and support of people around her, including her daughters, friends, therapists, fellow teachers, and church members. Her description of coming home for her first visit after her stroke was that it was like coming into a new world. "Just to look at the trees and the mountains, just to be outside and see God's gift of the earth to us was an undescribable feeling."

C. has always been one to accept a challenge, whether it involved moving to New York to find a job in a field traditionally dominated by men, or going back to school and completing a master's degree after she had her stroke.

An expression she frequently uses when describing her life now is, "I am *determined* to…" with emphasis on "determined."

> I was *determined* that I was not going to be frustrated at home. Things that I could not do, I would not worry about them. I had to learn to do things myself, and that's what I've done. You make adjustments. I found that I had to deny myself doing other things I wanted to do because I wanted to

> work. The classroom took up the bulk of my time and energy, so I had to let some church and community things go. Things around the house went undone, like dusting. It doesn't bother me now.

C. realizes the potential impact her disability has on her daughters. Her younger daughter was still living at home when she had her stroke, and it was a frightening experience for the young 18-year old woman. C. feared her daughter might not finish school or that she might not want to move on with her own life.

> I was *determined* that she would finish school. I didn't want her to feel like she had to stay here and take care of me. I needed to show her I can make it—it was my determination. I didn't want my girls to feel like they had to look after me. I want to project myself as "I can do it." That's why I tell people that we all have something—frustrations. Deal with it and go on. Have the determination and look at other people and realize you're doing great.

C.'s determination is also reflected in her outreach to others, which demonstrates her concerns for people in general and children in particular. Her own life was inspired by her mother, by some of her pastors, and by teachers. She ponders about who inspires poor children who live in environments that are unsafe, unhealthy, and with single parents who are struggling for their own survival. She believes that inspiration can come from someone in the community who takes an interest in these children and encourages them.

> I really looked for those children who needed that extra bit of support or encouragement, especially at an inner city school where I was working. I knew there was no follow-through or support at home for those children. One little boy especially was headed for a destructive life unless he got help. I was *determined* he was going to get help. Finally I got him involved in some mental health counseling. He was a very angry little boy who was reaching out for help. I would listen to him and get him to talk about his anger.

C.'s life and words reflect concern for others and personal integrity or wholeness. For C., "wholeness" is more than just adherence to moral principles. She is undiminished by her experiences, including the experience of disability. It has given her an added dimension or perspective that she lacked before, and it has increased her determination to continue to contribute to the lives of those around her. Her priorities and concerns have been, and continue to be, her church, her family, and people in the community in which she lives.

Sharing her life and resources with others is extremely important to C. and reflects the influence of role models she had growing up, such as her mother and others in her community. A successful family in her town impressed C. not only because of their ability to be successful as part of a minority group, but also because of their generosity in sharing their wealth.

> They were one of the few couples who owned a good car, and they would take my mother and me as well as other church members to regional meetings. At that time, most families, especially Black families, didn't own cars.

C. was raised with the belief that her decisions and opinions should be respected, as well as those made by others. When they are not, or when she feels that she is not being heard, she will let her opinions be known. For example, when she was recovering from her stroke and was asked to do tasks that had once been so simple, like getting dressed or learning to write again, she became extremely frustrated and upset with her doctors.

> When I was going to occupational therapy and learning how to write with my left hand, I was so medicated I couldn't hold my eyes open. I told the staff, "You need to tell the doctor to stop giving me so much damn medication. I can't do anything. I can't function!" It was the first time in my life that I cursed. They did—they got the message.

C. commented that sometimes people think they are being helpful when they make decisions for her. At school, the personnel director felt she would do better teaching in lower grades, but didn't give her a reason. C. felt that a first-grade teacher should model good penmanship, which was very hard for her to do right after her stroke. She asked for and was eventually transferred to the fourth grade. At a church event, a woman serving on the board with her decided that an upcoming trip would be too strenuous for her. "I was very unhappy about that and I let her know. I felt she was not listening to me, but she was listening to what she felt about me as far as what I could do."

C. gives careful thought to what she does and says and refuses to give in to anger at what she cannot do. Many times her solution to a difficult situation is to "sit down and think about it. I have to think about ways to eliminate my frustration." She sometimes comes up with alternatives, or she may decide not to do something at all. Things that cause frustration are changed or eliminated, such as trying to decorate a bulletin board. Since she could not reach up and use both hands and arms, after careful thought and consideration, C. turned the job over to her students who did a beautiful job. She contrasts her way of thinking with a recollection of a roommate who had also had a stroke. As she listened to this woman's bitterness and anger about what had happened to her, C. chided her for whining. C. philosophically told her, "Do what you can and accept what you can't. It could be worse."

In her retirement, C. has dreams about what she would still like to do. "I am constantly seeking things in my life that have to do with a quest for more knowledge and experiences." She is still searching for hidden talents that she may and can develop. She would like to write books, perhaps either inspirational or autobiographical. Challenges are there every day.

> Life goes on and I want to be a part of life. In spite of deterioration of my body I still have a quest to achieve and accomplish what I can with the least amount of help from others. I have things I can share with other people.

## Daily Experiences with Disability

C. is one of millions of people each year who acquire a disability later in life and who have to deal with the corresponding change in their ways of living. She has learned to live with her disability in a way that reflects acceptance and adaptation.

> If I find I'm getting agitated or annoyed by what I can't do, I go to my chair and just sit there and relax, close my eyes and think pleasant thoughts. I don't think about what is happening to me. When I need to make myself heard, I do it through my daily living, through things I'm capable of doing, by being involved in various activities, by maintaining a job, by letting people know I'm capable of doing things—without making a statement.
>
> My experience has made me aware that we all have limitations. Learning how to deal with those limitations is what makes us different. Persons who recognize their limitations can identify with me.
>
> Any time you experience a change in your life, especially a disabling condition, you stop and think about what it was like before you

> were disabled—the things you did and the things you can do now. It has made me a stronger person, a more self-willed person than I was before. It made me have a different perspective as far as life is concerned. You think about things you can do with your life that you didn't think about before.

For C., returning to work after her stroke was not only the realization of a dream, it was also an affirmation that she was able to do the work for which she had trained.

> Work has a lot to do with my self-esteem. I think of it as "building yourself." It's important to prove to yourself that you can do the things you once did prior to disability. That you can still be part of the work force and handle a job.

C. says that there are two facets to her life: an experience of being able to do anything, and a post-disability experience of limitations in how things can be done. Part of the post-disability experience is related to loss of control.

> You begin to think about the control that life can present to you and whether you are ever totally able to have the control you want to over your own life. That is a different perspective that you gain. I didn't think about control prior to my disability.

Another change in C.'s life has been her feelings about other people with disabilities. Her acceptance of others with disabilities has changed to being more sensitive to their needs and issues, more genuinely helpful, more caring, and more sympathetic. Her experience in the community as a woman with a disability has helped develop this sensitivity. She is more aware of the kindness of strangers and of gestures of help that were either not offered prior to her own disability, or that she did not notice. For example, grocery store staff offering to put her groceries in the car for her, or returning her grocery cart to the store are simple gestures of kindness and consideration that she did not appreciate or notice before.

> I've noticed that people as a rule are not sensitive to the disability experience, and that doesn't bother me. They've not had to deal with it, and they're not thinking. Some people with disabilities get very angry at this lack of sensitivity. Sometimes I just ask the clerks in the store to not make my bags too heavy, and sometimes I've not made that request just to see if they were aware of my needs. I didn't get angry when they forgot. I just stepped over to the end of the counter and asked for another bag. If they're not aware, then make them aware.

Many different words are used by people without disabilities to describe the disability experience: coping, adjustment, inspiration, helplessness, anger, stricken. C.'s words and strategy are fairly succinct: "I deal with it and go on." Neither does C. define herself as powerless or a victim.

> I'm 65, I feel very good about my life and what I've accomplished. I've got a good education and have been able to work in two fields I love, social work and education. I've raised two beautiful daughters of whom I'm very proud, and I'm learning to overcome my limitations from the onset of my disability. Those are my greatest accomplishments. I feel like I can do *anything* I set my mind to. I don't want to focus on disability. It's part of my life. This is what happened to me. Life goes on and I want to be part of life.

## *D.'s Story*

### Setting for Interviews With D.

I have worked with D. in a variety of settings over the years. Some of our meetings were in her office or mine, some in restaurants or other public places like hotel lobbies and once in her accessible van. Other settings included state offices, conference centers, and community centers where we were doing presentations, trainings, and workshops. We also frequently communicate by telephone and electronic mail. She has not been to my home, nor I to hers.

D.'s office was simple, uncluttered, and utilitarian. Her desk and adjacent book shelves were neatly arranged, files in place, telephone, pens and note pads handy, and furniture arranged so as to give her maximum accessibility. Her office had a gray area carpet with closely woven pile in order to facilitate the movement of her wheelchair. The only decoration, hanging on the white wall behind her desk, was a large framed poster of Dr. Martin Luther King's "I have a Dream."

I have had the pleasure of attending a reception in her honor at one of her city's finer hotels after she was given an award for disability awareness activities by her city. This was one of the few occasions that I saw her relaxed and at ease with those around her. She was attractively dressed, wore makeup and jewelry, and was filling the role of a gracious hostess. She circulated around the room, greeting people with hugs and handshakes, making everyone feel welcome.

On another occasion we were together at a national conference held in a resort center. She had been asked to entertain the group with one of her folk songs. It was another rare occasion in which she seemed to "let down" her defenses. D. sung many songs about disability rights to the accompaniment of a friend's guitar and seemed to thoroughly enjoy entertaining the crowd. Between songs she joked and laughed with the crowd and got us involved in the moment. With her rich voice and expressive movements, she took us back to the folk songs of the 1960s and 1970s.

After she moved to another city we continued to stay in touch, mostly by telephone and e-mail. We have met twice since her move. I have not been to visit her in the city where she now lives, but from her description, her life seems to parallel the one she had before she moved. She lives in an accessible apartment fairly close to her office and drives herself to work. She depends on attendants or hired assistants to help in some tasks of daily living like cleaning, laundry, and shopping. Her day is filled with meetings with her staff and public officials, spending time on administrative duties, planning public meetings and advocacy events, and writing.

## My Experience With D.

D. gives an impression of frailness when you first meet her. She is in her mid-40s, thin, shoulders slightly drooped, with light-brown hair that hangs straight on her back. She has a wide smile and hearty laugh. Her voice is low-pitched, and her words are carefully selected and articulated. One of her joys and gifts is singing songs written about disability rights.

D. was born with spinal muscular atrophy, which is a progressive disease in which the motor cells of the spinal cord deteriorate, affecting first the extremities. She now uses a power wheelchair for mobility, and although she can still use her hands, both her hands and feet are curved in as a result of her disability. D. moves quickly in her power chair, and most walkers moving with her have to move fast to keep up.

D.'s clothes reflect the hippie movement of the 1960s in that they are colorful, free-flowing, and creative. She leaves the impression that clothes are not important, but rather are for comfort, warmth and convenience. She prefers long skirts that cover her legs and feet and wears soft leather ankle-height black boots. I have seen an occasional necklace and earrings, but little other jewelry or makeup.

My first working knowledge of D. was when she joined the staff of an affiliated nonprofit disability organization in our state. We were part of a state-wide network of agencies that had received federal funding to do systems-change work. As part of that network, we met many times during the year to plan workshops and conferences, set state-wide goals, do staff development or presentations to various groups, and to participate on the state's advisory council. I had opportunities to watch her train other people with disabilities on how to become self-advocates as well as advocate personally for herself and others. During and after these meetings we would go out to eat, using the time to continue talking about issues, family, problems of daily living, and many other topics.

It took me awhile to get to know D. and to really like her as a person. She intimidated me at first, because she challenged my perceptions of what a person with a disability can be and do. I had not met a female lawyer with a disability before. She can be terribly objective in a conversation or debate, which leaves a person watching her with an impression of coldness. For example, in a meeting that seemed to be heading in one direction, such as developing a project's yearly goals and activities, D. would counter the direction the group was going, bringing to our attention that goals for disability-related organizations might not be the same as the goals held by individuals with disabilities. She could also disentangle herself from loyalty to her employer to address wider needs. I couldn't figure her out. It was an unsettling experience for me. I had heard rumors, also, about some of her advocacy activities away from her job. I had difficulty reconciling the cool, quiet, professional woman at the meetings with the disability advocate who participated in activities that might lead to arrest or jail. This woman, who is frequently called a "wheelchair warrior" by herself and others, was an enigma to me.

I wanted to know more about her and, more importantly, I wanted to try and understand her ways of thinking and doing. I have talked to D. for hours, observed her in many different settings, worked with her, read about her in the press, and listened to the songs she sings in an attempt to reach the heart of who she is. Understanding D. required me to think outside the model of linear, logical thinking.

## D.'s History

D. is extremely reticent about her personal life and history, preferring to talk about the disability movement that is so dear to her. Consequently, I had to go back to documents she had provided to me to piece together parts of her history. The following excerpt is taken from a speech she gave at a disability pride rally several years ago. It succinctly tells her history.

> I was raised by parents who adopted me at the age of ten days. When they found out that I had a disability, the foundling home offered to take me back. Fortunately, my folks kept me. I attended a segregated elementary school. There was not mixing between disabled and nondisabled children in the regular school, which was attached to ours by a corridor. We traveled down that corridor every Thursday to the regular school library, after they had cleared out all the nondisabled children.
>
> We were never allowed to see each other—they were kept safe from their discomfort at seeing our different bodies and hearing our different voices—and we were kept safe from their ridicule and rejection. At home in my neighborhood, all my friends then were nondisabled. We played in the sandbox, we played with dolls and games, and when the others ran up the street to see the horses in a field next to our post-World War II housing development, it took me a little time to catch up. (I walked until I was 11.) I always caught up, though, and tried to act and feel as though it didn't matter that I arrived last to be with my friends and look at

the horses. Then came junior high and high school. I was "mainstreamed," along with one other girl who used a wheelchair, amidst hundreds of nondisabled classmates.

From ages 12 through 18, I wore a Milwaukee brace on my back, which consists of three metal bars arranged vertically between a leather chin piece and waistband. I remember being in the hallway between classes, hearing a boy tease his friend, pointing to me and saying, "There goes your girlfriend." I became an officer in my senior class of 400, and graduated valedictorian, but the high school officials decided to have the class president and not the valedictorian speak at graduation.

College was my great escape. I managed to become independent in all the necessary activities of daily living. At this point, the last thing I wanted to be was disabled. For the next decade, I guess you could say I "passed," to coin a concept from the African American movement. I took it as the greatest compliment to be told by a nondisabled friend that they didn't think of me as "handicapped."

I built a life in the mainstream, the nondisabled world. I married and started a professional career. I didn't see any discrimination in my life, although my job didn't match my degrees. But I really didn't see discrimination as a major issue in my life. True, I couldn't use the inaccessible restroom for my first three years on the job, so I didn't drink liquids until 2 in the afternoon, but I didn't see any serious discrimination in that. After all, it wasn't intentional. Society just needed to be educated and informed about our common humanity, I thought, and these minor problems would be remedied.

Well, I was such a successful professional-type crip, I was asked to join the board of one of the largest independent living centers in the country. That was 11 years ago, and that was the turning point for me. As I became involved on more and more committees, commissions, and task forces, two things happened. The most important thing was that my disabled brothers and sisters shared with me their personal histories, and I got to see my life through their accepting, loving, angry and spirited eyes. The second thing that happened in all those endless meetings is that I saw, over and over again, that awareness and education are almost never enough. In one of the most aware states in the United States, our state university, which is subject to Section 504 of the Rehabilitation Act, still had no disabled parking on campus.

I served on the chancellor's disability task force that got nowhere. But on the day our community brought together a hundred people for a disability rights rally at the university administration building, a TV reporter touched the new designated parking places and announced on camera that the blue paint was still wet. 1987 was the year of my first arrest in our civil rights struggle for accessible public transportation. Then, for the first time in my life, I felt proud to be disabled…not proud of what I had accomplished in spite of my disability, but proud because I am disabled.

In our conversation and interviews, she elaborated on some of her early childhood and school experiences. Making friends was hard for her as a child, particularly when she went from special education to mainstream classes in the sixth grade. She did make able-bodied friends, though, which she considers an accomplishment for a teenager with an obvious disability. Like any teenager, her social life suffered because her parents had to transport her, although "it was a big production to get in someone's car."

In the fourth grade, a friend got her interested in reading, and her grades went from Cs to As. As a result, she made up her mind by the sixth grade to go to college. Her dad exerted significant influence on her as well. He encouraged her to strive for a career that would be able to provide financial support, and he stressed the importance of being successful. He told her she would be a "career woman" rather than getting married, in contrast to what he told her sister.

> I didn't believe it, but I internalized it. It hurt my feelings a lot, and that basic way I was brought up governed my life until I was in my late 20s. It evolved into a point of view. I should do whatever was as normal as possible. I didn't own my identity, and I guess it was my way of dealing with stigma, my way of proving I was okay. I adopted society's standards to fit in as best I could. I did meet a man, fall in love, and get married.

Her parents were conservative, and even at an young age D. realized that there was too much readiness on the part of many religious people to not speak against segregation. She also realized that segregation included *her.* She started reading philosophy and developed "some hodgepodge" of beliefs.

> I came to the idea that I have (we all have) an obligation to do the best we can with what we've got, and we all have a part to play. I have a personal sense of spirituality, but I can't define it. I have a belief that I should do what I can to foster personal growth, do what I can to assist the growth of others, and try to use my skills and abilities to do that.

D.'s career in law and social work was mostly caused by the fact that her school science lab was not accessible. In the late 1960s she had started her college studies in the fields of science and math with the intention of being a biochemist. She earned an undergraduate degree in psychology and worked as a medical social worker. D. wanted to do some kind of work that would have a positive impact on society. The protests of the 1960s had a significant impact on her, developing in her a strong sense of social justice and feeding her desire to see good people in government. Her MBA and law degrees were the first step in addressing the social needs of those without power.

> I grew up in the 1960s. Is my activism a result of the culture of the 1960s or my disability? I'm not sure. I know that my disability influenced my orientation, and the counter-culture notion that you can rebel and reject society's standards helped me become stronger. It was important for me to feel able to reject cultural norms. Little did I know that there would be no

> protesters in the early 1980s, which was the beginning of my involvement in the disability movement. That movement and my desire to assist in social change came together, and I began to feel or connect that people with disabilities are part of the civil rights movement. I always had a form of empathy with the Black civil rights movement, but I didn't see the disability struggle as a legitimate civil rights movement until my early 30s.

D. has continued her work in the field of social justice. Since the 1980s she has been an active member of several national disability protest groups that focus on issues such as transportation, attendant services, and assisted suicide. In 1996 she became the director of an independent living center in the belief that in that role she could more effectively work in the national disability movement.

## Who D. Is

"I'm a liberated person with a disability, and this is what has made me a person of strength." These words reflect the essence of D. She cannot think of herself apart of the disability movement and disability culture that has shaped her, influenced her friends, relationships and activities, and continues to direct her life. As a national leader in the disability rights movement, she speaks with eloquence and fervor to local, state, and national leaders. She says about herself, "Maybe I have a Messiah complex—or a huge ego!" She prefers to not talk about herself or her personal struggles, but rather to focus on the disability movement of which she is such an integral part.

