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To the Graduate Council:

I am submitting herewith a dissertation written by Laura Mellen Payne entitled "Voices through the margins : a qualitative study exploring voice and marginality in the experiences of three women who have physical 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.

Olga M. Welch, Major Professor

We have read this dissertation and recommend its acceptance:

James H. Miller, Laurence J. Coleman, Priscilla Blanton

Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

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

To the Graduate Council:

I am submitting herewith a dissertation written by Laura Mellen Payne entitled "Voices through the Margins: A Qualitative Study Exploring Voice and Marginality in the Experiences of Three Women Who Have Physical Disabilities." I have examined the final 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.

Olga M. Welch

Olga M. Welch, Major Professor

We have read this dissertation
and recommend its acceptance:

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Associate Vice Chancellor and
Dean of The Graduate School

VOICES THROUGH THE MARGINS: A QUALITATIVE STUDY EXPLORING VOICE AND MARGINALITY IN THE EXPERIENCES OF THREE WOMEN WHO HAVE PHYSICAL DISABILITIES

A Dissertation

Presented for the

Doctor of Philosophy

Degree

The University of Tennessee, Knoxville

Laura Mellen Payne

August 1998

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Acknowledgements

With the drawing of this Love, and the Voice of this Calling,
we shall not cease from exploration
and the end of all our exploring
will be to arrive where we started
and know the place for the first time.
–T.S. Eliot

Thank you to my doctoral committee: Dr. Olga M. Welch, Dr. James H. Miller, Dr. Laurence J. Coleman, and Dr. Priscilla Blanton. You led me through this adventure.

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Thank you to the three women who shared their life experiences.

Thank you to the girls in a Memphis rehabilitation ward.

ABSTRACT

This study investigates the lives of three women who have physical disabilities by exploring their individual constructions of voice and their experiences with marginality. Drawing on the work of Gilligan (1982, 1993), Belenky, Clinchy, Goldberger, and Tarule (1986), hooks (1984, 1989, 1990), and Reinharz (1994), the research focuses on voice as a metaphor for the women's personal identities. A metatheoretical definition of voice, based on knowledge (Belenky et al., 1986), expression (Reinharz, 1994), relationship (Gilligan, 1982, 1993), and resistance and transformation (Delpit, 1988; Freire, 1970/1993; Greene, 1990; hooks, 1984, 1989, 1990), was developed for application in this study.

The data were obtained through the use of qualitative research techniques, including three sources from each woman: (a) semistructured interviews, (b) constructions of life experiences, and (c) disability information. The findings are presented through the women's narratives in three case studies.

The major themes described in these studies are:

1. Personal Identity Description–how each woman sees herself,
2. Personal Identity Construction–how each woman defines herself, and
3. Personal Identity Location–how each woman positions herself.

Each woman's voice, grounded primarily in one aspect (e.g., knowledge, expression, and relationship), became resistant and transformative through her contexts of interaction. Coming to voice was a unique process for each woman, although there were striking similarities in the three women's experiences.

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CHAPTER I

NATURE AND SCOPE OF THE STUDY

Introduction

The purpose of this study was to examine the phenomena of voice and marginality in the experiences of three women who have physical disabilities. Using a metatheoretical and conceptual framework, this cocreated research drew upon the self-constructions, standpoints, and situated knowledge of three women. Voice was defined as a metaphor that represents the women's personal identity constructions: (a) in knowledge, (b) by expression, (c) within relationships, and (d) as transformation (Belenky, Clinchy, Goldberger, & Tarule, 1986; Gilligan, 1982, 1993; hooks, 1984, 1989, 1990; Reinharz, 1994). Their voices emerged from, in, and through the margins, defined as "the peripheral, boundary-determining aspects of persons, social networks, communities, and environments" (Hall, Stevens, & Meleis, 1994, pp. 24-25). Marginality occurs when people are peripheralized because they are unlike the norm and, therefore, distanced from "the societal 'center'" (Hall et al., p. 25). In this study, rather than focusing solely on disability conditions, the varied experiences of the women were explored through their contexts of interaction. The women's accounts provided an important lens for looking at the phenomena of voice and marginality.