She relies on a song about pride written by an English disability activist to describe herself and her life. This song also reveals the depth of her feelings about her own pride as a woman with a disability. Every word is important to her because through these words others may begin to understand how a person with a disability can feel strength and connection in the face of loss. This song has helped me understand that disability strength is not about anger but about pride. When I attempted to edit it for this study, she went back and hand-wrote in the remainder of the verses. D. never passes up a chance, even to the readers of this study, to change people's perceptions about disability.

> Pride is something in your soul;
> Pride is somewhere you are in control;
> Pride is peace within that finally makes you whole;
> Celebrate your difference with pride.
>
> Pride in yourself is bound to set you free;
> Pride in who you are—a person just like me.
> Pride and self-respect and gentle dignity;
> No one can take away your pride.
>
> Pride can make you angry, pride can make you strong.
> Pride's the key to unlock the doors to the rooms where you belong.
> Pride is our destiny and where we all came from—
> Turn around and embrace your pride.
>
> Pride can make you equal without your liberty.
> Pride can give its freedom to a prisoner like me.
> Pride is always with you wherever you may be.
> Once won, you'll never lose your pride.
>
> Pride is the rocky road that straight and doesn't bend;
> Pride's the path you follow,
> Pride's your closest friend.
> Pride's the source inside your heart from which you can draw
> strength;
> Begin all your journeyings with pride.
>
> Pride's the bond between us.
> Pride's the bridge we burn.

> Pride's the victory, the battle from which we shall return.
> Pride's the spark of fires within, the crucible, the germ.
> The seed of our power is our pride.

She scoffs at words like "dedicated," "inspirational," and "empowered." She defines herself by saying, "I'm a disability rights activist." When asked by a national reporter why she would want to go out on a cold January day to protest assisted suicide, she said, "The court's police…assumed there would be only a tiny group there. They thought we were weak and unable. We proved that we are strong and *disabled.*" She knows that many people believe they would rather be dead than be like her and others with disabilities.

> So if one of us becomes depressed and suicidal, most people conclude that our feelings are rational. They don't try to understand or respond to whatever our real problems might be, problems for which society is largely responsible. They base their decisions on their fantasies of how miserable our lives must be.

A *Not Dead Yet* poster says, "Sure cure for depression: don't take it personally. Take it politically." D. does. She sings, in a different song, "We've waited long enough…it's wrong to keep us waiting…all we ask for is justice." Her struggles, and those of other people with disabilities, must be in the form of resistance against discriminating policies or those that deal with unfair allocation of increasingly fewer resources.

D. believes that who she is and what she has become is a result of her disability and our culture. As a proponent of disability culture, she believes that disability is a difference and that being disabled in itself is neutral. “Society perceives disability as overwhelmingly negative, the Jerry Lewis-poor crippled people theory.” People with disabilities are a minority group that share certain commonalities and is heavily stigmatized and devalued by our culture. “We’ve got a lot of layers of pat-on-the-head b.s. to cut through to reach the heart of who we are.”

> We are a marginalized people, like women, people of color, people who are gays and lesbians. Our culture says we have no role except as victims or objects of pity in society, or a commodity around which money can flow primarily to others. We’re to be cared for by nondisabled folks who direct and control the resources.

Her remedy for disability-related problems is to change the interaction between the individual and society, which is the stimulus for D.’s disability rights activities. One of the philosophies of the independent living movement which guides D.’s life and activities is that “if we want something done, we can do it ourselves” (*Mouth,* July, 1996, p. 17). Another comment she frequently makes is, “Nothing about us without us,” referring to anyone who might attempt to make a decision for her without asking her first.

The result of a change in interaction between the disabled person and society is greater power for the person with a disability. D. defines power as having a greater number of alternatives and choices. D. says, “I hate the word ‘empowerment.’ As Lucy

Gwinn of the *Mouth* says, "Get rid of 'em' and 'ment.' We want the *power.*" What is often hard for D. is convincing other people with disabilities of the need for power. She is frequently frustrated by the fact that many people who have disabilities do not insist on real power, which takes learning how systems of authority work. It leaves the burden for pushing for disability rights on a few.

> Because they grew up non-disabled (and about 90% of people with disabilities have acquired them), they have internalized the perspective on disability prevalent in the main culture: they hate their disability and they hate being disabled and they don't want anything to do with it.

D. is also frustrated by the impact our culture has on the development and maintenance of friendships, something she learned about as a child. She admits to prolonged loneliness, calling it "...the hardest thing in life in adjusting to disability." She has developed close relationships to both men and women, but they have been affected by cultural stereotypes and discrimination.

> Disability-based discrimination is deep-seated, virtually unconscious, pervasive, and overwhelming. We are the proverbial canaries in the coal mine. We need to resist devaluation of our lives.

D. struggles to help society understand that being defined as disabled can be positive, not negative. Her perspective is counter to the notion that many families and caring service providers have that a disease or disability defines a person, or “spreads” to all parts of a person’s life (such as when uninformed people yell at a person who has a limp, for example). D.’s perspective is that this kind of “spread,” the spread of disability identity, is not necessarily negative *if* the person with the disability can embrace and act on the growth and development that comes as a result of the disability. If a person has embraced her disability, she will talk and act in such a way that reflects pride rather than shame.

D. believes that the impact of disability should not be measured by a person’s degree of independence or material productivity in society. In her opinion, people with disabilities have learned many skills that can lead to the survival, growth and transformation of all people. Some of those skills are learning to live with change, respect for others, and tolerance of difference.

> The most important survival trait of the human species is not the physical strength or intelligence of any individual. Our most important survival trait is caring for each other. It’s not our independence but our interdependence that teaches us how to live.

D. ends her stirring statement with the wry comment, “Now, having come from national demonstrations that confronted key players in the nursing home and managed care industries and in the U.S. Congress, I’d like to say this message another way, but it’s not printable.”

## Daily Experiences With Disability

D. does not talk much about the efforts she makes on a daily basis, such as getting out of bed, getting dressed, or going to work. When asked what strategies she employs for dealing with unpleasant or difficult tasks, she said, "I just do it. Like talking to someone who won't welcome you. Or I hire a housekeeper." She has used attendant care in the past to help with tasks of daily living, and she is very dependent on a cell phone and friends for assistance if she has trouble away from home. On more than one occasion friends have also had to bail her out of jail.

She prefers instead to talk about her challenges as a person with a disability and the struggles of the minority group of which she is a member. "I deal daily with other barriers. It's just routine. I do what I have to do." One of the greatest difficulties she faces on a daily basis is the development and maintenance of relationships with other people. Work sometimes causes her to neglect personal relationships, but she says she always seems to choose work over personal needs. She is looking for a better balance in her life, trying to figure out how to spend a little more time with people she cares about and less on work and disability-related causes; but, as she says it, she laughs and says, "Oh, well—"

Her belief that she has the responsibility and obligation to do the best she can in any given situation drives her daily decisions and actions. She looks for opportunities to contribute and learn, based on her belief that people with disabilities are a major part of the evolution of our culture and will become more and more significant in the future. D. is an active participant in groups that deal with issues faced by the aging population because of the commonalities shared by people with disabilities: attendant services, alternatives to nursing homes, and long-term care issues. As a result, daily activities may involve meeting with her state's legislators as well as representatives of lobbying groups or other agencies. Her schedule is full and her time is carefully allocated and planned. She feels an obligation to prod those in positions of power into making appropriate decisions for people who live on the margin.

> Marginal living isn't stable, but we do point to the direction in which society is moving. Our society is making a choice between people and money, and we're at a cross-roads, where we have to decide what is more important.

Issues of daily living take a second place in D.'s life to those related to the disability movement. She is a driven woman, and like other people who live with that degree of focus and intensity, she sometimes leaves the rest of us with our mouths agape. I won't say I have come a long way in understanding her and the way she lives. Her slogan of "Don't take it personally, take it politically," sometimes seems to apply to her personal life as well. However, I respect her enormously. Not because she has a disability, but because she believes in something so intensely that she is willing to give of herself for other's benefit. In my mind, she exemplifies subjectivity. Perhaps more than any other woman in this study, D. has shown me that being a woman is more about being strong and proud of who I am than what I look like.

## *K.'s Story*

### Setting for Interviews With K.

K. and her daughters live in a first-floor apartment in a large complex located off a busy four-lane highway. Within walking distance is a convenient store and a bus stop, and other buildings and businesses such as churches, beauty shops, and doctor's offices are close by.

K.'s apartment is sparsely furnished. She has placed a couch, one chair and floor lamp in the living room. The adjoining dining area has a round table and four chairs. A few small pictures of landscapes are hung high on the walls. The kitchen, which is an extension of the dining area, is completely free of all clutter on the counter top and stove top. There are no jars, bottles, decorations, spoon holders, or other paraphernalia that are found in most kitchens. The only cluttered space is on the door of the fridge, which contains magnets, school pictures, and notes. By the wall telephone in the kitchen is a small table on which is a portable Braille notebook.

The floor, which is carpeted, is also free of clutter. Personal things, such as books, music, and clothes are kept in bedrooms and closets. The dog's water dish is placed in one corner of the hallway leading in from the front door, and her leash is hung nearby on the doorknob of the hall closet.

There are sliding doors between the living room and a small outside patio, which backs up to a hillside covered in ivy. This is a private, quiet place that the family, including the dog, enjoys. K. has placed a swing and a few other pieces of outdoor furniture on this patio, and in the adjoining storage room the girls keep their bicycles.

When the dog is not working, she has the run of the house and is like any other dog. Her toys are kept in a place only she seems to know about, and during our interviews and discussions she would periodically bring K. or me a different one to throw for her.

K. explained that the floor is kept free of all clutter for safety reasons as well as for cleaning. She does the vacuuming, dusting, and most of the cleaning in her apartment, so it is important for her to know where things are. She is usually barefoot in the house so that she does not stumble over any items her dog might have left on the floor. Furniture is not moved around. Her daughters help with dishes, labeling food when they bring it from the grocery store, and folding clothes.

The simplicity in K.'s home and life is probably the result of her blindness and her economic condition, which allows her enough money for food and rent and little else. No luxuries or frills are evident. K. reads Braille, but there are no Braille books visible in the living areas of her house. Noticeably absent in the downstairs living area are other print materials such as magazines, books, and newspapers. She depends on taped books for most of her leisure reading.

Since the bedrooms are upstairs, the girls usually went to their rooms while we talked. Some of our talk was at the dining room table, after we had eaten lunch. Sometimes we sat on the couch, and other times outside, if the weather was nice. Most of our interruptions came from the dog, when she thought it was time to play, go for a walk, or eat. The girls rarely interrupted our conversation because K. asked them to let us talk in privacy.

I felt an underlying tension in her home. The family seems to get along well with each other and enjoy each other's company, but I felt that they were on guard. The experiences they have had with neighbors in their apartment complex and with strangers when they go out in public have left them with what might be called "an attitude," but is more likely a shield to protect them against further hurt.

## My Experience With K.

K. fits the description of many women in America today: She is divorced and mother of two young children. She lives in an apartment with her daughters on the outskirts of a medium-sized southern city, close to public transportation She depends partially on social security for her income and support from her ex-husband for her children. Her family live in the same city, although not close to her.

K. is blind, although that is not readily apparent. A stranger looking at K. would see that she is a small-boned, petite woman who looks younger than she is. She has shoulder-length blond hair, sometimes wears glasses, is attractively dressed, and walks quickly and confidently in her home without assistance, and outside her home with assistance from a guide dog. She looks directly at whoever is speaking, which sometimes allows her to pass as a seeing person. She laughs readily and easily, speaks quickly and fluently, and moves with grace and certainty. Those that take a longer look also notice her long, agile fingers that are used effectively in many ways, from strumming a guitar to manipulating puppets and reading Braille.

K. is a complex woman, a fact she readily admits. She does not easily accept or appreciate unsolicited offers for help, nor does she appreciate interference in raising her children. References to blindness irritate her. When people cross into her personal space, they are quickly and effectively rebuked. Her guide dog is included in that personal space, as are her children, but few others.

I have known K. for almost 10 years. We were introduced through an article about her in the local newspaper shortly after she completely lost her eyesight because of glaucoma. The newspaper story reported that her family had gone to a local restaurant to eat and had been denied entrance because of the presence of her guide dog. At that time I was looking for people with disabilities who might be interested in being part of an advisory group in an organization where I was working. I called K. and found out that not only did we know many of the same people, but that we also shared concerns about some of the access issues in the city where we both lived.

My phone call was the beginning of several years of working together and an ongoing friendship. K. and I worked together on an advisory group for the city, and I often provided K. and her dog transportation to and from the meetings. We went out to eat after the meetings, visited with friends, worked together on conferences and other public events, and helped each other in different ways. I asked K. to help me in a grant-funded project that was designed to increase awareness of issues relating to including students with disabilities in general education classes. She and her dog went to school, helping students understand how she accomplished every-day tasks. She encouraged them to ask her questions. "I love questions from children because of their honesty."

K. and I have done a lot of laughing together, as well as work. One particular incident that comes to mind is when I picked her up at the university on the way to an advisory council meeting. We were all thirsty—two women and one dog. The people at the drive-through window didn't understand the need for two glasses of iced tea and one bowl of water without ice! K. usually gave me directions to wherever we were going, because she knew I easily got mixed up in an office building where all the doors look the same. She says, cheerfully, "If you want good directions, ask a blind person."

I had an opportunity to help K. keep some equipment that vocational rehabilitation had provided for her to do her school work. Between health problems, stress related to going to college, and raising two children, K. was having difficulty going to school the number of hours that VR required her to go. A diligent and stubborn counselor kept track of details like this and demanded that K.'s equipment be returned. K. refused, and I agreed. We wrote the regional supervisor protesting the counselor's actions, and the case was dropped.

K.'s guide dog and I had a special relationship. Neither of us ever figured out whether or not we were friends. He usually greeted me with growls and snarls, stared at me if K. left him with me for even a few minutes, but always appreciated dog treats and other handouts left in the car. When K. gave him the command to follow me, he drooped, visibly. When we let him lead (even though none of us knew where we were going), he strode proudly, head erect. At home, he would bring me balls and other toys to throw for him. He usually laid on my feet during meetings, and particularly loved shoving his nose up women's skirts. K. knew of my love for dogs and would occasionally allow me to pet and play with him, but we understood each other's territories.

When K. asked why she was selected to participate in this study, I told her that it was because she was a friend, a woman with a disability, with whom I had shared experiences that included her use of agency. This study is as much about mutuality and what we have done together as it is about a common disability experience. K. says that having a disability is not about being brave or inspiring others, but about every-day living without someone getting in her face.

## K.'s History

K. was born in the 1960s, lived with her parents and sister in a neat middle-class suburban neighborhood and attended a nearby school with her sister. She was born with a disease called aniridia, a congenital absence of all or part of the iris. Until she was 27, she had some sight, although she was considered legally blind when in elementary school. Although it was standard procedure when K. started school to send children who were visually impaired to a school for the blind, her parents insisted that she go to the same school as her sister and be included in general education classes.

> My mother was real demanding in a good way. She never let me use my eyesight as an excuse for anything. She made me do everything that normal kids did, within reason….and there were times when I had to prove to her that I could do something. She didn't want to send me away to a special school because she wanted me with the family.

K.'s experiences going through school shaped many of her attitudes and actions as an adult. "Being mainstreamed is one of the most significant things that ever happened to me" because it showed the school system that it could be done. K. was the only child in her school who had a visual impairment, and although she had friends and teachers who helped her, that is not what she remembers most. She felt traumatized by her teachers' lack of sensitivity and training when it came to making modifications for her.

> The children were very cruel and the teachers were, too. I remember what all the other kids did and said, and their reactions....Those years were very difficult. It was real hard. The most equipment I had was a magnifying glass and big print books, but the books didn't help. So here I was sitting at this little desk and this little bitty kid smaller than my daughter holding a book this tall (moving her hands) and feeling like a freak already. I thought, I'm not going to use these books. At least with the small print books I had the ability to hold them close to my face!

K. admits that she was uncooperative and rebellious upon occasion, particularly when cooperation would have singled her out for more attention than her peers. "I was very uncooperative because I didn't want to be different." One of those occasions was when all the students received their annual eye screening. As she stood in line listening to the children in front of her tell the examiner the letters they were seeing, she memorized what they were saying. As a result, she didn't miss a letter and went home with a report of 20/20 vision. Her mother was furious at her and school staff. "That was so funny. I remember thinking, "Wow, I can really do this." I was proud of that for days."

Another example of rebellion occurred in the seventh grade, which K. almost failed. Schools in the 1960s and 1970s were dependent on mimeograph machines, and sometimes the copies were very light. K. simply could not see them, nor could she read them. When she told the teachers she couldn't see them, they would not provide her with darker copies. They told her, "That's all we have!" When K. asked her friends to read them for her, they got behind in their own school work. Because it was more important to her to be accepted by her peers than to do the work, she rebelled.

> I got so tired of trying to use those mimeographs that I quit doing it. I quit asking. I almost failed seventh grade. I got in big trouble. My mother said, "Why can't you tell your teacher?" I couldn't tell her that I *had* told him—but he wouldn't believe me and wouldn't help me.

K.'s frustrations at school were not limited to the classroom. She laughed as she remembered a playground experience, but her words "You never get any down time," are echoed in experiences she has had as an adult. What looks like an ordinary experience may not be, particularly when you're blind. These so-called ordinary experiences can produce significant levels of stress.

> When you go out to a playground...everybody *runs* to whatever they want to go to, and even if you know where the swing set is and the monkey bars are, you think, how many kids are in my way to get there? Or, who put the ball there I'm going to trip over? And you can't *run* out there. You can't do it. You have to walk s-l-o-w-l-y. And that may seem like a small thing, but it's not. It's a big thing. I want to climb the monkey bars. How many people are on it already? And then they yell at you, "Get down, kid. Wait

> your turn." You have to listen real carefully. You're concentrating so hard. You *never* get any down time.

"Because of how I had to grow up in school and how inferior and different I felt," K. turned to music. Listening to records and the radio was a favorite pastime. She took piano lessons for several years as well as being in the school band and choir. In high school she saved her money, bought sheet music and a guitar, and taught herself to play it. When her parents saw that she was serious, they paid for lessons for several years. She became proficient enough so that she substituted for her teacher in an introductory course at a local community college. Transportation was a problem since she had to depend on other people to take her to and from classes, and K. felt like she didn't get much support from home. As an alternative, she taught guitar lessons to others in her home for years. Music was an escape from the reality of daily living.

> If it hadn't been for my music, I would've gone insane. I would sit on top of my dog house for hours—just like Snoopy—and I would play for hours and hours. That's all I had.

After K. finished high school at 17, she again went against her parent's wishes and other's expectations. Although she was told she wouldn't get married, she did. And although she was told that she couldn't have healthy children, she had two. Her mother worried about how she would take care of her first baby. "Although she never let me set boundaries on myself, she put them on me, lots of times." That was a hard time for K. because she felt that she didn't have the support she needed from her family.

K. was divorced from her husband after 10 years of marriage, an experience she calls "more traumatic than losing my eyesight." She moved to a different part of town, partly because of the lack of public transportation where she had been living. She and her daughters have made friends in their new community. Her life now is divided between raising and home-schooling her daughters, church activities, and activities in the community which are important to her.

When K. was 27, she lost the rest of her eye-sight. This was a turning point in her life because she felt that for the first time in her life, people had to listen to her. "They didn't know what to do." She had two children who were dependent on her, and she had no intention of going home to live with her family. "I was not going to sit back or crawl into a corner." For the first time, she was able to be with other people who were blind. They gave her the support and encouragement she needed to become strong and resilient.

> I remember telling my sister in the hospital, "There's a whole new world out there for me to find out, and I'm going to meet that world. I knew I was going to take that world by storm—this new world I was going into, because I wasn't going to be the dirt ball in the corner in this world. I stopped feeling inferior when I met other people who were blind, who had been blind all their lives, who had gone through things I had gone through.

## Who K. Is

Describing and defining K. is difficult because she is reflective and reticent about herself. "I'm different from day to day, like the commercial. Some days I'm cotton, or denim, or silk." Some people say that K. is touchy and hard to get along with. Others call her moody, sometimes seemingly depressed. Her reaction to their opinions is that they are the ones who usually cause her moodiness or depression, like when they try to be helpful without asking her first.

> My story is not about preaching blindness on a street corner, but can I get to the local grocery store and back? Can I live my life without people getting in my face, and if they get in my face, dealing with them?

K. admits that she's sometimes rude, especially when she's had a bad day. "It's not the blind thing. Sometimes I walk off and sometimes I say something. What's so funny is that when I say something, people think I can't deal with my disability!" She refuses to be stereotyped into the "little blind person calling and asking someone to buy light bulbs." She also doesn't like to focus on "the blind thing." "It just happens to be something I have to deal with, and if I weren't blind there would be something else. Every person has barriers and walls."

K. suspects that several factors contribute to her defensiveness. One factor is that she didn't meet other children who had visual problems, so all her peers were able-bodied. Compared to them she felt different and inferior. She also is a very small woman, and that fact encourages people to treat her as if she were a child.

> I looked like a little girl, even when I was 17. I was short and skinny, and my mother always kept my hair short. I looked like a boy. It took me a long time to mature. I felt like a freak. I never met other people who were blind or visually impaired. I thought other people were better than me.

K. bases her strength to deal with daily issues and outreach to others on her faith in God and support from her church. "God seems to put me in touch with people who need help, and I can see Him working in every aspect of my life." She and her daughters live close to her church and all are involved in activities there, from singing in the choir to participating in women's groups. "At first everybody kind of walked on eggshells. It took awhile for them to get use to me, especially the choir director." In comparison, now, "The eggshells are broken—they'll talk to me like anyone. And they've gotten past talking to me about my dog. They see *me* now."

K. is active in the community, but she is "choosy" about her activities. She reminds people who ask her to be on a committee or to participate in an event that it might be "for only a hour" for them, but for her an hour-long event becomes all day by the time she waits on public transportation, transfers to other buses, walks to the meeting, and then reverses the process. Another reason that she has become more selective in her activities is because she accepts personal limitations and has learned to prioritize what she does.

> I've come to the point now where I really weigh what I do. I was never saying "no," and I was exhausted all the time. The issues will always be

> there, and it's not that I don't care about them. Before, when I lost my sight, I had to show everybody I can do this and this and this....But guess what? K. couldn't....And then I felt like a failure. I don't have to be this super-blind person anymore. I don't want to.

Activities that are important to K., besides her church, are related to disability awareness. One such activity is being part of the Kids on the Block puppet show in which she goes into area schools and helps children understand living with blindness. She loves the questions children ask her, from how she ties her shoes to how she feeds her dog and shops at the grocery store. When the puppet show is over she helps them understand that she does the same things they do and that she is not helpless. For example, she will tell them to shut their eyes, find something in their desks, and identify it without opening their eyes. She points out that they know what it is because it is familiar to them, and her experience is the same. "When you're doing disability awareness activities you don't want to scare people half to death. If you want to make people aware you want them to understand."

K. also helped start a support group for students with visual impairments. She remembers what it is like to be the only child in a classroom or school with blindness. She has learned about the need for support and companionship from others who are going through similar experiences.

> It's nice to be able to function with people who don't have disabilities, but it hinders your self-esteem so. When the kids in the support group get

> together, even if for summer camp for a week, it helps, for a little while anyway. I don't regret being mainstreamed, and I'm glad I wasn't kept in the blind world. You can't stay there. It's not reality.

One of the most important things K. does as part of this support group is to communicate to young girls who are blind that they are not ugly. Many have told her that this is how they feel.

> I tell them that they are not ugly and that God does not make mistakes. I tell them that blindness is not shameful, and that they are a whole person just the way they are. It's a cruel joke for churches to ask for people's testimonies after they have been healed. Are they implying that we have not been healed, or that God's glory can't be seen in our lives just the way we are?

One activity that is important to K. is being part of a committee that investigates how public buildings can be made more accessible. She and other committee members go through school buildings, museums, parks, and other public places, giving advice to architects and builders about access. She reminds architects that layouts of bathrooms can have a significant impact on a person who is blind, particularly when sinks, towel racks and trash cans are in a different layout in each place. "People just don't think!"

Another activity in which K. participates is as a member of a state chapter of a national organization that supports people who are blind. Her experience with this group is not always smooth and agreeable, however. One of her greatest concerns with this group is their tendency to stereotype people who are blind. She protested when she heard a commercial that this organization had sponsored about a product to improve memory that was so easy to use that "even the blind and mentally retarded can use it." She most definitely does not want this group speaking for her.

## Daily Experiences With Disability

K. separates what she calls "the blind experience" from other disability experiences. Her frustrations come not from daily living on her own, as a single mother, but from the barriers thrown up by other people through their attitudes and actions. She believes that people's reactions to her, although unintentioned, derive from the fear that "it could happen to me at any time." Unfortunately, in their focus on K.'s blindness or on her guide dog, people don't see *her.* "Where in this is *me*? I am coping because I would cope irregardless." Her home is her refuge, along with her church, faith in God, and her music. "I cope with bad days by just coming home. At home I don't have a disability at all."

K. relates more to women, with and without disabilities, who have had to fight for what they believe in. It is very important for her to be with other women with disabilities who have had experiences similar to hers. When she talks with them, she realizes that "you're not in this little box all by yourself."

> I can't relate to women who have never had to fight for anything. I call them the women who have always lived in their little white houses with

> little picket fences and their flower gardens in the yard. In fact, I don't have a single friend who has had the "all-American girl" life. I can't relate to women like that. I relate to women who have been through a lot of difficulty.

She resents being given advice by people who have not shared her experiences, whether as a mother, a woman, or as a person with visual impairments. The comment, "I know what you need," irritates her. Many times these comments come from people who make decisions about her, such as a vocational rehabilitation counselor. She compares the ludicrousness of it to a man counseling a woman about rape. "They can't relate. It's absurd."

K. gets upset when told that she doesn't know how to do something, can't do something because of her blindness, or that she needs to accept help from someone who is nondisabled. She makes a difference in accepting help from an able-bodied person and a person with a disability. Able-bodied people's efforts generally result in making her feel helpless. "When people with disabilities help other disabled people, we have the attitude, "This is just somebody who needs help and it happens to be something I know how to do. You help because they—and you—are human."

She recently told a vision rehabilitation teacher that her attitude and methods of teaching were in effect "telling kids that they can do whatever they want and then putting them in a box."

> Why do they *always* see the disability first? They never see the *person.* It's easier to fit the stereotype into your mind than to get to know somebody. Their attitude is: We know what you need so be quiet. I'm giving you this because I'm such a great person, and it's so wonderful of me to do this for you. The poor person can't do this by herself, so I have to do it for her.

K. gets angry at the assumptions people make about her. The comment that irritates her the most is, "I bet that your girls help you so much." The implication in this comment is that she has to be taken care of by her daughters. K. emphatically states that, of course, she and her daughters take care of each other. "That is what happens in families. My girls see me as Mommy—not blind Mommy." Blindness, however, does not relieve her of parenting and household responsibilities.

K. laughs as she describes a "classic blind day" or a "classic blind week," which is the culmination of days or weeks of frustrating moments. These CBDs or CBWs, as she calls them, are usually shared with a close friend who is also blind. Together they laugh (or cry) about the experiences that "make you look like a total helpless fool. It builds up and builds up…until you've had it."

> Maybe your dog is not in the mood to work. We go out of the parking lot and she's sniffing all the way to the store. We go into the store and someone yells, "There's a dog in here! Who let that dog in here? Get that dog out of here!" Then my dog wags her tail and knocks something off a

> shelf. If you leave to get on a bus, someone else sees the dog and screams. The dog thinks I'm in danger and blocks the aisle of the bus so no one can get on or off. If you think about it too much you'd go nuts.

K.'s has had other experiences that are examples of how traumatizing the environment can be and times when she felt that others had power over her. One was her time at a local university, and the other was getting her first guide dog. Going to the university was "like going to hell and coming back. I'll start crying if I talk about it too much. People don't realize...it's like being homeless. We were on edge all the time." Between lack of support from vocational rehabilitation and lack of timely modifications and accessible materials from the university, K. had to drop out of school. She still gets angry at the experience and the unreasonable expectations made of her. In particular, she believes that the university and vocational rehabilitation should have a deeper understanding of what is involved in being able to successfully go to school.

Getting her first guide dog was another traumatizing, dehumanizing experience for K. because she had to place herself in the hands of strangers who attempted to control her. K. finally rebelled. "I know what I'm doing, and you don't have to treat me that way. Or anyone else here." The trainers were told that if they continued treating her and others like "stupid idiots" she would contact the media.

Over the 10 years or more in which I have known K., I see many of the changes of which she is aware. K. has dealt with the anger and frustration of her youth. Her experiences as a woman who is blind have helped her to become strong. She has learned how to create balance in her life through her activities with her children, church and community activities, and by planning for the future. She recognizes the changes within her, and she believes it is for the better.

> I'm growing, definitely. More balanced. A little too lazy…the things I need to do I just haven't done. More laid back now. People say, "Oh, it's good to hear you laugh." And I think, "Yeah, and if you cross me, buddy, you'd better watch out!" That's just how I am. I'm not out to get you, *but…*

As she edited this story, she added the following words that she wants the readers of this study to know. "I still have inner joy. I can still laugh. But there is still hardness in my heart. I know it's there, along with the barriers and walls."

## *E.'s Story*

### Setting for interviews with E.

E. and I have met in many different places in the course of writing this dissertation. Because of mutually busy schedules, our meetings have been in odd places and at strange times of the day. Some of them have been held while doing other things, like moving boxes, weeding in a flower bed, or walking around the block.

E. currently lives in a large southern city in a rented house that serves as her office as well. This house is located in one of the city's residential suburbs and is surrounded by small older homes, trees, and neat yards. The houses in this neighborhood are not expensive or fancy, but owners and renters keep them very neat and clean.

Part of her home is her office, which is filled with books and bookshelves, a desk, and comfortable chairs. The rest of the house is living space, which has three small bedrooms, a living room, kitchen and bathroom. One bedroom is hers, one is for guests, and one is completely empty except for an easel in the middle of the floor. Walls in this room are painted white and are completely blank. When E. needs to think, design, or develop an idea or concept, she goes into this room. She keeps masking tape handy for taping her sheets to the walls.

Floors in this house are hardwood, and she keeps throw rugs only by beds and in the bathroom. In her living room she has a large, soft, comfortable couch and chair, a TV, and a fountain. Most of her evenings at home are spent on the couch because she can stretch out completely on it and sleep if she chooses to do so. Over the fireplace is a silhouette of a small African American boy and girl playing by the sea. Also in the living room is a coffee table made of planks and cement blocks.

There are few pictures on her walls or in other places in her home, including pictures of family members. She prefers her home uncluttered. Other than a few small sculptures and vases or pots of flowers, it is unadorned. She also chooses to not get a local newspaper and does not get any magazines or journals. Her reading material consists mainly of her own work.

When she is home, she spends all available daylight hours outside in her flower beds. Tucked around and under her flowers are small clay or metal animals or other statues, flower or herb markers. She has also placed many bird feeders and bird baths around the yard. The bane of her existence is a neighbor's pot-bellied pig which loves to root up her bulbs, and she has frequently threatened to shoot it.

Most of the time her refrigerator is empty except for a six-pack of beer, although she does have fresh food delivered regularly. Restaurants and coffee shops are close, and she eats out more than at home. When she goes to her place of birth in the mountains, she brings back canned food and fresh vegetables to eat.

Many of our meetings and conversations have been in her car on the way somewhere, with us taking turns driving. She has visited in my home, and we've found quiet, private places to talk.

We talk regularly by telephone and via e-mail. Our conversation and mail ranges from personal to professional experiences, meetings we've had, people we've met, and we also frequently share jokes. She is keeping those of us in her circle of support informed of the healing strategies she is using now for liver cancer.

At the time of writing, her boxes are packed and she is preparing to move to another city because of work and health reasons. She is feeling a bit uprooted and unconnected because, other than her home in the mountains, she is losing a base for awhile.

## My Experience With E.

E. offers a graphic description of herself as a starter for her story:

> I am told I am beautiful, attractive, gifted, that I am brilliant, creative, and intense. I see droopy jowls, grizzling hair, sagging flesh, eccentricity, and perseverance. My butt and thighs sag, and I'm out of shape.

When I look at E., I see a short, heading-for-middle-aged woman with cropped, straight dark hair turning gray on the sides. She usually wears glasses that cover large, brown eyes. Makeup and jewelry are minimal unless she is doing a public presentation or workshop. Her clothes are simple and in good taste. She prefers jeans or pants to skirts or dresses and wears practical, low-heeled walking and working shoes. Dressing up usually means a comfortable pair of knit pants and top.

The working E. lives fast, walks fast, talks fast, drives fast, and occasionally drinks fast. She usually is doing several things at once, such as driving while using her car phone to get directions to where she's going.

Her humor is dry and quick. Her accent ranges from the clipped, educated sophistication of a professional woman to an Appalachian hill woman. She frequently speaks in metaphors. An evening meal in a restaurant might start with a double cognac and dessert, with the quip "Life is short." The resting E. is reflective, quiet, meditative, preferring to putter in one of her flower gardens or sit cross-legged in a chair drinking tea or coffee. This E. prefers to eat fresh home-grown vegetables and tofu.

E. does not look like she has several disabilities, some of which are more debilitating than others. The scars on her legs left from childhood falls and surgeries are only visible when she wears skirts or shorts. You cannot see her giftedness or mental illness; however, these two attributes affect her more than her physical problems.

E. and I met in a most unusual way. About six years ago I was participating in a talk show about disability rights and law on a local public radio station, to which she was listening on her car radio as she passed through town. She used her mobile phone to call the number given at the end of the show, which was my office number. Her comments were short and to the point, “Appreciated your comments. Glad to hear these issues are being discussed here. If you ever come to the town where I live, maybe we could meet in person.”

Several months later I had to go to the city where she lived and worked for a conference and called her to see if we could meet during lunch. Our visit was unusual in that both of us had the feeling that we had met before. We spent very little time in the “getting-to-know-about-you” stage. I don’t remember much about our conversation except that we were immediately on first-name, friendly, mutual terms. We exchanged personal disability experiences, work history, jokes, and family information. When I heard my first, “Lord, honey,” I realized I had found a person worth knowing, one who could help take my awareness of disability issues to a deeper level, one who had experienced much but was also giving much to others, and one of the smartest and funniest women I had ever met. I’m not sure what she thought she’d met.

Since that time we have been in touch on a regular basis as professional co-workers, as friends, and then as participants in this study. We have made a point of visiting in each other’s homes, getting together for meals after a day’s work, helping each other in a variety of ways from professional assistance on the job to moving personal belongings from one state to another. I asked E. to share her knowledge, skills and abilities in conference presentations and workshops and to provide assistance to groups going through systems analysis and planning. We traveled together to some of these meetings, and I was a participant in some of her training workshops.

She is a busy woman who travels constantly, both nationally and internationally, so our visits face-to-face are infrequent. One of our best ways we keep in touch is through electronic mail. When we can synchronize our schedules we'll do so, if even for a brief cup of coffee or meal. We once met on the side of a hill close to an interstate exit when we were both going through bad times. Between us we shared one large cup of coffee, one napkin, a huge muffin, and a few tears.

## E.'s History

E. was born in 1953 in a small town she calls "on the near side of Appalachia." The home where she was raised had been in her family for several generations, and she was surrounded by a large extended family who lived close by. She admits that her family has frequently been sorry to see her come home, but that this is the place where, as Robert Frost says, "When you have to go there, they have to take you in" (*The Death of the Hired Man,* 1964). One of her most vivid memories is of sitting around on "Granny's porch and talking." The time spent on her porch with other family members gave her a feeling of being part of a community of caring, sharing people, a feeling which has become increasingly important to her as an adult.

Although this was a rural community where conformity and standardization of behavior was the norm, her mother, an elementary school teacher, believed differently. She told E. and her sister to not sound, look, or dress like "poor white trash."

> My mother broke some of the family codes and traditions. We were encouraged to act like we were *somebody!* As a result, we didn't have a lot of friends as children. My native voice is hillbilly, but we had to train our voices so as not to mark us. I heard a lot of "we and those people." *We* had

> pride; *they* didn't. My responsibility was to bring the community up, *imagine* it, to our standards. I remember wanting to be liked and accepted, but my family was so different from those of the popular kids in school.

The cultural environment in which E. was raised reflected the code of the hills: independence, self-reliance, pride, and self-sufficiency. She frequently heard words like, "You can be anything you want to be, you can be proud of who you are, and your family has meaning and dignity." She heard these words but did not internalize or believe them for several reasons, one being that she had physical problems from the time she was born that changed her family's expectations of her. In addition to being born with a congenital defect that caused both knees to dislocate, when she was five she developed St. Vitus' Dance, which is an involuntary action of the muscles caused by a neurological infection. Because of her physical problems, the "code of the hills" was changed.

> Much of my childhood was spent on the ground as a result, and I grew into my middle school years in casts, having surgery, trying to get my knees corrected. I was held back from doing things physically but encouraged to do things intellectually. I also experienced fear and isolation. There was not a lot of encouragement or support because I was not "always" disabled. It was not consistent or visible. Sometimes I was accused of making it happen, and there was not a lot of support for my fear of, "What would happen if my legs give out and I fall." I lived with fear of what might happen. I also got very comfortable with the concept of being

> handicapped. I learned there were some real benefits from it. People felt sorry for me. I got lots of pity and sympathy, and I certainly got a lot of attention from those big red stripes on my legs. I kept seeing myself as "separate from": *no,* I can't do that, *no,* I can't run, *no,* I can't swim, *no,* I can't do this, *no,* I can't do that, I'm different, I'm separate.

The feeling of being different and separate has been with E. for most of her life, although not by her choice. Even in seemingly insignificant ways, E.'s family seemed to want to remind her of that difference. E. remembers one event that she describes as a pattern to much of her life growing up. Her mother had made her sister and her a new dress, and they were walking together to a concert nearby. E. fell, resulting in her new dress getting ruined. Her mother was angry and upset, and her sister embarrassed. E. felt shame and disgrace. She was left with the message that she couldn't even walk to a concert without causing trouble. Her family felt shame because she was not living up to the image her mother wanted to project. This and other experiences had a profound effect on E. "How your family deals with you is where your foundation comes from."

E. remembers a lot of anger and rebellion as a youth. She had the "simultaneous experience of growing up with honor and dishonor" because of her physical disabilities: Honor because of her obvious giftedness and abilities in school; dishonor because she was not living up to her family's expected standards of independence and self-sufficiency. When she was not liked or accepted, she rebelled against their definitions and attitudes, including that she was "tetched."