Although the Americans with Disabilities Act of 1990 established the rights of people with disabilities to equal access in all areas of public life, there are still unexplored issues that threaten that access (Asch & Fine, 1988; Hershey, 1993; Lisi, 1993; Shapiro, 1993; Treanor, 1993). By exploring the processes of

marginalization in the participants' lives, it was possible to examine the dynamic influences of power structures and mythical norms about ability, normality, abnormality, and roles (Asch & Fine, 1988; Ferguson, 1990; Ferguson, Ferguson, & Taylor, 1992a, 1992b; Fine & Asch, 1985; Hahn, 1983, 1990; Hannaford, 1985; Higgins, 1992; Hillyer, 1993; Lonsdale, 1990; Lorde, 1984; Morris, 1991; Wendell, 1989; Wright, 1983). The conceptualizations of voice as described by Belenky et al. (1986), Gilligan (1982, 1993), hooks (1984, 1989, 1990), and Reinharz (1994) and the conceptualizations of marginality as described by Ferguson (1990), Hall et al. (1994), and hooks (1984, 1990) were used as frameworks for this research. The phenomena of voice and marginality provided a framework within which to explore the women's unique experiences. By utilizing the concept of voice, greater understanding emerged about how these women have identified themselves, how they have come to know what they want to say, how and what they say, and how they are heard. The concept of marginality provided greater understanding about how these women have experienced marginalization as a process on the basis of their identities, activities, and environments and if and how they experience margins or boundaries related to their disabilities and other aspects of their lives.

Through the examination of the lived experiences of women with disabilities, often not included in feminist, critical theory, and related research, understanding regarding the phenomena of voice and marginality was extended. Knowledge was gained about how these women with physical disabilities construct their realities through narrative inquiry. Underutilized as phenomena, voice and marginality possess great explanatory power for disability studies. To illustrate, in "The Second Phase: From Disability Rights to Disability Culture," Longmore (1995) stresses:

> Disability studies should serve as an access ramp between the disability community and research universities....
>
> The traffic of ideas and persons on that ramp should flow in both directions. It must be a two-way street. The disability perspective, the insights, experience and expertise of people with disabilities must inform research, producing new questions, generating new understandings. (p. 11)

Selected by using a community nomination process suggested in the work of Foster (1995) and Ladson-Billings (1994), each woman agreed to participate and provide an "emic," or insider's, perspective. The women's participation in this study affirmed their commitment to research that positively inquires of and impacts the lives of people with disabilities. The participants were: Hope Smith, a White, 34-year-old woman, diagnosed at age 21 with multiple sclerosis, with symptoms such as weakness, numbness, impaired sensation, unstable equilibrium and mobility, and heat sensitivity; Victoria Greene, a White, 46-year-old woman, who, at age 35, first experienced symptoms of olivopontocerebellar atrophy, a degenerative coordination disorder that affects her speech, manual dexterity, and walking; and Samantha Johnson, a Black, 52-year-old woman first diagnosed at age 9 with polio, which initially resulted in paralysis. With surgeries and rehabilitation, she learned to walk again; but scoliosis weakened the capacity of her legs, hips, and back and affected her appearance. Several years ago, she began to experience symptoms of postpolio syndrome.

I viewed all of these women as coinvestigators of the phenomena of voice and marginality, since each woman's story revealed how her identities and interactions were constructed. Further, each woman described her realities from her standpoint rather than mine. As in Wolcott's one-person study (1990), each woman's story helped me to learn all I could about her experiences with voice

and marginality. The women's unique standpoints and their honest dialogue contributed to the study's relevance to feminist, critical, and disability research.

Statement of the problem

There is a great deal of information available about disabilities and individuals, but little that emphasizes actual accounts by the individuals themselves. As a result, these experiences have not been fully recognized in the dominant discourse of ideas, norms, and expectations regarding disability (Aptheker, 1989; Asch & Fine, 1988; Collins, 1991; Deegan & Brooks, 1985; Fine & Asch, 1985; Gatens-Robinson & Tarvydas, 1992; Hillyer, 1993; Lonsdale, 1990; Wendell, 1989). It is these accounts that the study sought to examine through three women's experiences. A review of the literature in sociology, anthropology, rehabilitation, and feminism revealed that the perspectives of women with disabilities have been largely absent (Asch & Fine, 1988; Atkins, 1982; Browne, Connors, & Stern, 1985; Danek, 1992; Deegan, 1985; Fine & Asch, 1985, 1988; Hanna & Rogovsky, 1992; Hillyer, 1993; Keith, 1996; Lonsdale, 1990; Morris, 1991; Saxton & Howe, 1987b; Spencer, 1993; Wendell, 1989; Willmuth & Holcomb, 1993).