> When I was 18, I decided that it was up to me to frame it—not up to other people. I'm not crippled. My legs just don't work like other people's legs. The moment I made the decision about how I was going to frame it, I began to define myself rather than let others define me. If they're not going to accept me, they might as well not accept me for anything. I was angry and I wanted them out of my face.

E. left her community and completed high school at a private school where she decided to be a writer. Upon graduation, she went on to get a bachelor's degree in sociology. She continued to search for ways to be connected to people and involved in meaningful work, finding employment in jobs as varied as physical therapy, social work, and shoe repair. She was torn between her physical problems, her desire to contribute, other's reactions to her, and beliefs instilled in her by her family. The four or five years following her graduation from college were years of physical and mental stress that E. prefers not to discuss except for one comment.

> I remember, maybe in the early 1980s, maybe due to pot or alcohol or drugs, thinking: Oh, my God. If I'm supposed to fail and not amount to anything, then I really am succeeding. So if I'm really going to fail then I have to amount to something. This was the beginning of my own redemption, literally. I had tried desperately to please my own family, but I didn't understand the code.

For the next 10 years she was involved in many different activities, some of which she prefers to remain private. She spent a number of years as a professional mystic, relying on clairvoyant, clairsentient, and clairaudient skills to support herself. She furthered her education by participating in workshops and symposiums on total quality management, stress management, and workplace design. Her resume reads:

> Over the past 15 years, she has been active as a lecturer, trainer, and consultant all over the world. For 12 of the 15 years, she has owned her own company, which is an organizational and resource development firm. She has published more than a dozen books, articles, commercially available computer based training programs and corporate games. She has consulted with over 30 companies in areas including systems development, change management at the social and technical levels, training and development issues, productivity improvement and synchronous processes, Total Quality Management, program development, and human resource management.

Her base of operation for these activities has been from her home and office in a large southern city. She makes a few visits to her birth place in the mountains each year, but these visits are usually brief. Time spent there brings back unpleasant memories, and she often wonders why she goes back at all.

In 1990, E. was diagnosed as having multiple personality disorder. This is a dissociative disorder that is a chronic response to repetitive experiences for which a child does not have adequate coping mechanisms. It may be brought on by relocation, accident, illness, or grieving over the loss of a family member. Most often it is a response to severe abuse, or childhood trauma. A child does not feel safe from danger and harm, and when the child can't leave the situation physically, she leaves mentally and emotionally. The result is dissociation from what she is experiencing by not knowing what is happening, not feeling it emotionally or physically, or not being aware of the facts about it (description provided by E. and based on her personal experiences).

> The minute the woman said, "You have multiple personality disorder," I could feel the fear and anxiety rising. I had to ask, "What is the change for me? These feelings that I'm having come with change." I had to apply what I had been teaching others to myself. I had already been doing a lot of public speaking on change, but I had an immediate crisis after my diagnosis: How do I handle this public relations crisis? Do I cover up or be up front? What will people think? I wanted to create a niche that would let me continue the path I was on to success. That's why I decided to go public. People look at me and don't see disabilities. It's a shock for people to find out I can't do what other people can. All of us who are multiples (have multiple personalities) have one thing in common: We've been through more stuff than lots of people can even imagine. When I found out why I had been called brilliant and eccentric all my life and began to find out what society expected me to be like as a multiple, I got angry. What's "crazy" about being a multiple is the "not knowing," the conflict among

parts of our selves, and the degree to which our internal states become real on the outside.

To address the "not knowing" part of having multiple personality disorder, E. chose to think through her own healing process, preferring not to read what others had written about dealing with multiple personalities. As she thought, she began to realize that the knowledge and skills she had about how organizations work could also help her manage internal organizations. Learning to manage diversity within, she says, was "a little like learning how to herd cats." Rather than thinking in terms of managing, she sought for new models of relating. New ideas such as parallel universes and concepts that point towards multiplicity as valuable became the focus for her work and writings. She also relied on her Christian heritage and applied concepts of discipleship, forgiveness, honoring the stranger, reconciliation, and understanding from the teachings of Jesus about how to embrace pain and suffering. Her private consulting business expanded to include writing, teaching, and counseling others about multiple personality disorders.

Because E. had experienced rejection from her home church as well as many others, the church became a primary target of her training, in the hope of changing its attitudes about mental illness in particular. She had to contend with the full range of biases stretching from belief that she was possessed of the devil to belief that she had supernatural gifts. Her orthodox Episcopal upbringing did not equip her to deal with these issues, so she sought answers elsewhere, such as in mysticism, Buddhism, Hinduism, and in Native American Culture. Making a conscious decision to look elsewhere for answers was an important choice.

> It helped me get in touch with the commonness of people. It helped me understand that the strength of creation is in difference. I don't think in linear terms. My grandmother was part Cherokee, and her spiritual ability came from her heritage. I learned to suspend my judgments, use deliberation and conscious awareness. I'm not in to "fixing" people's lives.

Several years ago she made a conscious decision to return to a "traditional, yet more mystical, Christianity." In one of her training manuals she reveals the depth of pain she has experienced from the church. In spite of this pain, she continues to feel the need to be part of a church and reach out to others.

> For those led to believe that their abuse was sanctioned by God; their multiplicity purely from the enemy of God; and whose dignity has been stripped from them by Christ's believers. For those in the Body of Christ who wound others from fear, who do not know or will not know the horrors others have endured. For those who believe that we who have endured know no truth and have no light in us, calling us liars rather than remembering the practices of Baal and Molech which surely continue both inside and out of the Christian Church. May God restore us all.

E. continues to do the work she has done for the past ten years, consulting with businesses and individuals on coping with organizational diversity and change, writing new books and instructional materials for businesses, and speaking to groups about a wide variety of topics. Two years ago she completed a master's degree in Human Resource Development. When she is home, she attends an inner-city church that has a strong outreach to needy people in the community and to those who feel rejected by mainline Christianity. E. is an active and involved member of this church.

## Who E. Is

On the surface, E. is a creative, successful business woman who owns her own business, drives a nice car, wears nice clothes, has a professional hair cut, is generous to everyone she meets, is kind, considerate, and caring. She is a spiritual—not religious—person. She is funny and earthy. Next to the computer in her trunk might be a box of fresh vegetables to take home. She frequently gives most or all of them away before she gets home.

She usually refers to herself as "we" rather than "I." The fact that she has multiple personality disorder does not alter who or what she is. In the time I have known her, I have come to recognize three personalities or "alters." E. says there are more, but recognizes that as she continues to heal there will be fewer alters. The three personalities I have seen are a young teenage girl, an older mountain woman, and the person I simply call E.. I have seen the young girl only a few times, in times of particular stress or crisis. I have had the feeling that this personality is very fragile. The older mountain woman is seen in much of E.'s writing and talking, particularly when she lapses into the vernacular of the hills. E. recognizes this personality as being funny, profane, ornery, earthy.

All of these, and others known mostly to E., make up who she is, and who she is cannot be understood without taking them all into consideration. In her writing and teaching, E. has provided many explanations and examples of what having multiple personalities is like and how she has experienced it. Although her books and instructional manuals are designed to help others, much of their content is autobiographical.

> I think of alters as senses of self, each of whom has some separate traits and all of whom have some things in common. Each part is as valuable as the whole. Each self was created because of pain. Selves experience differences in faith and beliefs, in values, food preferences, sleep patterns, recreational preference.
>
> The greatest challenge...is in resolving the need for group agreement to be able to continue functioning. The conflict and chaos that some (selves) carry are not who they are; those characteristics are representatives of the pain from which they were created. Much of the conflict that can render us unable to function comes from the prolonged amnesia and conflict internally.
>
> The horrors which we have endured and in which we have participated are unspeakable to the eyes of almost every person: they are what I call "concentration camp experiences," or our own private Vietnams. They are without social validation; and we are, after all,

> "mentally ill." We are told our lives are stories unable to be heard except by clinicians.

At our first meeting, E. asked me if I had any questions about multiple personality disorder, and if so, to feel free to ask them. I didn't know enough at that time to ask, I wasn't sure how to ask, and I didn't want to injure a new and fragile friendship by asking the wrong questions. Over the last six years E. has helped me understand who she is through patient guidance, sometimes informing me of the presence of a different self, and by making herself vulnerable to me. The vulnerability has been based on friendship, in the mutuality between us that helps us reach out to each other when in pain, trouble or difficulty. Because of my heightened awareness of the potential presence of different aspects of the self within E., I have made a conscious effort to accept the reality of her experiences and to affirm the person I might be hearing or seeing. I have also become more aware of how a casual comment can cause injury and pain, and sometimes even a relapse into pain from the trauma of her past.

I have been with her when she has had to decide to reveal herself or to "pass" and have witnessed the struggle as she has attempted to counter public images or notions about people with multiple personalities. The public's belief about who she is and the role she should play is in effect "a cognitive filter over their field of vision." When people refute her experiences or imply that they never happened, the effect is that she is "erased."

> Imagine the tension this creates! The ongoing struggle to prove one does exist, the slow anger and rage deepening, the ripping of the soul when such acts occur, and the pelting it takes trying to defend against such intrusion!

E. explains that her need for recognition, acceptance, love, and the power to choose is common to everyone, yet often denied to people with multiple personalities. As she retells her childhood and adult experiences of "living in the skin that is different," she is cognizant of the impact of not being allowed to make choices by those with power and authority. A child's basic needs for affection and autonomy are often not met.

> Children in those families are often invisible—not recognized or accepted, so they may not recognize their own power to choose as they grow up. Affection and love get confused with the traumatic events the child experiences, making it hard to get these basic needs met in adulthood.

E. is healing herself through her own training, nontraditional spirituality, and through "self-discipleship." She had to learn to love, care, and value herself. Part of the process for her has been to carefully choose words that encourage collaboration and compliance among her selves, saying "do" instead of "don't" and "could" instead of "never." Part of self-discipleship for E. has been in learning to make choices that are affirming and positive. She has learned that it is easier to teach herself through acceptance than through judgment.

> Through self-discipleship we change our behavior to reach a goal, like when we start saving money to buy a new house. We need to learn ways that let us be associated with what happens to us. I think we need to be connected with our will, too—the place inside us from which we make choices. You *can* change the image of your self or any internal self. It takes choosing, time and practice: It takes being willing to learn and letting yourself learn. *You can't keep pictures of yourself in the future based on damaged pictures from the past.*

E. is also dependent on a support system of friends and family, because she believes that healing is cyclical. When business is slow, contracts fail, or when she is physically frail are times when she is particularly susceptible to dissociation. She has told me that events like driving down a familiar road, passing a neighbor's house, hearing or reading news about child abuse, or being rejected by someone she perceived as a friend can cause her to "space out" or even dissociate.

> When I found out there were more of me than I knew about, I needed to figure out how to build a support system. I thought through how I would choose who to tell, and what I would say, how I would handle the responses I might get. Here's what I said to the people I decided to tell: You know how little kids can daydream and space out so you have to really yell to get their attention? That's called dissociation. When life was

> too tough for me to hang around, I spaced out so far that it was like watching someone else go through whatever was tough. And, by a process I don't understand, another "me" developed. Because I lived through what was tough, I kept making more MEs every time life got too rough.

E. uses the example of "welcoming the stranger among you" as a fundamental requirement of the Christian tradition, and one that describes how we should act towards those who look, act, or in fact, are, strange. It is an attitude that has helped her embrace her own "strangeness" as well as that of others.

> In the Shamanic tradition, when trauma occurs, a piece of the soul is broken off and carried away. By keeping myself to myself and mastering myself I didn't give as much of myself away when trauma happened to me. I know *me.* I can say that bad things happen to good people, and this has nothing to do with *me.* It is about power, anger, and violence. I own it, but it doesn't run my life.

E. teaches organizations from multi-national corporations to churches how they can incorporate the principles of "welcoming the stranger" into their policies and practices. However, her belief in this way of thinking goes much deeper because of her innate spirituality and desire to help others.

> The one who welcomes the stranger is said to welcome God. If each person is made in the image of God, there can be no one-type-fits-all image….The good news is that God prefers the pluralism of the world of strangers to the uniformity of a sacred society. God loves difference! Physics and spirituality are fundamental to embracing the differences found among people. Physics teaches that we are all made of the same stuff, and spirituality teaches us that all of the Creation is worthy of dignity.

E. is a hard-working woman who honestly and diligently tries to make sense out of her world. She struggles with the reality of her daily experiences. She continues to consider herself a failure because she doesn't own her own home, have a husband or financial security. The damages to her self-esteem are deep. "To become me, I had to find out who 'not me' is." Through the gifts that have been given her, she attempts to give to others in order to change their perceptions toward her and other people not perceived as normals. She focuses her time and energy on health and healing, both for herself and others.

> I am resilient. I do my best to honor and respect others, to think before I speak as much as I can. I've had to learn to roll uphill. Persistence is rolling uphill against the old familiar patterns for about twice as long as it feels good.

## Daily Experiences With Disability

It is a tremendous challenge for E. to "hold things together" on a daily basis.

> People have no idea of the amount of skill it takes to create some appearance of a coherent life.
>
> Growing up with a physical disability was good grounding for being diagnosed with multiple personality. You can't afford complacency.

E. faces circumstances on a daily basis that most of us never even think about. Activities such as driving have sometimes been impossible because of dissociation. She has been extremely vulnerable to harm, danger, and hurt. Because of experiences in her youth, she cannot always determine if a situation is dangerous. As a result, she may place herself in stressful or dangerous situations that are simply familiar. Avoidance of stress and stressful situations are important to her, because stress can cause dissociation.

> Chronic childhood trauma teaches you to believe that dangerous situations are safe, so learning more about what safe really is and how to get and stay safe is a very important task. You have to pay attention to emotional, mental and spiritual safety as well as physical safety.

Travel can also be challenging for E. because of the potential danger of dissociation. I have been with her when she has said, "I don't think I can drive right now." Early in her recovery, she was frequently lost or depended on her car phone to get directions to where she is going.

> My solution was to figure out how to make my driving less automatic and more deliberate. Being deliberate is a way of staying associated. To do something deliberately says that someone knows it is happening and in driving, that's you.

She also has to decide whether to "pass" each time she meets a stranger or deal with the consequences of revealing. She also has to deal with her response, which is to internalize their reaction or to resist. If she internalizes their response, which is usually that she is "deemed wanting," she falls back into defense mechanisms like retreat. On the other hand, transparency, or "revealing" can be dangerous.

E. makes her decision to reveal that she has multiple personality disorder based on "where I have an emotional bank account," which is usually with other people with disabilities or with people who are receptive to what she has to say. These situations vary from one-on-one conversations with new acquaintances, persons attending her workshops, doctors and other health care providers, to members of her church. She has learned to "give people what they want for themselves" in order to build power for herself. It was something she had to experience personally.

> One definition of power is compromise. It gives you the public visibility to act as though you're powerful, which is paradoxical. Deming talks

> about profound knowledge, which is taking things we know internally and teaching them to others.

E.'s emphasis on choice and change in her writing and speaking is based on the choices she has to make many times a day and the ongoing internal and external changes in her life. In one of our meetings at a coffee shop in the city where she lives, we found ourselves seated one table away from a casual acquaintance, within hearing distance. As we exchanged introductions, the person observed the tape recorder on the table and asked what we were doing. I asked E. if she wanted to move or wanted me to answer.

> My choice was, do we move, or do I alter what I'm going to say. Am I going to change the nature of this experience because he's sitting there?
> My choice was to speak.

She told him, deliberately, that she had been selected to participate in this study about a select group of women with disabilities because she had a disability. His reaction was a mumbled apology, "I'm sorry...I didn't know..." and a quick exit. Her reaction was to "not contaminate the situation with my expectations of how it might or ought to be or what might happen."

On another occasion, E. revealed the depth of her indecision about what to tell a group of professional employment and social service providers for people with disabilities. She had been asked to conduct a workshop on "barriers and bridges to empowerment." As we drove to the workshop, she debated about how much she should reveal about herself. She voiced concerns that her words would be devalued if they were told at the beginning about her multiple personality disorder. Because of her belief in “openness in the universe,” she didn’t want her words to result in “restricting the choices” the audience made about her presentation.

> Will they understand that I am speaking from a place of authenticity about empowerment? Will they see me as defective? Can they understand that there is something on the continuum of empowerment between raising hell at one end and helplessness on the other?

She also realized that she had to confront the fact that, as service providers for people with disabilities, they controlled the power and resources that had affected her life as well as the lives of other people with disabilities. They needed to be made aware of the fact that they held their jobs because of her “defectiveness.”

> I have to ask them, “Who looks bad if I’m okay? If I don’t do what I’m expected to do? I have to tell them about the stigma of labeling and ask them how to get unlabeled. It’s like living with a felony record. Why can’t I be called mentally healthy instead of mentally ill? I’m going to ask them, “Are we the type of person who needs someone to ‘fix’ us?” Normal should be a range of behavior rather that what people in power define as acceptable.

E. continues to learn to live with dissonance between what she believes and knows about herself and what others believe and think they know about her and about multiple personality disorders. Frequently what they think has ramifications beyond her control, such as denial of health care. She also knows that sometimes, to survive, she must chose to be invisible, such as when she needs medical care.

As the healing process continues, she grows spiritually and emotionally in self-awareness about her needs and abilities. She focuses her energy on preserving the sense of wholeness she has achieved and selecting areas where she can cause positive change to occur. In spite of medical problems, she makes herself available 24 hours a day to others with multiple personalities and has an 800-number so that they do not have to pay for her counseling and advice. She is extremely concerned about the public's perception toward those with invisible disabilities. Her belief in the fluidity and recursiveness of life comes from her Native American heritage and friends. Change is the one certainty in life.

> My goal is to get through life filled with change using the one tool we'll always have: choice. Nobody ever died from pain. Pain is part of change and growth, just like awkwardness, irritation, embarrassment, fear, and anxiety. Instead of becoming martyrs, masochists, or madmen, why not become people of strength who can face the unknown with courage and grace, and go on?

And then E.'s humor surfaces in the midst of her philosophy on living, "Sometimes only the hope of dying was keeping me alive and Jesus wasn't coming fast enough!" These words take on particular relevance now that E. is dealing with cancer.

> Where is it written that life is fair? You may not be able to alter an event of change in your life, but you do have the power to choose how you feel. Disability is a process of being constantly and forever adaptive. We, too, hold up the sky. The problem is not our presence, but others' fears.

## *S.'s Story*

### Setting for Interviews With S.

Most of the interviews with S. were conducted in her home, which is located in a rural setting close to the mountains. She and her husband built their home, which is a modified log cabin with wooden logs outside, a wide front porch filled with chairs and toys, and painted walls inside. Although the house is small, it feels and looks roomy and open. The kitchen, dining room, and living room flow into one another, and the master bedroom is located close to the living room. A wide arch divides the space between the living room and master bedroom. The children's rooms, bathrooms, and small office are down a hallway leading to a garage. Over the living room is a loft which is also used as a bedroom or playroom by the children. Steps go up from the living room to this loft.

The living room has a stone fireplace with a wide hearth, windows and doors covered with hand-made white tie-back curtains, and carpeting on the floor. The dining room table is covered with books, papers, maps, pens, crayons, glasses, and other litterings of daily living. Small touches reveal something about its inhabitants: a piano has been moved into the small living room so that the children can play and sing. The children's rooms are filled with bookcases and books. Hand-crafted wooden grab bars are beside the toilet in the guest bathroom. Mirrors are over the stove and washing machine so that S. can see the contents of pans or clothes left in the bottom of the washer. A sophisticated high-tech lift goes from the ceiling in the bedroom to the bathroom so that S. can independently go from her bed to the toilet or tub in her bathroom. Her office and kitchen contain other adaptations to accommodate for changes in the use of her hands and arms.