As this study found, women's lives differ significantly based on constructions, such as gender, race, class, and disability (Andersen & Collins, 1992; Asch & Fine, 1988; Collins, 1991; Danek, 1992; Deegan & Brooks, 1985; Hannaford, 1985; hooks, 1984, 1989; Krotoski, Nosek, & Turk, 1996; Leal-Idrogo, Gonzalez-Calvo, & Krenz, 1996; Morris, 1991, 1994a). Thus, studies of women with disabilities are necessary to better understand the interrelationships between and among these constructions.

Purpose of the study

The purpose of the study was to examine the phenomena of voice and marginality in the experiences of the participants, centering on their personal identity constructions within their contexts of interaction. Using the work of Gilligan (1982, 1993), Belenky et al. (1986), hooks (1984, 1989, 1990), and Reinharz (1994), the study focused on voice as a metaphor for the women's personal identity constructions in relation to (a) disability, (b) decision making, and (c) participation and power in social contexts. The research also examined issues of oppression and discrimination and their roles in the construction of the women's personal identities. With respect to marginality, the study explored if, and, if so how, margins became sites of repression and resistance (Asch & Fine, 1988; Blumer, 1969; Denzin, 1992; Ferguson, 1990; Ferguson et al., 1992a; Ferguson, Ferguson, & Taylor, 1992b; Fine & Asch, 1985; Hahn, 1983, 1990; Hall et al., 1994; Hannaford, 1985; Higgins, 1992; hooks, 1990; Thomas, 1982; Wendell, 1989).

Research questions

The study focused on the following research questions:

1. How are the phenomena of voice and marginality experienced by three women with physical disabilities?
2. How is disability and its related health and medical issues experienced by the women?
3. What is the nature of the women's interactions with professionals, family, friends, and other people with and without disabilities?

4. What have been the significant events and experiences in the lives of the three women?
5. How do the women construct personal identities in relation to disability, decision making, participation and power in social contexts, and issues of discrimination and oppression?
6. Do margins become sites of repression or resistance in their experiences? If so, how? What situations, if any, are identified by each woman in which she has encountered physical, attitudinal, interactional, and other barriers?
7. How do the intersections of race, class, and gender affect the experiences of marginality among these women with physical disabilities; and how is voice affected by those experiences?
8. How is voice affected by experiences of marginality in different contexts of interaction? Under what circumstances do the women believe that their voices have been heard, been silenced, and/or affected change?

Significance of the study

Little research has been pursued that directly asks women with physical disabilities about their experiences. Therefore, the realities of their lives have remained underutilized as a knowledge source. Personal and professional experiences and existing research have convinced me that the voices of women with disabilities have been marginalized and even silenced (Asch & Fine, 1988; Fine & Asch, 1985; Hall et al., 1994). Further, too often representations of people with disabilities have been hegemonically constructed by people who are nondisabled. Such misunderstanding and misinterpretation of these experiences can greatly affect societal views of

persons with disabilities (Doe, 1994; Gill, 1994; Hevey, 1992; Morris, 1994b, Shapiro, 1993; Shaw, 1994).

To examine the experiences of the participants, this qualitative interview study was developed within a metatheoretical and conceptual framework that included conceptualizations of voice and marginality drawn predominantly from existing feminist, critical, and disability theories and literature. Much of the information in the literature about women with physical disabilities has been anecdotal in nature, with little theoretical grounding. Thus, the study's framework attempted to provide such a lens for exploring the participants' experiences by drawing on the self-constructions, standpoints, and situated knowledge of these women (Collins, 1991; Fine, 1994; Haraway, 1988; Lincoln & Guba, 1985). Rather than focusing solely on disability conditions and limitations, the study also sought to examine and understand the three women's sociocultural backgrounds and their perspectives on their lives, including the realities from which they constructed daily, contextual meanings (Aptheker, 1989; Collins, 1991; Dembo, 1974; Denzin, 1989).

Although the data in the study represent one interpretation of the women's shifting and evolving experiences and constructions, the use of narrative enhanced the power-sharing relationship between the participants and the researcher. Thus, the study contributes to the research literature on the phenomena of voice and marginality within the disability experience (Fine, 1994; Hall et al., 1994; Mishler, 1986).

Theoretical framework and assumptions

Theoretical framework

An interpretive paradigm was utilized to explore the experiences of these women with physical disabilities within their contexts of interaction (Denzin, 1992; Ferguson et al., 1992a, 1992b; Guba & Lincoln, 1994). Foundational interpretive, symbolic interactionist assumptions, as presented by Denzin (1992), guided the study:

> Interactionists assume that human beings create the worlds of experience they live in. They do this by acting on things in terms of the meanings things have for them (Blumer 1969: 2). These meanings come from interaction, and they are shaped by the self-reflections persons bring to their situations. Such self-interaction "is interwoven with social interaction and influences that social interaction" (Blumer 1981: 153). Symbolic interaction (the merger of self and social interaction) is the chief means "by which human beings are able to form social or joint acts" (p. 153). Joint acts, their formation, dissolution, conflict, and merger, constitute "the social life of a human society" (p. 153). A society consists of the joint or social acts "which are formed and carried out by the members" (p. 153). (pp. 25-26)

The research focused on how each woman constructed her personal identity within her contexts of interaction. Individuals create and interpret their experiences through interaction with self and other people. How a woman with a disability establishes her identity and engages in interactions can only be understood through her own stories.

Feminist standpoint

From my standpoint as a woman with cerebral palsy and as a researcher, I have engaged in this study as part of my lifework. My research questions have emerged over many years, particularly from experiences in a Memphis rehabilitation hospital in 1976. Within that context, I have attempted to move beyond my own experiences to research those of other women with disabilities. Within the interpretive framework already discussed, attention was given to the experiences of Hope, Victoria, and Samantha, which "provide a unique angle of vision on self, community, and society–and theories that interpret these experiences" (Collins, 1991, p. 22). Factors such as age, ethnicity, type of disability with accompanying limitations, class, and interactions with others resulted in diversities among the women. As a group, women with physical disabilities may have shared experiences and perspectives, but self-defined standpoints must be differentiated to enhance understanding. Women's constructions of their experiences should shape "life related" (Dembo, 1974, p. 125) and life-relevant disability theory, research, and practice.

Assumptions

The study was based on the following assumptions:

1. In the interview process, the women communicated information and viewpoints, which were valid and authentic for them. Trust was important because, as the researcher, I asked the participants to reveal detailed life experiences and perceptions.

2. The women clearly recalled their experiences and accurately reported their perceptions.
3. As the women told their stories, my understanding of the phenomena of voice and marginality in their experiences increased.

Data sources and procedures

A descriptive case study approach, utilizing semistructured interviews as the main source of data, was chosen for the study. Selection of participants developed as a result of my contacts within the disability community in Jamesville and the community nomination process suggested by the work of Foster (1995) and Ladson-Billings (1994). The women agreed to participate voluntarily and without compensation or incentives.

Case studies

Data from three sources, narrative interviews (Mishler, 1986; Reinharz, 1992; Weiss, 1994), disability information, and constructions of life experiences (Adler, 1927/1992; Clandinin & Connelly, 1994) provided by the women, were collected, analyzed, and interpreted. Disability and vocational information was provided voluntarily by each individual. I requested no documentation from institutions or physicians. The women discussed their disabilities, but none of them were able to obtain records from their doctors. Since the research focused on the construction of identity through the participants' lived experiences and "inside" knowledge, no further "outside" information was required or requested (Dembo, 1974, 1977, 1984).

Data collection procedures

Before the research project began, the interview guide was pilot tested with another woman. For the pilot interview, audiotapes were made and transcribed. Data were analyzed inductively and deductively according to approaches suggested by LeCompte and Preissle (1993), Weiss (1994), and Yin (1994). Based on the pilot interview process (see Appendix A), minor changes were made in the initial interview guide for the study (see Appendix B).

Interviews with each woman focused on how she constructed meaning about her experiences (see Appendix C). The following topics served as guides during the interview process:

- Disability Experiences
- Health Care and Medical Issues
- Family Experiences
- Relationships and Roles
- Activities and Interactions
- Education and Employment
- Gender Issues
- Ethnicity Issues
- Class Issues
- Descriptions and Interpretations of Marginality Experiences
- Descriptions and Interpretations of Voice Experiences

The participants were interviewed three times, with each interview lasting approximately two hours. At their suggestion, the interviews took place in their homes. The first interview with each woman focused on her Experiences as a Person, the second on her Construction of Life Experiences, and the third on her Experiences in Society. Between the first and second interviews, each woman developed a written construction of life experiences by utilizing a structure of her own choosing that recorded significant incidents, events, years, relationships, interactions, and places. Although not provided with a

predetermined structure, each woman was asked to record demographic information on a sheet and was given a few questions to help her think about her own construction (see Appendix C). Also, each woman was asked to talk about and interpret her construction of life experiences and asked questions about significant periods and goals in her life (Adler, 1927/1992; Clandinin & Connelly, 1994). To field-test the bracketing component of the methodology, I also developed and shared a construction of my life experiences and was interviewed by another person utilizing the interview guide. The interview sessions with each woman were audiotaped to facilitate transcription of the information. Each interview was transcribed as soon as possible in preparation for subsequent interviews and data analysis. To further ensure accuracy, each woman was asked to review the transcripts of her interviews. As soon as accurate transcriptions were completed, audiotapes were erased.