The back entrance and deck are ramped, as is the entrance from the garage. The rest of the back yard is filled with children's toys, from bikes and tents to balls, plastic toy kitchen parts, and a good-sized above-ground swimming pool.

S. and I usually talked somewhere in the house. We were either in the middle of the living room, at the dining room table sorting clothes, making sandwiches for the children in the kitchen, or outside on the deck. Sometimes we sat and looked at photo albums of the family's adventures. S. very carefully keeps pictures, newspaper clippings, and other collectibles in albums that she has dated and labeled. Once S. drove me in her adapted van to her daughter's school.

Sometimes S.'s husband or children were present when we talked. Their presence did not seem to inhibit S. in any way. When the children were there, they were usually outside playing, in their rooms reading, or occasionally pestering each other. The phone was almost always ringing. Other friends or family members stopped in to visit as well. In the midst of the chaos S. sat, somewhat like a whirling dervish. Her body was never still. She was either wheeling around in circles, tipping herself back as if doing wheelies, or moving so that she could prop her feet up in chairs while we talked. Her hands were also moving, folding clothes, creating an outfit for the children, making sandwiches, stuffing envelopes, or combing her daughter's hair. An occasional yell would erupt from S., particularly if the children were arguing or if she needed them to do something like answer the phone.

Being around S. and her family is exhausting and exhilarating. She is the most alive person I know, and she lives each day as if it were her last. Everyone around her is also affected by her actions and energy. I got the impression that there are few secrets in her family.

After our interviews, details were confirmed by phone or e-mail, as she and her family have been traveling for much of the past year. When she is in town we get together for brief visits, lunch, or phone calls if time is limited. When she is out of town we stay in touch via e-mail, cards, and letters.

## My Experience With S.

The experiences I had with S. for over eight years are the basis for selecting her as one of the participants in this study. During that time, I had many opportunities to observe her in different roles, leaving me with the impression that she was different from other women I knew with disabilities.

When I first met S. almost eight years ago, I had not formed close relationships with other women with disabilities, so meeting S. was an amazing experience. She was hosting a meeting for parents of children who attended a rural school specifically for students with disabilities. My first impression was of a small, pretty, physically fit, young woman sitting at the front of the room discussing an upcoming fundraiser for the school. One of her legs was stuck straight out in front of her, and I spent most of the meeting wondering why, and then how she could conduct a meeting while holding her leg in that position without any means of support. I was not aware that she had a disability. I thought she was one of the most alive, dynamic people I had ever met. She was working the audience like an auctioneer: joking, teasing, cajoling, bullying, calling on people in the audience to give time and money, and tugging on their hearts as well as their purses. No one refused her requests. Except for her leg, her body was not still.

During this time, S. worked as a special educator in a rural school system, where she had a self-contained classroom of nine children with severe disabilities "that no one else wanted." She implemented programs in her classroom that had never before been considered in the school system, including an infant stimulation program.

My next contact with S. was when a mutual friend shared with me the news that S. had received a severe injury from a fall and was hospitalized for three months, fighting for her life. I learned about her disability at this time and its effect on her mobility. Her chances of living were slim. I kept up with her status through this friend until she was able to leave the hospital. Because of the fall and subsequent injury, she had significant damage to parts of her body, including her back, arms, and legs that resulted in her use of a wheelchair for mobility.

S. also lost her job. The school system maintained that a teacher in a wheelchair could not manage a class of students with significant disabilities.

In early 1991, I asked S. to come and work for our nonprofit center in order to do outreach, advocacy and public awareness activities for persons with disabilities and their families who lived in rural areas. It was a new program, and S. had primary responsibility for organizing and developing it as well as for working with other staff to implement it. The job required extensive travel. For two years we visited many schools, community centers, businesses, and social services agencies in rural Appalachia. We co-presented at local, regional and national conferences and conducted many different workshops.

These trips were always an adventure: fun, hectic, wearing, and sometimes disastrous. One particular conference was spent dealing with her 250-pound power wheelchair that was broken by airline personnel who failed to catch it as it rolled down the airplane's conveyor belt to the ground. We felt the fright of being in a strange city for a week, dependent on a broken chair for mobility, and without proper tools to repair it.

We frequently had to change plans at the last minute because the places to which we had been invited or stayed were inaccessible, including the doors of hotel rooms, bathroom doors, and steps into buildings. These trips forged a bond between us that can never be forgotten. We learned to depend on each other's intuition, wit, intelligence and initiative, and how to creatively and often, diplomatically, handle the challenges of the moment. We laughed and sometimes cried together as well. We also had major disagreements when we worked together about how to do certain tasks.

Several other events happened during the time S. and I worked together. She had a serious "bleed" caused by her disability that required hospitalization. I spent as much time with her in the hospital as possible in order to help her and her family. S.'s life was in the balance several times during this crisis. It was hard to watch a friend breathe more and more slowly and wonder what the next few minutes would bring.

Part of S.'s healing process after her hospitalization was the realization that she needed to work closer to home where she could spend more time with her family. She also recognized before I did that it was time for her to move on to other things. We continued to work together on various state-wide projects and saw each other frequently, and the friendship between us and between our families continues to grow.

## S.'s History

S.'s experiences as a child shaped her actions and attitudes as an adult. She was born in the 1950s as part of a busy, active family of five children in New Jersey. Because of the size of her family, she was frequently on her own when it came to playing or learning. She jokes that because her family was so busy she learned to read from the tombstones at the cemetery across the street from her house, where she went for peace and quiet.

Unknown to her family, both her parents carried a recessive gene for a rare disorder, called Ehlers Danlos Syndrome, which is a severe abnormal platelet aggregation disorder. In simple terms, S. lacks the connective tissue to stop "bleeds" when they start. A simple bruise can result in a life-threatening bleed. Severe bleeds for long periods of time have destroyed nerves, her spinal cord, and joints.

S. was born with this disorder; however, she led an active life as a child and teenager—skiing, swimming, biking, and participating in many other sports and activities to the dismay and disapproval of her mother. Normal bruises and bumps led to hospitalizations and time spent on crutches or in leg braces.

> When I was 16 I fell off a ski jump and broke my leg in 16 places. All hell broke loose. It never healed right, and that's when I found out about Ehlers Danlos and connective tissue disease.

When she was on crutches or in leg braces she went to an Easter Seals Center, since students with disabilities in the 1960s were not allowed to attend regular schools. S. has vivid memories of learning algebra while watching other students with developmental disabilities paint pictures or play with clay. She was glad to be mentally challenged and learning the same curriculum as her able-bodied peers; unfortunately, she was working on her lessons in the same setting as children who were playing with pudding for tactile stimulation. In this environment, S. learned to maximize whatever potential the setting offered and to react to the disadvantages with humor.

When she graduated from high school, she went first to a small college in the South, but she found she could not live independently. She moved back home and finished her undergraduate degree there, after which she received her master's degree in education from Columbia University Teacher's College in New York City. Her first job was as director of a segregated school for students with disabilities run by Easter Seals in a New England town. She also met her husband, someone she calls "one of the miracles in my life."

> At that time I was very ill and needing blood. Friends called around to find donors, and we found out that Jim was a perfect match. So I married him for his blood! My father made him go talk to my oncologist, who told him that I might or might not be here in six months.

S.'s decision to have children reflects her indomitable spirit. Both Jim and S. wanted children and explored the possibility of adopting. After being refused because of her life-threatening disease, they decided to have their own. She lost several babies. Their first son was born while she was project coordinator in a school system with 725 students with disabilities in her program.

> Twelve weeks before I had my son, my mother found out I was pregnant. So I wasn't prepared, but I had a baby—and it was hell. Eight months of it—every day—going and getting blood every day and working....It was tough, but I did it.

S.'s second child was "an absolute, total miracle." Doctors told her that she had a six-pound tumor, and her daughter was born eight weeks later, 22 weeks premature. S. spent many hours in pediatric intensive care rubbing her daughter's little ears, shaping them, talking to her, and praying for her as well.

Taking care of and being with her children is one of S.'s greatest joys. She and her children have a unique relationship in which the children have had to learn to behave like adults. Her son met many of her basic needs when he was only three years old, such as helping to prepare meals. Her family's experiences have helped S. learn about interdependence rather than independence.

> You're not independent, you're interdependent. You feed off each other's strengths and help each other with your weaknesses. This isn't about disability but meeting needs.

At the time this is written, S. and her family live in a house they built together in a rural part of Appalachia. S. home-schools her son and her daughter. Her son is a fledging actor and musician who has parts in local and national shows, musicals and movies. The family supports his talents and travel with him around the country, living in a small camper when necessary. In S.'s mind, the inconvenience and discomfort are a small price to pay for the family to be together.

S. is active in the disability community, locally and state-wide as well as nationally. She helped develop disability awareness guidelines that are used by many organizations across the country and was a witness to the signing of the Americans with Disabilities Act by President Bush.

> I brought new awareness in a small rural hillbilly town that people with disabilities just want to be included. Before awareness raising, I had to go through the drive-in window of a local fast-food restaurant in my power chair because I couldn't get in the store.

## Who S. Is

S. describes herself in terms that reflect her determination and that she sees herself as a person, not as a disabled person. Her words also reveal her pride and resilience.

> I am a rainbow. I'm all the colors of the rainbow. When I'm red, I'm angry. I'm yellow—I'm as bright as the sunshine. I'm purple—I'm moody. I'm me. I'm just an individual person, different from anybody else. Period. And I take pride in that. I've always been that way. If everybody wore dresses, I wore pants. If they wore pants, I wore knickers. If anyone says I can't, I say, "Damn it, I can, too." I thrive when people say can't or no. I prove them wrong every time.

S. recognizes that she is a "strong woman, opinionated, and verbal," which must be balanced with roles she has to play as a mother, wife, and disability activist.

> I refuse to change who I am or what I believe it. But I'm also very sensitive to the multiple roles I have to play. Being yourself and being a parent are two different things. That means that sometimes I have to tone down my passion for what I really believe in.

For example, when her son was invited to be one of ten children nationally to perform with a celebrity in one of the opening ceremonies of the Junior Olympic Games, the parents were asked to sit in a special section, which was not accessible. Her son wanted her to sit with all the other parents.

> What he meant was, "Don't raise hell. I just want to be one of the other kids. Just sit there and be with the other moms. Don't make this an accessibility problem."

S. acquiesced, allowing her husband to carry her up the stairs to the section set aside for them. She called this experience "swallowing a lot of myself."

> What really bothers me most about being disabled is that I can't always be who I am. Not being who I am is like giving away a piece of my soul.

In this example, if she had fought for her right (guaranteed by law) to sit in an accessible place, she would have left an impression in people's minds about her that has little to do with who she is. That impression blocks the formation of future friendships and relationships. In addition, a public confrontation about her rights as a person with a disability would have taken precedence over mutuality and interdependence within her family, which S. will not do. She maintains that the public forms an impression of who and what she is before they ever attempt to understand the underlying reasons for the decisions she makes.

> I have to fight for basic issues first to be able to tell who I am. By then an opinion of me has already been formed, and people never get to know me. They say, “She’s rebellious! She’s the wheelchair woman! Disabled activist! Hell raiser!” But that’s unfair.

S.’s friends would concur that she can be opinionated, sarcastic, and verbal. She has yelled at all of us, including her husband and children. We also know that these are some of the ways in which she copes with unpleasant situations. Her reactions, however, contribute to how she and other women with disabilities are perceived by others in our society.

S. is very concerned about society’s perceptions. Some women with disabilities are considered tragic or brave, and others fighters and hell-raisers, as S. can be. Neither perception recognizes the reality of a woman’s life, including S.’s.

> I’ve heard, “Oh, you’re such an inspiration. You’ve overcome.” That makes me gag. The biggest barrier we all face is preconceived attitudes about our disabilities. They don’t know what you’re capable of because they haven’t looked beyond the disability.

She feels that she gives away more of herself when her children or family are involved. The need to compromise for their sakes or protect them means that she might not be able to act on issues important to the disability movement. The result for her has been a tough shell or wall that she has erected to protect herself from outside forces. She might look and act obnoxious because she believes that she has no other choice. She can be cuttingly, hurtfully sarcastic, offensive, and defiant when she has to compromise her beliefs. In times like these, she does three things: puts up a wall that keeps others out, falls back on her faith for understanding and forgiveness, and goes home to her family.

> If all I have is my husband, my kids, and my faith, I have everything I need. We could live in a one-room shack with a dirt floor and eat bugs if we had to.

## Daily Experiences With Disability

For S., like with most women with disabilities, the greatest challenges she faces are in ordinary, daily activities like shopping, picking up her daughter at school, going out to eat in a restaurant, or dealing with finances. Again, her words reflect her insistence on being recognized as a person rather than as a wheelchair and her frustration at not being able to do ordinary activities.

> I'd like to be able to go somewhere—anywhere—and be inconspicuous. Not be gawked at. I'd like to be invisible for once. You're announced wherever you go, as soon as you come in in a wheelchair, whether it's a church, public function, or out to dinner. There's an announcement: "Wheelchair coming through!" NO! There's a *woman* in that wheelchair!

Grocery shopping is another nightmare for S. Because she has the use primarily of just one arm, an arm needed for driving her power wheelchair, she is unable to push a grocery cart. Her words reflect the fact that disability is a family affair, and that even in the closest of families, ordinary experiences can be unnerving.

> It's a nightmare and totally exhausting for all of us, but it's also comical. My little boy is like the boy in *Home Alone* when I announce we're going shopping. He slaps his face with his hands, rolls his eyes and says, "Oh, my God, we're going *shopping*?" It's a three-hour ordeal and we're all ready to kill each other by the time we're done.

On one of our trips together, S. and I went to pick up her daughter at kindergarten in an adapted van which she drives herself. S. can only drive the van, however, when she is in her power wheelchair. If she is in her power chair, she cannot get in the door to her daughter's school. Going from the van to the school illustrates how frustrating ordinary tasks can be for S. as well as how she deals with barriers placed in the environment by unthinking people.

Other parents who come to pick up their children at school walk from their cars (on gravel) to the small fenced-in yard, open the four-foot gate by reaching over it and unhooking the latch that is cleverly placed on the inside of the gate. They then walk up one step into the narrow door of the small school. S. has a different experience because she uses a wheelchair.

> I could've raised hell. Sometimes I take my manual chair (if someone else will drive) and bump the steps to get in. Or I have to yell for someone to open the gate for me. But I want to go every day to pick her up, like the other mom's do, but I can't get in the door in my power chair. And if I don't have my power chair, I can't drive my van. It takes me 45 minutes to go there from home, open the damn van, put down the lift, drive over, reverse the process there, get the gate…and then wait for someone else to go get my daughter.

As an outgoing person, friendships are important for S., and she wants her children to have friends as well. Part of being a friend and having friends is visiting in each other's homes. Visiting, however, is not now part of S.'s or her family's daily experiences, and loss of contact with friends causes pain to all of her family. Not being able to get into friend's homes makes development of friendships a challenge and makes her more reliant on their calling or visiting with her in her home.

> When I ended up in a wheelchair, it was two or three years before I stepped foot in another person's home. Since then, I've maybe been in three or four people's homes. That's it. My sons says, "Mommy and Daddy, why are we never invited to someone's house? Why are they always here?" It's hard to explain. I answer, "I don't know why, Son."

S. and her family spend an inordinate amount of time and energy dealing with insurance, doctors, repairs to her equipment, and financial matters. She says, "Learning to live with disability is about learning to live with less."

> For people with disabilities, finances are the biggest problem. Everything costs so much. Our key to success can't be measured in terms of money. You learn to deal with less, whether it's a physical body or physical capabilities or money.

Like other women, S. has had to make many decisions with the entire family in mind rather than just what she needed or wanted. The fact of disability in her life, however, has a more significant impact on her family because of her need for their support and assistance. It was important to her to show the world that she could work full-time, particularly after being told by her school system that she was no longer able. At the time she made the decision to go back to work she depended on her husband for transportation.

> For me, working was an inner passion. To be able to do something I wanted to, and to feel that I still fit in to society was important. But the cost was too great, as well as the inconvenience for the rest of my family.

S. frequently responds to others' preconceived notions about her as a mother with sarcasm. She just "tells them off." One particular episode occurred when she was pregnant with her daughter. She was waiting in a doctor's office, and a woman sitting next to her was staring at her rather obviously. The woman finally ventured a question as to why S. was there. S., although feeling it was none of the woman's business, replied that she was having a baby. The shocked woman asked, "Well, will it be just like you?" To that question, S. sarcastically said, "I hope so. With a little luck it will be born with a wheelchair just like mine, with cute little wheels, and it will be pink for a little girl and blue for a boy."

S. feels fortunate that she has the support from her faith, family, and friends to move beyond the "hell of living every day." She says, "And the hell is complicated by all the little devils from people adding to it and making it worse."

S. recognizes the effect of growing up in a society which frowns on women showing anger as well as a desire for power and control over our lives. Women with disabilities in particular are supposed to be helpless and dependent. S. has felt negated, invalidated, and ignored. Perceptions about her have been formed that do not accurately reflect what she feels about herself, causing her to build walls and barriers. Her family has had to experience similar discrimination because of their close proximity. She feels that it is important to fight for her rights, including rights to be a parent, have a job, and get into public buildings, because of the impact her actions will have on other people with disabilities. She also recognizes the personal cost of her activism and has learned to conserve her energies for things that really matter.

> I want to be included in society. I have a right to be a mother and have a job. But I'm not included in society. I'm an outcast, period. I'd love to

> change it, but the energy that goes into changing one person's attitude is so great.

Although loss of control is a daily experience for all of us, it is magnified for a person with a disability. Choices are fewer, such as being limited to shopping at stores that are accessible. A person with a disability is also at the mercy of service providers and medical professionals. Having control over choices, then, becomes very important.

> If you're not in control of your life, your feelings, your emotions, then you can't deal with what you're going through. There are so many things I'm not in control of that change every day in my life, that change my life and how I do things and who I am. I've changed because of the things I didn't have control over. That's probably true of everyone, but it may be greater for a person with a disability. I can't control a damn thing except myself.

She has to continually balance her desire to be in control with her need to ask for help. When help comes from her family it is called mutuality and interdependence. When she has to ask for help from outsiders, it becomes "begging" and requires "swallowing some of my pride." She hates having to act pitiful and helpless to get things she needs, but she also knows that most people understand this portrayal of her. It is a price she is willing to pay for freedom.

> I had to ask for help from people to get my power wheelchair and my van, and that was tough. I wouldn't have freedom now without them, but you have to beg to get them. "Please help me! I'm so pitiful!"

S. recognizes the impact disability has had on her and her life as well as how our culture has influenced her interaction with others. She says she is more than she was prior to her disability, which she defines as the time she started using her wheelchair for mobility. The results, however, are not always pleasing to herself or others.

> My biggest challenge is to be me in spite of me, to be the real person who's inside, the person I want to be and still am, but am not allowed to be sometimes.

The biggest challenge sometimes is getting her to let us through the wall she's built to protect her and her family. When we are turned away, we realize that it is her way of dealing with situations beyond her control. Offers of help are refused, not because she doesn't need the help, but because she is asserting her need to be in control of the situation. Being with S. can be a painful and experience, but it is never boring. I have learned to dodge, whether from words that are said out of frustration and pain, or actions that might hurt worse.