Data analysis procedures

Data analysis was conducted through analytic induction, systematic comparison, and typological analysis to develop categories and themes (LeCompte & Preissle, 1993; Weiss, 1994; Yin, 1994). As part of the process, each woman was given the initial data interpretations and asked whether these interpretations accurately represented her experiences. Only those interpretations approved by each participant are included in the study.

Limitations and delimitations

1. The study was delimited to the examination of the phenomena of voice and marginality in the experiences of three women with physical disabilities.
2. The study was delimited to their experiences. For this reason, no attempt can be made to generalize the experiences or perceptions of the participants to other women with physical disabilities.
3. Data were limited to the participants' recollections of their experiences and their perceptions.

Organization of the study

Chapter I contains the introduction to the study, including the statement of the problem, purpose of the study, research questions, significance of the study, theoretical framework and assumptions, data sources and procedures, limitations and delimitations, organization of the study, and definition of terms. Chapter II presents a review of related literature. Chapter III explains data collection methods and analysis procedures. Chapter IV focuses on data presentation, discussion, and findings. Chapter V discusses the conclusions, implications of the study, and recommendations for further research.

Definition of terms

Disability. According to the 1990 Americans with Disabilities Act based upon Section 504 of the 1973 Rehabilitation Act (Rubin & Roessler, 1995;

Treanor, 1993), a physical or mental impairment that substantially limits one or more major life activities. In the Americans with Disabilities Act, no specifics about the nature of impairment are given other than that the impairment must limit one or more major life activities.

Emic Perspective. The "insider" perspective on experience (Dembo, 1977; Denzin, 1989; Foster, 1995; Ladson-Billings, 1994).

Experience. The personal stories that people live and tell about what happens to them (Abrahams, 1986; Bruner, 1986; Clandinin & Connelly, 1994; Hall et al., 1994; Kapferer, 1986; Randall, 1995). Experiences are the inner stories that women with physical disabilities define as their own. Definitions of disability experiences have been viewed as socially constructed phenomena (Ferguson et al., 1992a, 1992b; Gliedman & Roth, 1980; Higgins, 1992; Thomas, 1982).

Hegemonic Constructions. Constructions that dominate the "common sense" understanding of experience, such as the normality of ability and the abnormality of disability (Ferguson et al., 1992a, 1992b; Glick Schiller, 1992; Gramsci, 1971; Hannaford, 1985; Higgins, 1992; Wendell, 1989).

Hegemonic Processes. Processes through which people are subordinated and experiences are labeled, dominated, shaped, and understood (Glick Schiller, 1992).

Hegemony. Hegemony can be understood as dominance, and Gramsci's theory of hegemony can be applied to understanding the experiences of women with physical disabilities (Glick Schiller, 1992; Gramsci, 1971; Morrow & Torres, 1995).

Interaction. "Symbolically taking the perspective of another, and acting on that perspective; interaction is always emergent" (Denzin, 1989, p. 141).

Margins. "The peripheral, boundary-determining aspects of persons, social networks, communities, and environments. Margins are established in several ways: in contrast to a central point, according to the separations they maintain between the internal and external, or as distinctions between the self and others. From this perspective, persons are viewed as relatively different from the norm or as cast out to varying degrees from the societal 'center' to its periphery" (Hall et al., 1994, pp. 24-25). Margins can be sites of repression, resistance, and transformation (hooks, 1984, 1989, 1990).

Marginality. "The condition of being peripheralized..." (Hall et al., 1994, p. 25). Hall et al. take the position that the process of marginalization is not oppression, alienation, stigmatization, or segregation but may involve them and, therefore, provide useful insights for exploring experiences.

Marginalization. "The process through which persons are peripheralized on the basis of their identities, associations, experiences, and environments" (Hall et al., 1994, p. 25).

Meaning. "What an experience means to a person, defined in terms of intentions and consequences; meaning is always triadic, involving interaction between a person, an object, and action taken toward the object; meaning is interactional, interpretive, open-ended, often ambiguous, inconclusive, and conflictual" (Denzin, 1989, p. 143).