> I'm learning it's okay to be human. Crying is okay once in awhile. It allows you to let go of things that are beyond your control. It's part of

> grieving and growing. I have always thought it was a weakness, but now I realize it is a strength. Disability can kill…it kills friendships, relationships and families, but those that survive are the strong ones. They are fighters and soldiers in the new disability war.

## *Commentary on Women's Stories*

Each of the women participating in this study is uniquely different and our relationship has been different as well. Our personal and professional experiences vary in terms of depth, time and type. I know some of these women better than others, simply because I have either spent more time with them or the time spent has been more profound. For example, staying with S. in the hospital when she was in critical health placed our relationship on a deeper level than that with C., K., or D. Another participant, E., has become an integral part of my life because she has included me in the circle of friends with whom she can feel safe.

The stories that you just read are the foundation for the "Second Data Analysis" located in the next chapter. In order to understand the processes by which these women have become subject, I had to search for patterns and themes across stories rather than within stories. As I analyzed and agonized, I began to recognize differences in what they talked about, how they spent their time, and what seemed to be important to them. I also realized that two were more political and global in outreach, while the other three were focused more on family and the community close at hand. It was not until I laid aside my own preconceived notions about subjectivity that I was able to write the next chapter.

# CHAPTER 5—SECOND DATA ANALYSIS

The five women participating in this study were selected based on two things: mutuality and awareness that they were operating from a position of subjectivity as indicated by their use of agency. The presence of mutuality allowed me to be a part of their lives and struggles rather than operating from the position of an "other" who would objectify them.

Mutuality is defined as "a condition or quality of being mutual; reciprocity; mutual dependence," (*Webster's Encyclopedic Unabridged Dictionary of the English Language*, 1989). For almost 10 years, these five women and I have been open to each other's influence, willing to be affected by the other, and emotionally available to each other. At the heart of our mutuality is the recognition of our need to establish connections with each other.

These women have helped me recognize my need for their wisdom and experience in my own life, as I have faced personal disability as well as disabilities in my immediate family. They have also developed in me a deeper understanding of the experiences they have had as women with disabilities. Sometimes gently and sometimes abruptly, they have sharpened and focused my awareness of the meaning of living with a disability. Our shared experiences have developed a deep commitment to each other and a relationship built on respect.

Because of the many personal and professional experiences I have had with these five women, I grew in awareness over time that these women were different from many other women with disabilities, including those about whom I had read and those whom I had met. They did not see themselves in the same way as others saw them, and they acted in ways contrary to what was typical for most women with disabilities in America. These women had jobs, raised families, were active in their communities, and were disability activists. As an advocate for my own son as well as for other people with disabilities, I began to realize that I did not need to advocate for them. They were doing it themselves. Other perceptions of these women also gradually crawled into my awareness.

Having a disability seemed to increase their capacity for being women, in spite of how they "looked." They seemed to be unconcerned about society's perceptions of their appearance. In fact, they frequently joked about how they looked. They railed against the use of words like "special" to describe them. Sometimes they vehemently spoke out when their words were discounted or when they experienced discrimination. Sometimes they also chose to walk or roll away, giving an appearance of retreating. In spite of my knowledge of them, I simply did not understand the contradictions in their lives, but I gradually began to understand that what I was seeing and hearing could be described as acting from a position of subjectivity.

E., a participant in the study, when asked what being subject meant, said, "Refusing to accept the defining gaze of the Other. When we refuse, we gain the power to become ourselves and become the subject of our own lives, in charge of ourselves."

As I now understand it, subjectivity has two components: *being* subject and living in a *position* of subjectivity. Being subject includes freeing oneself from cultural expectations, acceptance of the self, and "personal agency," or the ability to speak out and act, to acknowledge the use of personal power to evoke change in one's life. Being subject is a continuing process, a *becoming*, acted out in historical settings that are socially constructed. Being subject also includes critical consciousness, or an awareness of how structures in society affect one's life and the desire to change them. For example, a subject would not accept social invisibility or rolelessness.

The position of subjectivity is unpredictably contradictory because it is continually being negotiated. Freire says that the position of subject is living "between what has just happened and what will happen next," an accurate portrayal of the uncertainty and shifting circumstances of these women's lives (quoted in Peters & Lankshear, 1994, p. 181). The position of subject could also be considered a marginal position because of the resistance required to maintain it. These women refuse to internalize the dominant belief about them, but by their refusing they place themselves out of the mainstream of society yet negotiate it.

The following section describes the processes by which five women with disabilities have become subject. Based on participants' words as they describe their lives, it is divided into two main parts. The first part is experiences they had as youth that may have contributed to being subject; the second part deals with their experiences as adults.

## *Experiences as Youth*

Significantly, all five women spent considerable time describing in detail experiences they had as youth, although I was already somewhat familiar with their background and families. They shared some common experiences in their youth even though disability has affected them in different ways. They had different family structures and socioeconomic status and lived in different parts of the country.

One common experience is that they were placed in positions where they had to develop strategies for coping and surviving and had to learn to negotiate boundaries, sometimes literally. For example, D. had to learn to navigate the halls of an inaccessible school when she went to middle school. K. had to make daily decisions about how to do her school work, given that she could not use or see the materials her teachers gave her. As they reflected on their youth, they are not certain whether they were placed in those situations deliberately by their parents and teachers or accidentally because of where they lived, existing laws, or societal norms. It is, however, apparent from their words that their families did not shelter them.

C.'s experiences in coping were caused by discrimination based on color and socioeconomic status. K.'s, S.'s, and D.'s experiences occurred as they went through school, and C.'s and E.'s experiences were more a result of where they were raised and their family's values. K. was the first student considered legally blind in her school system who was mainstreamed into general education classes. Her mother insisted on her daughter being educated in a local school rather than at a distant school for the blind. S. was educated in a self-contained school away from peers without disabilities. Her school was not physically accessible, nor did she have legal rights to insist on it being made accessible. D. started school in a segregated setting and was mainstreamed (as it was called until recently) when she was in middle school upon the insistence of her family.

K. stated that "being mainstreamed" into public schools was probably the most significant thing that had happened to her in her life, even more so than losing her eyesight completely when she was an adult. "My experience was so horrible…I just try and forget about those years. But I showed the school system that it could be done." Those experiences also helped her learn how to get along with people without disabilities, how to get what she needed, and how not to surrender her identity.

The four women who were born with disabilities experienced accompanying shame and stigma, or the experience of being judged defective by others. As youth they began to cope by resisting, using humor and sarcasm, and attempting to "pass" (Goffman, 1963).

Their use of resistance included refusing to do some of their school work, such as when K. told her teachers that she was not going to use any more faint purple mimeographed sheets. Their use of humor and sarcasm masks the hurt and shame they experienced as they retell what happened to them, such as when S. laughs about learning algebra and geometry with younger students getting tactile stimulation.

> I had a lot of fun learning algebra while trying to protect my paper and books from the pudding that other kids with disabilities were using for tactile stimulation.

In their attempts to "pass," they hoped to persuade adults and peers that their disability didn't exist, or at least didn't matter. One example is when K. tried to fake the vision test or when D. laughed at the boy who called her "his girlfriend." When D. was younger, she tried to keep up with her peers as they ran down the road to look at horses in a neighboring field.

> It took me a little time to catch up. I always caught up, though, and tried to act and feel as though it didn't matter that I arrived last.

K.'s description of going outside to the playground demonstrates her awareness of the effect her presence had on her peers. Playing with other children seemed to be more important to her than the risk she was taking of being embarrassed or failing in front of her friends. K.'s. decision to go out on the playground and put herself in a position of being hurt or yelled at reflects a deliberate choice. She described herself as being a "little bitty kid," so she had some notion of her size in comparison to those of her peers.

C. was not born with a disability, but she was born Black. She was raised by a single mother who did laundry for a living and who lived in a segregated community in the South. As she reflected on her youth, C. wonders if some of her experiences affected her determination now as a woman with a disability. She knows that she was encouraged to be an individual and to make her own decisions. In high school, while augmenting the family's income by doing laundry, she experienced her first awareness of discrimination in the form of an employer wanting to be called "ma'am." This experience perhaps prepared C. to respond to people who tried to make decisions for her after she became disabled. Her mother showed her that she had the power to refuse to do certain things, that her refusal could be couched in language that was gentle but firm, and that people might expect things of her that she did not have to do. This experience was a step in the formation of a core of determination that has surfaced since the onset of her disability.

E.'s experiences growing up in a matriarchal family in the mountains of Appalachia were the beginning stages in the notions of autonomy and agency she now has, and she recognizes the impact her family's thinking had on her.

> The attitude that parents take about disability affects how a person incorporates it into her self-image and self-esteem. I was allowed to fall on my face a time or two. You didn't…ask for help in my family.

There were times in E.'s life when she needed her family's acceptance, and their lack of support planted in her a need as an adult for support and acceptance. It may also be why she speaks so eloquently now about the need to "welcome the stranger" and embrace diversity. Because she felt she could not live up to her family's expectations, when E. was in high school she made a conscious decision to define herself. She felt that this was the only way she could defy their expectations of her.

> When I was 18, I decided that it was up to me to frame it (disability)….I decided how to frame it…I began to define myself. I decided that I have to amount to something.

These women's families also seemed to influence their adult notions about advocacy, both for themselves and other people with disabilities. K.'s parents insisted on her being in a neighborhood school. S.'s mother required the school system to hire a tutor since the school was not accessible, and C.'s mother demonstrated how to quietly resist external domination.. All five women are now strong advocates for people with disabilities being fully included in the mainstream of society, including having families and being employed.

These women also recognize that some of their families' beliefs and practices haven't necessarily helped them as adults. E. ponders whether her Appalachian rearing was supportive since it encouraged the notion of independence. As E. has gone through life, she has learned to value interdependence and mutuality rather than independence. K. has been hurt and frustrated by the lack of support she received from her mother at crucial times in her life. Her experiences may have contributed to her present notions about mutuality and the need for support from close friends who have had similar experiences.

The commonality in these women's experiences is that they were placed in positions in which they had to develop strategies for coping and surviving. Noticeably absent in their discussion about their youthful experiences are words like "anger." None of the women talk about being "angry" at how they were treated, although K. mentioned "feeling like a freak" as she went through the "awful experiences" of being the only child in the school who was blind. As they describe their experiences, they do so with humor, although their words are frequently sarcastic. Their words also reflect the hurt they experienced when made fun of by other children.

Each woman learned processes of negotiation as a youth, whether with people who treated them differently because of color or because of disability. Through their negotiations they learned to hold on to their identity while attempting to get their needs met. The experiences they had are part of the process of becoming subject.

## *Experiences as Adults*

The process of becoming subject, as fully known by others and themselves as women with disabilities, where disability is incorporated into their being, has happened over time and as a result of a myriad of experiences. Each of these women, by society's standards, should be pitied, pitiful, helpless, hopeless, and dependent. Instead, in the course of every-day living, they have become subject as they have learned to negotiate survival on their terms and take the position of subjectivity. They have had experiences similar to other women; however, they have disabilities, and the fact of disability *for these five women* has made a difference in who and what they are today. They perceive disability as an asset rather than a liability, and they use words that affirm their experience, rather than deny it.

> D: I like to focus on personal empowerment. I am a liberated person with a disability, and this is what has made me a person of strength.

The process of becoming subject is one which is complex and unique for each woman. While each has had different experiences, they also have had comparable experiences that help us understand the process of becoming subject.

Experiences that are common to each of these five women include the following:

- A catalyst for becoming subject is present in each woman's life.
- Each has grown in acceptance and understanding of the self and her identity.
- Family structure is an influencing factor in the process of becoming subject and the course it takes.

- Each woman has learned to use anger and power to effect change in her life.
- Each has experienced *communitas*: living in a community of support and obligation.

In the next section, I will use their stories to illustrate these points.

## *Catalyst for Becoming Subject*

As adults these women have had experiences that seem to have acted as a catalyst for change in how they perceive themselves, the control they have over their lives, their connections with others, and how they react to external forces. Three women's experiences, K., E., and S., were tied to progression of their disabilities. C.'s is connected to onset of disability, her stroke and subsequent tumors. The fifth woman, D., ties her change and development to prolonged contact with other people with disabilities. Each woman's "moment of awareness" is described in more detail in the following paragraphs.

S., who was born with a congenital and progressive disability walked with the assistance of crutches or braces until her late 20s. As a youth she was active and athletic, enjoying outside sports like down-hill skiing. Because she was upright, on eye-level with her peers, and appeared to be "normal" other than occasional crutches or braces, she "passed." In her 20s, because of damage to parts of her body, she started using a wheelchair for mobility. Once she started using a wheelchair people reacted to her in a different way. Their reactions triggered a corresponding change in S., particularly in how she thinks about herself and her subsequent reactions to what other's say or do.

> …the experiences I had because of people's attitudes…were the reason I got involved in [disability] issues. [I've learned] it's a fight every day…

The event that K. remembers as producing more change in how people reacted to her than in what she thought about herself was when she lost the rest of her eyesight. She realized when she was in the hospital that people were going to have to deal with her in a new way. She was able to meet other women who were blind, and they gave her the strength to demand that people listen to her. Her comment also reflects a positive change in attitude or perception about herself.

> I said, "There's a whole new world out there for me to find. And I'm going to meet that world, because I'm not going to be a dirt ball in the corner in this world."

Although E. had been "living in the skin that was gifted" as well as dealing with legs that periodically and spontaneously gave out on her, the diagnosis of multiple personality disorder was the most significant change in her life. Until this point in her life she had been able to "pass" and ignore her differentness.

> The minute the woman said, "You have multiple personality disorder," I could feel the fear and anxiety rising….My expectations of myself altered when I was diagnosed as a multiple. It was if I lost the grace to be who I

> was and work with it and had to suddenly wrestle not only with how to manage but also how to confound others' expectations. It was awful.

C., the only woman in this study who was not born with a disability, stated that she really did not think much about people with disabilities or having disabilities prior to her stroke. "You think about things differently after you have a disability, especially loss of control." Her reactions to the experiences after her stroke seem to be based on skills developed through the years, perhaps rooted in discriminating experiences she had as a youth or as a young social worker in the slums of New York. Many of C.'s stories relate to her intervention in the lives of families, particularly single women and children. Her words demonstrate a deep concern for people who "don't have a chance," or "children who have no one to believe in them." She seems to have made a practice of putting herself in unlikely situations, including taking on an occupation that was considered questionable for any young woman in the 50s, regardless of race. C.'s vocabulary reflects the change in her after her stroke with her frequent use of and emphasis on the word "determined," as she applies it to things she wants to do as well as things others do or do not want her to do. For example, she was *determined* to not live with her daughters after her stroke, she was *determined* to learn to live by herself, she was *determined* to return to work, and she was *determined* that another woman in her church committee would understand why she should go on a trip. Her experiences also increased in her an awareness of the needs of others, the need for being part of and building community, and the need to increase others' awareness of her needs.

> I want to project myself as, "I can do it." Being disabled has made me a stronger person, more self-willed. I can do *anything* I set my mind to. And I learned that if people aren't aware of what I need, then I need to make them aware.

D., who describes herself as "a successful, professional-type crip" until her late 20s, tried not to think about disability at all. For her, the greatest compliment someone could give her was that they didn't think of her as "handicapped." The catalyst for D. was becoming involved in an independent living organization in the city where she was living. As a loner and extremely private person by nature, connecting to other people and allowing herself to be known to them was perhaps her first experience in mutuality, or sharing her life with others.

As she shared her life with people with disabilities, she realized that many of her experiences, such as not having access to public bathrooms and being passed over for jobs for which she was qualified, were forms of discrimination. She became aware that education and information were not enough. Her personal sense of social justice, coupled with identification with the civil rights movement sweeping the country in the 1960s and 1970s came together.

> Two things happened...the most important was that my disabled brothers and sisters shared with me their personal histories...and I got to see my life through their...eyes. The second thing that happened...is that I saw that awareness and education are almost never enough. When I was

> arrested for the first time…for the first time in my life…I felt proud to be disabled…not proud of what I had accomplished in spite of my disability, but proud because I am disabled.

Each woman has had an experience as an adult that caused a shift in her way of thinking about herself and others. Each can mark when that shift occurred, and each realizes the impact it has had on her subsequent thoughts and actions. From these experiences, each has arrived at a position in which she has allowed disability to be part of her identity. From this position of subjectivity, she has continued to struggle for new ways of being known.

## *Naming and Becoming*

Subjectivity is about becoming the author of one's own life, of owning and accepting one's life. Part of the process in becoming subject has been the recognition each woman has of her own inner resources. The words they use also reflect the changes that have taken place in them in their process of becoming subject, including growth in personal identity and development of an identity with other people with disabilities. Their words also indicate that becoming subject is an ongoing process.

Naming, or being able to recognize and state the names to her identity, is part of the affirmation of her life as a woman with a disability. The concept of naming, taken from feminist literature, implies a connection between words or language and identity.

The ability to name is extremely important in a culture in which women with disabilities are considered voiceless, or having nothing worth contributing. For these women, naming is reflected in their ability to state the sources of their oppression, as they describe the self, and as they speak out on behalf of others. It is seen in their freedom of expression, in their experiences, and in their perceptions. Oppression for these women includes discriminating experiences, lack of access to public buildings, and lack of control over the resources that affect their lives and well-being.

They share a common language, using more inclusive words like "both-and" rather than "either-or" and words that indicate they see more shades of gray than black and white. They describe themselves in words that suggest variation and change.

> K: I'm different day-to-day. Some days I'm cotton or denim or silk.

> S: I am all the colors of the rainbow. I'm red and angry…I'm yellow and happy…I'm purple and moody…I'm different. I'm me. And I take pride in being different.

Naming includes the use of strong verbs and humor as these women speak about their self-awareness and as they speak out against unfairness and prejudice; and they use words that indicate they are spiritually, mentally, and emotionally strong. Humor is used as a form of expression as well as a way to mask hurt. For example, after a traumatic event E. was heard to say, "Only the hope of dying is keeping me alive!"

They recognize and can name the sources of their oppression, both internal and external and trust their reactions to experiences that constitute a rejection of the self as they know it. For example, medical care providers and insurance companies are sources of external oppression and are primary irritants in their lives, along with other service providers who presume to make decisions for or about them. Internal sources of oppression includes anger turned inward and stereotypes about people with disabilities different from theirs. For example, K. resents being included in a description of a product that is so simple that "even the blind and mentally retarded can use it."

Their language also reflects their reaction to those who control the power in their relationships, such as vocational rehabilitation providers.

> K: It's kind of like having men as rape counselors. What do they know about a woman's experience?

They are aware that some types of charity, supposedly for the purpose of "curing," constitute oppression because it fosters stereotypes.

> D: People in this country are comfortable with the Jerry Lewis theory, which is the poor, crippled people theory…in which disability is a personal tragedy that is dealt with by cure or kindness.

They are also frequently not impressed by attempts to provide them access to public buildings.

> S: Attitudes haven't changed much. People say, "I see more handicapped signs." No. You see more signs. And you see more people

> blatantly ignoring them. You think if you put up a stupid sign in an inaccessible spot you're serving society? Get lost.

Their words also signify their awareness of growth of the self and affirm their dignity, identity and wholeness. In their words I also hear some of the process of becoming subject.

> E: We are all negotiating our identities at different moments in our lives and in different contexts….Our identities are always developing; we are continuously negotiating, defining, and redefining….Disability is a process of being constantly and forever adaptive.