Narrative. Both the stories that people tell about their experiences and inquiry about those stories (Clandinin & Connelly, 1994, Hall et al., 1994; Hatch & Wisniewski, 1995; Polkinghorne, 1995).

Voice. Referred to frequently and associated with notions of being heard or silenced, it is rarely defined in feminist and other literature (Reinharz, 1994). In this study, voice is a metaphor for the personal identity constructions of the

women within relationships (Brown & Gilligan, 1992; Gilligan, 1982, 1993; Gilligan, Lyons, & Hanmer, 1990), in knowledge (Belenky et al., 1986; Haraway, 1988), as transformation (Delpit, 1988; Fine, 1992, 1994; Foster, 1995; hooks, 1984, 1989, 1990; Lorde, 1984; Sparkes, 1994), and by expression (Reinharz, 1994). Hall et al. (1994) define voice as "The languages and forms of expression characterizing marginalized subcultures" (p. 31). Voice implies the possibility of being silenced and misunderstood as well as the possibility for expression.

Gilligan's (1982, 1993) use of the metaphor emphasizes care, responsibility, and relationship. Belenky et al.'s (1986) use of the metaphor emphasizes construction of knowledge, development of voice, and personal control. hooks' (1984, 1989, 1990) use of the metaphor emphasizes self-transformation and coming to voice through dialogue (Delpit, 1988; Freire, 1970/1993, Greene, 1990). Reinharz' (1994) use of the metaphor emphasizes the rights, the means, and the ability for self-expression. For the purposes of this study, voice was defined as a metaphor for personal identity constructions developed through the women's life experiences.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

Using the work of Gilligan (1982, 1993), Belenky et al. (1986), hooks (1984, 1989, 1990), and Reinharz (1994), this research focused on voice as a metaphor for women's personal identity constructions in relation to disability, decision making, participation and power in social contexts, and issues of oppression and discrimination (Asch & Fine, 1988; Blumer, 1969; Denzin, 1992; Ferguson et al., 1992a, 1992b; Fine & Asch, 1985, 1988; Hahn, 1983, 1984, 1990; Hannaford, 1985; Higgins, 1992; Thomas, 1982). With respect to marginality, the study explored if, and, if so how, margins became sites of repression and resistance (Ferguson, 1990; Hall et al., 1994; hooks, 1990; Wendell, 1989). Thus, this chapter focuses on a review of the literature on voice and marginality and relates that literature to perspectives on the meanings of experience from constructivist, anthropological, societal, and feminist perspectives. This chapter begins with a discussion of these perspectives. I have chosen this framework in order to create an arrangement in which women with disabilities are not spoken of but, rather, speak for themselves.

Through her seminal disability and rehabilitation research, Dembo provides an avenue through which to explore the lived experiences of people with disabilities (Dembo, 1974, 1977, 1984; Dembo, Leviton, & Wright, 1975; Walker, 1993; Wright, 1983). Dembo's work focuses on understanding the perspectives of "insiders" (1984, p. 91), identified as those who actually experience disability, such as patients and family members, as well as the

perspectives of "outsiders" (1984, p. 91), those who observe disability experience, such as doctors and researchers (Dembo, 1974, 1977, 1984). In Paths to Useful Knowledge (1974), Dembo initiates an important direction in research and theory. She asserts that knowledge must not only reflect but be relevant to the experiences of people with disabilities:

> A different approach to gaining knowledge, which I am calling *life related*, is characterized by its concern with usefulness from the beginning of the acquisition of knowledge, rather than afterward. From the start and throughout the investigation, the question is kept in mind of whether the knowledge will have a bearing on the everyday life problems for which the solutions are sought. And further and most important, the appropriateness of the assumptions on which the research is based must be thought through carefully. The assumptions which are made must have a relationship to the objectives of life related knowledge. This approach requires checking and questioning the basic theoretical assumptions which are implied in research. Thus, from the start, such research has to be not only practical but highly theoretical. (p. 125)
>
> This is only a note. It indicates two possible and, I believe, necessary ways of making research useful in rehabilitation. Application of old knowledge is only one way. The other way, the life related approach, is actually a very theoretical and at the same time a very practical way. It requires the consideration of new basic conceptual assumptions, and also, from the start, taking into account everyday life problems. It also raises the two most practical questions–for whose benefit is knowledge sought, and who is to decide whether the knowledge gained is to be really useful? (p. 128)

One of my primary research goals was to increase understanding of the experiences of voice and marginality in three women with physical disabilities from their perspectives.