These women do not deny or reject the labels used to describe them: crazy, disabled, handicapped, crip; nor do they use politically correct terminology to describe themselves. In fact, they strongly protest against labels such as the word "consumer" and politically correct terms like "inclusion." They realize that changing the label doesn't change their reality. They might say like Kate Gainer, "I was born coloured and crippled but now I'm Black and disabled," (Gainer, 1996).

When K. described her experience growing up with a significant visual impairment, she used words like, "I had to prove….She made me….I felt like a freak….I was uncooperative….I quit asking….He wouldn't help me….They yell at you." Now, after onset of blindness 13 years ago, her words reflect the changes in her: "I can get people to listen to me….Sometimes I'm rude….I weigh what I do….We don't need healing." These words substantiate her statement, "Now I realize I don't have to show the world that I'm a super-blind person."

The participants' language also reflects the tension and dialectic in their daily lives, particularly as it relates to being included in society, and their words reveal the depth of the feelings they have as a result of their experiences, perhaps as youth.

> S: The way kids with disabilities are being included now is sickening and patronizing. When they're older they're going to think what ADAPT members think of the Jerry Lewis Telethon: "How could you have done that to me?"

The disability experience has helped them to become emotionally and mentally strong and resilient. They are also more accepting of themselves, as if in the process of naming they have developed a stronger sense of who they are.

> K: It's taken me 40 years to learn to like myself in spite of the bumps. I'm at peace.
>
> D: Disability is not the opposite of strength and beauty or outside the realm of power, growth, wisdom or love.

The concept of naming, as applied to the experiences of five women with disabilities, illustrates the strength and development of the self in these women in their position of subject, as they negotiate the terms of their lives. In the words of an African proverb, "It's not what you call me but what I answer to." Through the use of naming, they choose how they will be represented, to whom they answer, and how they affirm the presence of disability in their lives. If they were to reject disability, in their opinions, they would in effect repudiate their lives.

## *Family Structures*

For these five women, presence or absence of close family seems to play a role in their process of becoming subject, particularly as it has influenced their outreach to others with disabilities. K., S., and C. are part of close family structures that includes children. K. & C. are single mothers with daughters, and S. has a husband and two children. All three women emphasize the importance of family in helping them endure the "hell of everyday living."

S. and K., in particular, since they have children living with them, have learned to rely on their families for help in everyday activities. For example, S.'s children remember when their mother's power chair is not working, and without being asked, appear to push her up the ramp into her home.

> S: We need each other and we are very dependent on each other—collectively interdependent. We feed off each other's strengths and help each other with our weaknesses.

K.'s daughters help their mother sort laundry because "this is what happens in families. It's not about disability, it's about being human. It's about doing things out of love and concern." Within their family structure these two women in particular have been able to construct an element of trust that includes building natural supports and a willingness for weaknesses to be seen and acknowledged. They both make a point that if all they had was their family, it would be enough.

Lessons learned from living within a close family has strengthened their position of subjectivity and has given them a pattern for helping others. K., C., and S. are all active in disability awareness activities in their communities; however, they freely admit that it is not their primary concern.

> K: My story is not about preaching blindness on a street corner, but can I get to the store and back...can I live my life without people getting in my face, and if they get in my face, dealing with them?

D. and E., on the other hand, are not part of close family structures. They live at some distance from their families, by choice. Neither woman is married and both live by themselves. They embrace a wider group of people with disabilities as their family, particularly those who have had experiences similar to theirs. Their atypical family structures seem to influence the intensity and frequency of outreach they provide to other people with disabilities.

> D: The most important thing that happened to me...was that my disabled brothers and sisters shared with me their personal histories...and

> I got to see my life through their accepting, loving, angry, and spirited eyes.

D. & E. have a global concern for the needs and rights of people with disabilities. E., who is very technology dependent, has an 800-number, e-mail address, fax number, cell phone, and pager that she uses to communicate with other people who have mental illness and other disabling conditions. Her numbers are available to anyone who asks. In fact, her answering machine says something like, "Hello, you've reached the voice mail address for E. You can reach me by fax at —, by phone at —, my cell-phone number is —, and my pager number is —. I'll call you back as quickly as possible." She always returns calls within a few hours, regardless of where she is in the world. She travels around the world, focusing on activities that support self-esteem and empowerment for people with disabilities.

D. says she probably has a "Messiah Complex." As a child she was encouraged to get a job and use her brains because her father didn't believe that women with disabilities got married and had families. She used her brains to get two master's degrees, one in law and one in business. After years of being what she called "a professional-type crip," she came under the influence of people in the independent living movement, and her focus changed. She has helped found two national disability activist movements. Both groups deal with issues of concern to people with disabilities such as attendant services and assisted suicide. D. not only does not like to talk about her own family, but she calls other people with disabilities "her brothers and sisters." "It's hard for me to think outside the disability movement."

In summary, the process by which these women have become subject seems to be at least partially related to their existing family structures. Existence of close family ties and support seem to give three of the participants a more local focus for their activities and energies, and more immediate events seem to have a greater impact on them than those at a distance. The two without close families are more global in their activities. Their concerns and energies are focused on national issues like existing laws, health care coverage and support services for people with disabilities and those who are elderly, and changing societal perceptions and attitudes. For each woman, her immediate or extended concerns has in turn effected change in her.

## *Using Anger and Power*

Part of the process in becoming subject relates to how these five women have learned to use anger and power in their lives. They have been placed on the margin of society because they are women with disabilities, yet from this place they resist attempts to limit them. They have learned to use anger to effect change in others without letting it damage themselves. They know that there is very little in their lives they can control except how they react to change, and that turning anger inward at the things they can't control is damaging.

Their anger is seen and heard primarily when they are exercising control through the use of power. K. used the threat of contacting the media to effect change in her guide dog trainers, recognizing that in this area she had power. S. and D. have used their knowledge and power to change building owners' attitudes about accessibility. Since both have had legal training, they confidently told businesses to abide by the letter and intent of laws like the Americans with Disabilities Act. I call this type of anger *affirming* because of the effect it has had on their self-esteem and sense of agency. The ways in which these women use anger seems to support Butler's (1995, p. 47) supposition that subjectivity is a precondition or foundation for agency, which is always a political act.

In the process of becoming subject, they have learned to use anger, and their use of anger is directed outward to effect and control change in their lives and in the lives of others. K. says, "I get angry when people don't listen to me. It takes a lot of energy to get angry, and I use my anger for things that affect people other than me." D. says, "Anger is a resource, not a problem." C. says, "If they're not aware of what I need, then I need to make them aware."

> E: When people deny my experiences and say they never happened, they erase me. Imagine the struggle to prove I exist, my anger and rage slowly deepening, my soul ripping, and then the pelting I take when I defend my experiences.

Perhaps one of the most significant steps in their process of becoming subject is their awareness of the damage that unacknowledged anger can have to the self. C. identified this attribute in some of the women she met as she went through rehabilitation, as indicated by her references to "people stuck in the grieving process," "people who are bitter and angry," or "people who can't move on with their lives." Interestingly, all five participants do not have close relationships with people "who can't move on with their lives." D. comments that it may be because these individuals have internalized society's perceptions of them.

The relationship between anger, power, and control is not fixed. Assumptions about these women, such as having their personhood negated, makes them angry, and they use that anger to effect change in others' perceptions and to gain some control over the situation. On a parallel plane is the fact that there is very little in their lives they can control given the changing nature of disability, status of equipment and health insurance, laws, and other policies that affect them. Therefore, they only have power to choose how they react to their circumstances. One of the participants, E., explains the relationship between these concepts as she has experienced them.

> For us, change is inevitable. We can't control change, but we do have a choice about what we do with those changes—how we frame them. When we face a change and make a choice, we exercise our power over our direction. For things we can't control, where we feel directed by an Other, we can perceive increased agency or power only in conscious choice making.

Part of the process of becoming subject is related to perceptions and use of power. The women in this study have several notions about power. One notion is that they have power *to,* or recognizing that they have and can use personal power in their own lives to make choices and to effect change in other people's perceptions of them. For example, K.

chose to go to university and confront on a daily basis lack of accessible materials and buildings, lack of support from teaching staff, exhaustion, and trauma.

Another form of power they use is compromise. "Compromise gives you public visibility to act as though you're powerful." E.'s statement helps explain why, in certain times in my experience with these women, I have seem them turn away from confrontations that were an affront to their identity. When S. was given a choice of sitting in inaccessible bleachers to watch her son or making a scene, she chose to be quiet. Although she said that having to keep quiet in the face of discrimination was like "giving away a part of my soul," she has learned that compromise is sometimes necessary.

These women also contest other's use of power, or power *over* them, such as when people make decisions for or about them. For these women, these decisions are primarily connected to their disabilities and relate to perceptions about their abilities to be parents, have jobs, or live by themselves. C. had to confront her daughters, doctors, and employers about her ability to live by herself and return to work. "They were making decisions *about* me, but they were not listening *to* me."

These women realize that when they contest cultural attitudes and perceptions, they are laying themselves open to being labeled as a hell-raiser, militant, or not coping. It is a definition they all are willing to take in order to effect change.

These women have also learned to *appropriate* power or take power which others may not want them to have in order to exert some control over the systems that affect their lives. D.'s rallying cry is, "Don't take it personally, take it politically."

> We've learned about political leverage. Since we don't have money, we have to use the media, demonstrations, and protests to trade political power. I personally felt power the first time I was arrested.

Through their use of power and demonstrations of agency, they have revealed their position as subjects, perhaps because they understand the relationship between the use of power and the self. These women have used anger and power to refute rolelessness, which is common fate for most women with disabilities in our society. Instead, through the use of anger and power, they have developed new roles for themselves and in doing so have strengthened their position of subjectivity.

> E: Social systems require that people take certain roles. Someone in power determines what those roles will be. The owner of the belief about the role of a person assumes the power to determine the other's belief, imposes it on her, and in so doing, erases her, replacing her with a version newly constructed to conform to the beliefs in operation.

## *Experience of* **Communitas**

There is a communal aspect to the process of becoming subject as it has been experienced by the five women in this study. In *communitas,* lives are lived within a network of support and obligation in which its members share values and are seen as whole people. Because of the recognition that people change and grow and need different forms of association at different points in their lives, this type of community is not static.

There is also an awareness of the need to "keep alive a critical distance" between self-identity and social identify (Kirp, 1995, p. 130). These women have learned about the strength of being with like-minded people, particularly when they join with other people with disabilities to advocate for changes in existing laws or policies.

As part of the community, they have also learned about "welcoming the stranger." This meaning of community has helped them develop an attitude of acceptance toward differentness or diversity, including changes in their own bodies. They have learned that in giving, you receive, that in giving yourself away and letting yourself be seen, you become more, not less. E., who "sat at the feet of Sister Joan," remembers her calling this notion of community "distributing yourself for the sake of others" (Chittister, 1990). C. exemplified this meaning of community when she went home to take care of her ailing mother even though she was still recovering from a stroke.

Community builds trust and provides support, particularly a community of people "with whom you can experience some down time," (S. & K.). The five women in this study have gained strength from being part of a network of people, although each woman defines community somewhat differently. K.'s community includes her children, a few women who have experienced difficulties in their lives, her church, and a few disability organizations.

> It is important to have a friend like you. If I couldn't talk to my friends when I'm having a Classic Blind Day or Classic Blind Week, I'd go crazy.

For S., her community is her immediate family, her church, and a supportive group of friends who live in different parts of the country. C. is very connected to her church and its outreach activities to people who are marginalized, such as those who are homeless or those with AIDS. She also is close to her daughters.

E. & D., who have no close family connections, are very reliant on people in the disability community and friends.

> E: I have a whole network of people that I feel safe being vulnerable with…mostly women. My community expands as I heal, becoming more inclusive. The key for me is the process of developing mutual reciprocity.

> D: I deliberately chose to identify with the disability culture and to help those without power. I had to learn the system and use my energy and strength to get information out to people with disabilities who don't know they have choices.

D.'s statement reflects the belief each woman has about her responsibility to participate in her community. Each also recognizes the power in building community because of the existence of mutual support and acceptance of them and others in the doing. They are very aware of the needs of others who are also marginalized, including children and adults with disabilities, the elderly, people who are homeless and unemployed, and people with AIDS. Their words and actions reflect their concerns.

C: I think you build community by how you speak and what you say as well as by what you do. To be part of a community, you have to *experience* community. My experience in the community as a woman with a disability has helped me become more sensitive to the needs of others with disabilities and their issues, more genuinely helpful, more caring, and more sympathetic.

E: Our experience of community depends on where we are accepted and where we experience shame and stigma. In a community of people with disabilities, we aren't in the position of the Other. The attributes we possess are neutral. A factor in creating community is respect for and honoring diversity.

The process of becoming subject seems to require a commitment to and involvement with others. Although none of the five women are particularly close to their immediate neighbors, all are part of a network of people to whom they feel obligated and from whom they receive recognition and support. Perhaps because of physical limitations caused by disability, the "distribution of themselves" (Chittister, p. 42). for others is important to them, and each woman finds some way to contribute to her community. Visiting with people in their homes, getting in a car and driving somewhere, or dropping by the neighborhood bar are simply not options for most of these women. Instead, their connections to the community are by phone, all-day visits, intensive committee work, or through the media.

In the community they have learned interdependence and trust. Miller (1986) says, "When you develop opposition to the prevailing framework of the dominant culture, a community of like-minded people is essential" (p. 132). These women have experienced the power of the community and support from being in the community.

## *Living as Subject: An Ongoing Process*

Part of the process in this study has been developing and then deepening my own understanding of the position of subjectivity from which these women operate. My understanding of their disability experience has developed along a parallel track. It has been difficult to continually use words that affirm their experience, meaning that I had to avoid phrases like "progression of disability" or "deny the reality of their experience." They refuse to think of themselves as courageous, as inspirations or brave. It has also been difficult to understand the process by which they are becoming subject because of contradictions in their words and actions and the ongoing dialectic in their lives.

To aid my understanding, I followed up on a comment made by E. in our interviews and discussions.

> We need to use notions of power from indigenous people and from the new science (systems thinking, physics, and chaos) to turn notions of power upside down in less threatening ways. We need to remember that in human behavior, the greatest energy is expended in holding to the extremes rather than balanced between these two reactive extremes. This model accommodates a variety of extremes or opposites.

To understand this way of thinking, a model that accommodates a variety of extremes and that "turns notions of power upside down," I turned to systems thinking and chaos theory for explanations.

Chaos theory helped me understand the acceptability of disequilibrium, or constantly being in a state of change or flux, which is part of each woman's experience. I suspect it is part of the experience of every woman with a disability. More growth and development actually happens when systems (including human systems) are in disequilibrium, and fluctuations are a primary source of creativity. Chaos theory highlights the active nature of being subject, because of constant, ongoing change and constant weaving of energies that merge and change. As I reflect on these women's lives, I recognize the constant change in the patterns of their lives because of interaction of many variables. Understanding of these women's lives does not come with linear thinking, which demands that we see things as separate states: either normal or exceptional. Chaos and order, change and stability, are two complementary aspects in the process of growth, and this theory embodies the "concept of allowing," or trusting that new and appropriate forms will emerge. Margaret Wheatley (1994) uses the metaphor of a stream to explain chaos theory. Like a stream, a person has the ability to adapt, shift configurations, let the power balance move, and create new structures.

The point learned from chaos theory is that we are not a closed system. We each need to be able to let go of our present form so we can reemerge in a form better suited to our environment, which is what the women participating in this study are learning to do.

To understand systems thinking and how systems thinking can be applied to the management of conflict, I had to go back to the participants for answers. E., who teaches systems thinking to others as well as applies it in her own life, describes how it works. The following section reflects the terseness of her words. As she described this process, tears were running down her cheeks.

> When you discover you have a disability, there's a desperate struggle for control—to not lose the sense of who you are or who you think yourself to be.
>
> So there's a barrier-ing process to preserve your image. You build walls, shut people out, protect yourself. You also keep getting smacked in the face with how out of control you are.
>
> It leaves you with two choices. You can have an anal-retentive response: develop paranoia about your body, your health needs, an attitude of "you owe it to me," or entitlement.
>
> Or you can feel the feelings that come with it—which is a total plunge into despair. This is a fall into chaos, darkness and confusion. You desperately long for some sense of grace. You realize you can't control what is happening to you, but maybe you can influence it. You might get lucky. You look for "wiggle room." You might turn to some form of spirituality. You realize that you have to think out of the box.
>
> The only choice we have is how we react to the changes in our bodies and in our life.

## *Closing Thoughts*

The four other women participating in this study affirm E.'s words. At the root of their process of becoming subject is acceptance of all the experiences and feelings that have encompassed them since they were youth. Although they don't always understand what is happening to them or even always consciously act upon the awareness of their position, they recognize the power of the margin and use their position to evoke change in themselves and others.

The process of becoming subject seems to be the result of several things. Experiences in their youth taught them coping and negotiating skills. As adults, they had some experience that caused a change in their way of thinking about themselves and reacting to others. They learned to speak out for themselves and others and to identify sources of oppression and discrimination. They have found power and strength living on the margin and from this position effect change for themselves and others. Through the presence of families and friends, they have experienced *communitas,* a sense of wholeness and an obligation to others.

# CHAPTER 6—REFLECTIONS AND CONCLUSION

## *Thoughts About This Type of Research*

This study was extremely difficult to do because I had to continually find the balance between the mythically neutral “objective researcher” and researcher as participant. I was concerned about readers’ perceptions of trustworthiness, given my long and close association with these five women. It was also hard to find the right terms to describe their lives in ways that would be acceptable to them, honor them, and tell their stories of becoming subject.

The stories reported in Phase 1 took almost two years to write. I agonized over every word included and the many left out. Sometimes these women’s words made me cry because I had been part of the situation they were describing and knew the trauma that had occurred. It cost these women to open their lives to me. To future writers who are considering a co-participant type of study, I can only say, be prepared to reveal your soul.

I wrestled with how to portray these women. I know that describing them in terms that made them look like heroes would bring their wrath on my head as well as drastic editing of the text of their stories. I also know they would not accept from me negative descriptions of their disability experience, such as use of words and phrases like “complications,” “loss of function,” or “struggle.” These five women have faced personal tragedy and death but did not focus on it in their conversation. Therefore, neither could I. Their patient instruction on disability terminology and etiquette over the last 10 years has helped me focus on them as a person rather than on the wheelchair or the dog. Their stories are not about overcoming. Disability has been incorporated into their being to the degree that they are insulted by the phrase, "Focus on ability." We are all also painfully aware that they do not represent most women with disabilities.

## *What I Have Learned*

In spite of personal experience with disability and living with disability in my son and husband, I still do not completely understand the complexity of these five women's lives. All five women state that no one knows the reality of their experience, except possibly God or someone who has been through the same thing. "A disability visitor misses the most essential part of the disability experience—the psychic change that comes with the realization that social devaluation...is yours for life," (McCoy, 1998). As a disability visitor, I have not experienced that psychic change and therefore cannot fully understand the experiences of those who have.

These five women have had a tremendous influence on my way of thinking about disability as well as living as subject. They have taught me to not fear death or disability. They have also helped me understand that disability, or limitation to the use of my body, is part of the human condition. Disability does not determine quality of life, nor does it destroy you. It is more about how you react to change with the choices you make. One of the most significant things I have learned from them is about the impact that my reaction to change can have on myself and others. Through my life I have seen people react in ways out of proportion to the event, such as when a car has a flat tire on the way to a concert. These women have helped me understand the necessity to "save myself" for situations that require active and vocal intervention, and that it is more important to focus on the choices you make caused by change than the event itself. Through their words and actions they have demonstrated the effect choice has on the self as well as on others around me, including family and co-workers.

My notion of subjectivity has changed from a perception of "in your face" to "I am more than my face." In the beginning of this study, I thought subjectivity meant using anger to force people or agencies to comply with laws, such as making shop owners move racks that blocked aisles. Each woman was selected to participate in this study because I believed that a woman acting from a position of subjectivity must be a rabid activist. From these five women, however, I have learned that anger comes in many forms and that activism is not the same as anger. Activism may not even be loud or frequent, because it is a state of mind. It is a way of thinking about yourself, others, and the world. D. lives activism to the extent that her personal life is almost obliterated. K. has learned that activism can be personally wearing. All five women have learned to be selective in their activities, realizing that the degree or extent of activism does not change who and what they are.

Each woman was initially selected because her use of agency revealed the presence of subjectivity. I have learned that there are not degrees of subjectivity, although there may be stages of agency. The women participating in this study have become subject in different ways and reflect this position in different attitudes and activities in their lives, as their stories reveal. C. has shown me the power of effecting change quietly and with dignity, while D. has taught me how to become a stronger woman by rejecting cultural norms about women's appearances. K. has shown me how to see with my heart and S. how to laugh at myself and life's ludicrous events. Finally, E. caused me to let down my own barriers through the gift of her friendship.

I have also come to realize that not all women with disabilities reach a position of subjectivity. In my experiences outside this study, I have learned that many women with disabilities are still stuck in an entitlement attitude of "You owe it to me," or, "You must do it for me because I'm helpless." Many are angry—at themselves, at God, at caregivers. Anger is not the same as agency. Many blame everyone and everything for whatever is wrong or doesn't work in their lives or bodies. Most remain objects, such as those adults with Muscular Dystrophy who allow Jerry Lewis to pat them on the head and call them "Jerry's kids." They don't recognize, as do the women in this study, how their involvement in such events is fostering stereotypes and reinforcing their role as objects of pity.

These women have shown me that subjectivity means learning to use power and anger in new ways and that when giving up control *as defined by our culture,* personal strength, agency, and autonomy is gained. My knowledge of subjectivity has expanded to value interdependence more than independence because only through trusting other people can we gain the strength and wisdom to survive on a daily basis. This, I think is the meaning of *communitas,* the power of community. It is a willingness and trust to see and be seen by others, a revealing of the soul. It is allowing yourself to be vulnerable to others you trust, with others who accept you for who or what you are. The women in this study have found *communitas* as they rely on friends who have had similar experiences to theirs.

Included in my broadened definition of subjectivity is the awareness of its spiritual nature. Each woman has learned to turn to a power greater than herself, whether in her Bible, her church, Native American spirituality, or philosophy. It has been a "stepping out on nothing, hoping to land on something," (hooks, 1995). I think it is a need to feel, on their part, that we are part of a plan or scheme that has some meaning or purpose. Just as Margaret Wheatley's stream may change in size, shape, depth, or rate of flow, its essential function to respond to gravity doesn't change. Spirituality seems to help these women understand the essential function of living.

Finally, learning about subjectivity has helped me understand that we cannot give simple names to complex experiences. Disability is a complex experience that cannot be understood in linear terms. "Disabled" does not say it all. We seem to have a passion in this society for polarizing issues, of placing people in categories of our own making. We're not either ill or healthy, weak or strong, tragic or brave, dependent or independent. Our experiences are on a continuum. The disability experience isn't about transcendence or repudiating pain, but using pain as an experience to evoke change, a notion that does not fit an either-or scale. By thinking in terms of cycles and a continuum rather than disruption and separation, we can more nearly begin to understand the reality of these women's lives.

In order to more thoroughly understand these women's lives and their position of subjectivity, my own theoretical perspective has broadened to include chaos theory as well as critical and feminist theories. Critical theory's focus on oppression and suffering, and feminist theory concepts of ultimate emancipation based on social criticism, agency and autonomy are important, but they do not completely explain factors of randomness and change. In addition, feminist theory does not fully explain the lives of women with disabilities because of many authors' assumptions. They assume, as speaking from an Outsider position, that the experience of disability can be added to that of being woman. We are beginning to learn, through the works of hooks, for example, that an "additive explanation" does not fully explain or reveal women's lives. Underlying feminist theory is an assumption of a metanarrative, a universal female experience that does not seem to reflect the reality of experiences of women with disabilities.

Chaos theory provides an explanation of how something or someone can hold its purpose while changing form and direction. Hockenberry says it is like learning to have two bodies occupying two places at once (1995). Chaos theory also helps explain how we can create structures that are flexible, adaptive, and that enable. It focuses on holism rather than reductionism, which has influenced our way of thinking since Sir Isaac Newton. In the machine model, we can only understand the whole by analyzing the workings of each part (Wheatley, 1994). Chaos theory explains that there is a relationship between disparate events that may seem unrelated, and that nothing exists purely independently. This theory has, above all, helped me understand how these women feel about change in their lives and live in a body that requires them to be "constantly and forever adaptive" (E.'s words).

## *Positioning This Study*

These five women have become adults in the last 25 to 30 years, a time that has brought significant changes in disability laws and practices. New laws, such as the Americans with Disabilities Act (ADA), have set the stage for emphasis on equality rather than inclusion. People with disabilities have greater access to public buildings and transportation and are subsequently more visible in our society. Practices that affected the women in this study, such as attending segregated schools, are no longer acceptable. Change is also apparent in words used to describe them. No longer is "the handicapped" politically correct terminology. Instead, we now use words like "people with disabilities," and if we're really politically correct, "differently abled."

Significantly, people with disabilities have been the leaders in change, rather than their advocates, parents, or other people concerned about inequities in society. One of the women participating in this study witnessed the signing of the ADA and has been instrumental in making public buildings accessible across the nation. Another woman is frequently seen on the front cover of magazines, leading a protest rally against assisted suicide, living in nursing homes, or lack of attendant services. These women and many others are making all of us aware that the issues for which they are advocating are quality of life issues that will ultimately affect everyone. D.'s rallying cry, "Don't take it personally, take it politically!" is being picked up by many others with and without disabilities, particularly those who are elderly.

During the last 30 years, movies and films about people with disabilities have also influenced the public's perception about people with disabilities. Films are the major source of information about disabilities, but unfortunately, they still contribute to stereotypes. People with psychiatric disabilities are most commonly portrayed, leading to false notions about the nature of mental illness (Byrd, 1989; Norden, 1994). E. is particularly sensitive to the fact that most movies and news stories about multiple personality disorder focus on the aspect of irrational, violent actions that usually result in murder.

Movies also target extreme examples, showing people with disabilities as having unique gifts (*Rain Man,* 1989), as pitiful and pathetic (*Charly,* 1967), as heroes or super-crips (*Forest Gump,* 1994), or as dependent (*Scent of a Woman,* 1992). These movies also foster our fears of losing control since we can see on big screen what happens to those who aren't in control of their lives (e.g., people with disabilities).

E.'s question "Who benefits or loses if I'm okay?" gets to the heart of concerns voiced by these five women about charity events and other "lost causes" events that are intended to raise money for cures. The message that is sold in these events is that people with disabilities are pitiable, pathetic, dependent, and have difficulty in adjusting to life with a disability. A more subtle message is that disability is a personal problem rather than a problem created by physical and attitudinal barriers in society. The ultimate message is, "Pray to be normal."

Toy makers such as Mattel contribute to existing attitudes about disability. When Mattel came out with Barbie's pal, Share a Smile Becky, a few years, many women with disabilities were highly insulted. Mattel's intended message was that "Barbie's world should reflect the real world and in the real world we have friends with disabilities," (quote taken from a Mattel advertisement). The message received and interpreted by some women with disabilities, particularly D. and S., was that people with disabilities need cheering up because they are so pitiful. S. was amused by Mattel's mistake in not making an accessible house to go along with the doll, since it so closely paralleled her own experiences of not being able to get in her friend's homes. All the women wished they had bodies like Becky's.

Laws, policies and practices are gradually changing in this country, particularly as people with disabilities become more politically active. They continue to speak out against their depiction in news stories, movies, and the media through protest marches, articles to editors, and appearances before Boards of Directors or elected officials. Counter-balancing their increasing activism and society's awareness are economic boundaries being placed by those in power who are debating the value of keeping alive people with significant physical disabilities. As D. continues to remind us, people with disabilities may have the secrets to living on a planet with shrinking resources and increased need for learning to live with less.

## *Contributions to the Field*

This study has made several contributions to disability studies and to our knowledge about the nature of subjectivity in five women with disabilities. It has also added a dimension to feminist literature that includes the perspective of a small sample of women with disabilities.

This study has focused on women who are subjects, meaning those who know and act, in contrast to objects, which are known and acted upon. Paulo Freire, echoing Karl Marx, may have been one of the first people to critically discuss how oppressed people become liberated, or subjects. His writings indicated that he understood the transformative nature of becoming subject. He also emphasized the role of dialogue in helping people come to an awareness of their situation, or a perception of themselves and the world in which and with which they exist (Freire, 1970).

This study has helped me understand that Freire's work and subsequent interpretations may apply to women with disabilities perhaps more than any other oppressed group. Although Freire's concerns were about men whose oppression included being denied adequate education so that they could learn to liberate themselves, his theories about liberation apply particularly to women with disabilities who embrace the sociopolitical model of disability. People who recognize themselves as oppressed, such as the five women in this study, have taken the first step in liberating themselves.

This study has also contributed to ideas about subjectivity. hooks states that "the process of becoming subject emerges as a person comes to understand how structures of domination work in her life, as she develops critical thinking and critical consciousness," (*Yearning,* p. 15). The emphasis placed by these women on experiences in their youth seems to indicate that the process of becoming subject may begin before a person is actively conscious of "structures of domination." At least for women with disabilities, the process of becoming subject may be more related to learning skills of negotiation and compromise and new uses of power. This broadened notion about subjectivity seems to be supported by Butler's theory that subjectivity is a foundation for agency (Butler, 47).

A thorough study of how women come to know and understand themselves conducted by Belenky, Clinchy, Goldberger and Tarule in 1986 provides significant insight on how women become their own authorities, or what the authors call "the emergence of subjective knowing or subjectivism." Women who have reached this stage have changed from "passivity to action, from self as static to self as becoming, from silence to a protesting inner voice," (p 54). Their research implies that the process of becoming subject is developmental, is marked by an absence or crisis of trust in male authority, and experiences women had as youth were mostly irrelevant. The authors suggest that this stage in development is marked by a shift in orientation toward authority, from external authority to reliance on listening to an inner voice and to the voice of others most like themselves. They also state that subjectivists often prefer to express themselves nonverbally or artistically in order to bypass the labeling that the use of language implies (p. 74). The authors do not specifically state whether or not any women with disabilities were included in the 135 women in this study; however, absence of any reference to disability gives the impression that they were not.

Absent in the discussion of Belenky et al. (1986) about subjectivism are notions about the use of language and the power of community that I found in the lives of the five women participating in this study. The authors also do not include experiences as youth that may have contributed to the women's position of subjectivity. Completely left out of their discussion is the presence of external forces that are instrumental in causing women to become subject. In none of the stories of the five women participating in this study did I hear any reference to "crisis in male authority" as a catalyst for becoming subject. It simply does not seem to be an issue.

Also left out of the Belenky (Belenky et al., 1986) study are the concepts of relational thinking and mutuality, which can be found in studies conducted by Jean Baker Miller. Her work provides more insight in how women become subject when they are a devalued group in our society, although she does not use the word "subject." The purpose of her research is to refute the notion that development is a process of separation from others; however, she sheds considerable light on notions of power, conflict, and anger. She suggests that when women recognize and support weaknesses and limitations, they develop a new or different understanding of themselves. Miller criticizes the definition of the word “autonomy” when it means the fullest development of a person at the expense of relationships. She also puts the word “authenticity,” or “becoming oneself,” into a relational setting, in which relationships can lead to more, rather than less, authenticity. Miller’s research adds to knowledge about subjectivity, although she focuses on development of the self. She does not specifically use the word “subject,” yet her writing indicates an awareness of the ongoing process of development in her description of women as “being in relationship.” Miller also does not specifically include or mention women with disabilities in her studies. She gives more references to external forces in shaping women than does Belenky, et al.; however, her writings reflect the psychology of becoming, rather than social or political influences (Miller, 1986).

Miller (1982) suggests that women hesitate to use power or admit the need for power, which she defines as the capacity to produce change. In my study with these five women, I did not see a hesitation to use power. I also believe that they have a broader understanding of power than what she describes, including uses other than power to foster the growth of others.

A contribution this study has made to the field of disability studies is its elaboration on the concepts of liminality and *communitas* as explained by Robert Murphy (1990) in an autobiographical book about his experience after acquiring a disability in middle age. He likened the experience of disability to being in a liminal position, similar to that associated with rites of passage in other societies. In one such society (e.g., the

Nambikuara Indians of central Brazil), liminality involves transformation of a person from one position in society to another. In the transitional state from isolation to emergence, a person is said to be in a liminal state, literally in social limbo and outside the group's formal social system. As an anthropologist, Murphy's notions about liminality and *communitas* were influenced by Turner, who stated that *communitas* was experienced by individuals who were separated or disconnected from those around them (Turner, 1974). Turner and Murphy considered liminality as preparation for *communitas.*

Murphy's (1990) work has had significant influence on people who have disabilities and those of us who work in the disability field because it gave us a new understanding or explanation of the experience of disability. The five women participating in this study, however, do not think of themselves in these terms. They use expressions like "living on the margin," but in no conversation have they indicated that they think of themselves as undefined, ambiguous people, which is how Murphy describes liminality. Their definition of *communitas* is closer to the community of obligation and sharing explained by Kirp (1995) than the one of seclusion discussed by Murphy and Turner. Interestingly enough, another man with an acquired disability, John Hockenberry (1995) says that living with a disability is like "living in the crawl space between our strangeness and other people's reactions and fears," (p. 337). One reason for Murphy's and Hockenberry's feelings about disability may be based on the fact that they acquired disability rather than being born with one. Four of the women in this study were born with disabilities and had experiences as youth that prepared them for society's attitudes and perceptions. The fifth woman, C., who is Black, also had experiences growing up that helped her become subject today. A contribution this study may make is to help us stop assuming that every person with a disability experiences liminality or even assuming that there is one disability experience.

Feminist theory has not widely or generally included discussions about women with disabilities. One of the flaws of feminist theory, as discussed earlier, is that it has assumed a metanarrative, or when applied to this research, a universal experience for women, including women with disabilities. Another flaw of feminist theory is its assumptions about independence, power and control. This study points out that, at least for these five women, feminism does not equal independence. The core of these women's position of subjectivity is recognition of the need for support from others, nurturance, and companionship. The essence of being a woman, for them, is guarding the soul, the "I," expressing themselves eloquently, and constructive uses of anger.

Issues raised by this study that may lead to a broadening of feminist theory include: How do we define differentness for all women? How can we as women remain critically conscious of control of the Other while achieving unity of purpose? How can we become more accepting of diversity? I believe one answer is to look closely at how the women participating in this study use power and at their patterns of relating to others, within their families and in their communities.

These women refute the 1990s notion of a successful woman in other ways. Our notions of feminism have progressed from thinking that we have to have it all (a family, a career, a headache) to belief that we can still be feminists and choose to be nurturing, stay at home, and wear bras. We have also progressed from thinking we have to wear business suits to the realization that what we wear does not make us more or less a feminist. The participants in this study, however, broaden our notion about how we can look. These women may be pioneers of a "new aesthetic," redefining the parameters of what constitutes an anesthetically acceptable image. We, like they, need to reject the whole social message that women are meant to be looked at, or that a major part of a woman's identity is tied to how she feels about how she looks.

This study might contribute to the field of feminist literature in one other area and that is in notions of power. Miller suggests that women as a rule hesitate to use power, particularly power over others. The participants in this study suggest a contradiction: the power of powerlessness. E. refers to this type of power when she talks about compromise, that is, when you give others what they want you gain personal power. It is as if these women have learned that there is power to be gained by being powerless by choice. The women in this study have introduced a new concept of power, particularly for those who are thought to be powerless because of their assumed rolelessness in our society. We need a deeper or more thorough understanding of why women in the position of subject choose to be powerless. Part of our understanding may come in learning about the relationship between power and fear. These women have lost the capacity to fear because of their life experiences. They are not destroyed by something dreaded. These beliefs and experiences may have changed their notions of power.

## *Informing Future Research*

Several authorities, including Audre Lorde (1990), suggest that the future of the earth may depend upon the ability of all women to identify and develop new definitions of power and new patterns of relating across difference. The women participating in this study and other women with disabilities who are in the position of subject may be able to contribute to that dialogue because of their experiences.

Future researchers in education might also want to follow up on comments, particularly by S. and K. in this study, about their need to occasionally be with peers with similar disabilities as they went through school. If we could break out of a linear way of thinking about teaching children with disabilities, we might be able to develop new ways of assuring an equal, inclusive education at the same time as addressing their needs to build self-esteem. K. in particular mentioned the need for "down time" in many references to her school experiences. Although students with disabilities are supposed to have an individualized educational program that meets their unique needs, they frequently get caught between polarities of philosophy or beliefs held by parents and educators. As parents of children with disabilities, we may also need to learn new ways of fostering autonomy and teaching interdependence rather than learned dependence or independence.

Finally, there are many implications in this study for future research related to aging issues. These women have learned to live with less yet live with dignity and quality. K. says that maybe one of the reasons that people tend to avoid individuals with disabilities is because they fear that disability will happen to them. They're right. It will happen to everyone who lives long enough. D. suggests that lessons learned by people with disabilities will help others.

> We're more accepting of what it means to be a human being. We're cross-culture, class, and nationalities. We're open minded, and we require resources that is forcing our culture to come to grips with priorities.

It would be an investment in all our futures to develop a deeper understanding of how we can achieve new definitions of community, support autonomy, and learn to use power and agency in new ways. The women participating in this study have some of the answers.

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# VITA

Lois Symington was born in Knoxville, Tennessee, on February 9, 1948. She attended Knox County School System's public schools and was graduated from Central High School in May, 1966. She attended The University of Tennessee, Knoxville, from 1966 to 1967 on an education scholarship. From 1967 until 1983 she was involved in family and community events, living in other parts of the country. In 1983 she returned to university with the intention of earning a degree in economics. Because of the needs of her son, she became interested in improving teaching and learning for students with disabilities. She earned the Bachelor of Science in Business Education in 1986 and a Master of Science in Special Education in 1990 with credits earned from Harvard University's Graduate School of Education Leadership Institute in Assistive Technology. She has taught grades K-12 in Northern Wales and in the United States. In 1988 she became director of a nonprofit assistive technology center that focuses on providing people with disabilities the resources they need to reach their goals. From 1988 until the present, she has focused her time and energy on helping general and special education teachers across the country learn new ways of teaching. She has presented at local, state-wide and national conferences as well as doing specific training for the departments of education in Georgia, South Carolina and Tennessee on subjects related to using technology to teach all children. She has co-authored one book and contributed to two others as well as to several journals on subjects related to using assistive technology to teach and learn. In December, 1999 she received the Doctor of Philosophy Degree from The University of Tennessee, Knoxville.