Perspectives on experience

Explorations of experience

Because experience is individual, an interpretive paradigm that centers on how people explain their lives was utilized to explore the experiences of three women with disabilities (Denzin, 1992; Ferguson et al., 1992a, 1992b; Guba & Lincoln, 1994). According to Guba (1990), a paradigm is the interpretive framework or "a basic set of beliefs that guides action" (p. 17). Such an interpretive paradigm was utilized to explore constructions of life experience and disability experience through the lens of a symbolic interactionism framework. Denzin (1992) presents these foundational assumptions:

> Interactionists assume that human beings create the worlds of experience they live in. They do this by acting on things in terms of the meanings things have for them (Blumer 1969: 2). These meanings come from interaction, and they are shaped by the self-reflections persons bring to their situations. Such self-interaction "is interwoven with social interaction and influences that social interaction" (Blumer 1981: 153). Symbolic interaction (the merger of self and social interaction) is the chief means "by which human beings are able to form social or joint acts" (p. 153). Joint acts, their formation, dissolution, conflict, and merger, constitute "the social life of a human society" (p. 153). A society consists of the joint or social acts "which are formed and carried out by the members" (p. 153). (pp. 25-26)

Individuals create and interpret experiences through their contexts of interaction. Ferguson et al. (1992b) underscore the relevance of the interpretive paradigm as a framework for the living and telling of stories:

> For it is only in "the telling" that both a speaker and an audience are implicitly included, and that is where interpretation comes in. We tell our stories to interpret our lives for other people. Upon hearing them, other people interpret our interpretations. All individuals have their own particular stories. However, it is your telling of your stories that best reveals

> how you really make sense of your world: which stories you choose to tell about your life; what words you use; to whom you tell your tales. (pp. 1-2)

Regarding the study of disability using an interpretive paradigm, they find:

> The first, and perhaps most fundamental, promise of interpretivism for special education and related fields has to do with what we understand about disability itself. Interpretivism encourages us to re-examine the basic questions we ask as researchers and practitioners....Instead of asking about the "nature" or "essence" of disability, intrepretivists are more likely to ask: "What is the experience of disability?"....That is, ask for the context, the construction through which physical reality takes shape. Interpretivism maintains that disability is not a fact or an entity, whose nature is just waiting to be discovered. Disability is rather an experience waiting to be described, or, more precisely, a social construction of multiple experiences waiting to be recognized. (Ferguson et al.,1992a, p. 296)

Little research has been done that explores the distinctions between different experiences based on gender, race, class, and different types of disabilities among women (Andersen & Collins, 1992; Asch & Fine, 1988; Collins, 1991; Fine & Asch, 1985, 1988; Deegan, 1985; Deegan & Brooks, 1985; Hannaford, 1985; hooks, 1984, 1989; Morris, 1991; Sacks, 1989; Whyte & Ingstad, 1995). Disability is not the major definer of women's experiences (Higgins, 1992). Distinctions in experiences are reflected in Ingstad and Whyte's Disability and Culture (1995), which examines and analyzes the experiences of people in different cultures through ethnographic case studies. They emphasize that experience with disability can be studied according to social features, organizations, and contexts within a culture. Cultural expectations for women regarding ability, disability, abnormality, and normality along with specific characteristics of race, ethnicity, and class affect women with physical disabilities (Hannaford, 1985; Higgins, 1992; Morris, 1991; Scheer, 1994; Scheer & Groce, 1988; Wendell, 1989; Whyte & Ingstad, 1995).

Definitions of experience

Experience is unique, whether described from an individual or a collective perspective. Frequently used but infrequently defined, experience is also not often referenced in real life and in research (Clandinin & Connelly, 1994; Randall, 1995; Scott, 1991). People refer to "my experience," "from experience," "through experience," and gained "experience" as a possession (Randall, 1995). Experience can be described as the personal stories that people live and tell about what happens to them (Abrahams, 1986; Bruner, 1986; Clandinin & Connelly, 1994; Hall et al., 1994; Kapferer, 1986; Randall, 1995).

Experience is a universal conceptualization of undeniable importance that has been written about by Dewey, Dilthey, and many others and, yet, rarely has been defined (Adler, 1927/1992; Bruner, 1986; Clandinin & Connelly, 1994, Randall, 1995; Scott, 1991; Weiss, 1994). Regarding the understood and not so understood meaning of experience, Scott (1991) observes, "Experience is at once always already an interpretation *and* something that needs to be interpreted" (p. 797). The work of Turner and Bruner (1986), Clandinin and Connelly (1994), and Randall (1995) provide insight into the meaning of experience. Clandinin and Connelly (1994) call experience the cornerstone of social science research:

> The social sciences are concerned with humans and their relations with themselves and their environments, and, as such, the social sciences are founded on the study of experience. Experience is, therefore, the starting point and key term for all social science. But scientific, social, and philosophical conditions conspire to create frames of reference that shift the definitions of what is acceptable in the study of experience. (p. 414)

Geertz (1973) asserts that there are many approaches and a central issue in the study of experience, "How to frame an analysis of meaning–the conceptual

structures individuals use to construe experience–which will be at once circumstantial enough to carry conviction and abstract enough to forward theory" (p. 313). Experience can be distinguished as the beginning for all social sciences from which various perspectives and methodologies diverge. The experiences of women with physical disabilities can be investigated conceptually and utilized to construct credible theory. Unger, Draper, and Pendergrass (1986) point out that "Personal experience can sensitize people to different aspects of problems and leads some to question the assumptions taken as self-evident by others lacking such experience" (p. 67). Because of this, there is no singular interpretation of an experience or situation (Denzin, 1992; Guba & Lincoln, 1994).

Anthropological perspectives on experience

Within the social sciences, the anthropological perspective on individuals' experiences is situated within cultures (Geertz, 1973; Turner & Bruner, 1986; Whyte & Ingstad, 1995). Several of these perspectives are presented in The Anthropology of Experience (1986) edited by Turner and Bruner. According to Bruner (1986), "The anthropological enterprise has always been concerned with how people experience themselves, their lives, and their culture" (p. 9), and "The anthropology of experience sees people as active agents in the historical process who construct their own world" (p. 12). Bruner describes reality as "what is really out there, whatever that may be" (p. 6), experience as "how that reality presents itself to consciousness" (p. 6), and expressions as "how individual experience is framed and articulated" (p. 6).

In his chapter "Ordinary and Extraordinary Experience," Abrahams (1986) makes another important distinction between events, as "things that happen" (p. 55), and experiences, as "things that happen to us or others" (p. 55). Some experiences are typical and can be shared by people both through what happens to them and how they respond through meanings and feelings. About common experience, Abrahams observes

> the existence of the experience of experience, that is, the recognition even while something is taking place in one's own life that it is a replaying, in some dimension, of things that have happened to others. This self-perception is especially important when the experience is not only typical but intense and potentially disruptive. At that point, being able to recognize typicality becomes a means of recognizing how to feel and interpret what is going on. (pp. 60-61)

In "Performance and the Structuring of Meaning and Experience," Kapferer (1986) refers to R. D. Laing's assertion that individuals cannot experience one another's experiences but contends that "It is true nonetheless that individuals understand that aspects of their experience are shared in common with others" (p. 188). In summary, these authors suggest that experience can be understood to mean what happens to people, which may or may not result in shared understanding or common experience. Even though shared experiences may have many aspects in common, each individual experience is unique and must be addressed through the exploration of lived experience. About an anthropological approach, Sacks (1989) emphasizes:

> Two contradictory missions lie at the heart of anthropological practice. The first is to understand, appreciate, and interpret cultural uniqueness in its own terms, a mission in which ethnographic case studies have been central. The second mission is to generalize, to discover similarities amid diversity, and to develop cross-cultural explanations and theories that proceed in practice from a much more restricted range of Western cultural frameworks. (p. 534)

The missions and tensions that she describes can be applied to theorizing and researching about women with disabilities. Focusing on the personal experiences of individual women through case studies and on the similarities and differences in their collective experiences in cultural explanations creates necessary, inherent tensions.

Constructivist perspectives on experience

How people create their own experiences through the stories that they live and tell can also be explored through a constructivist perspective. Clandinin and Connelly's (1994) and Randall's (1995) research best illustrates this perspective on experience. Clandinin and Connelly (1994) emphasize that "Experience, in this view, is the stories people live. People live stories, and in the telling of them reaffirm them, modify them, and create new ones" (p. 415). They point out that experience can be focused in four directions: inward, outward, backward, and forward. They explain:

> By *inward* we mean the internal conditions of feelings, hopes, aesthetic reactions, moral dispositions, and so on. By *outward* we mean existential conditions, that is, the environment or what E. M. Bruner (1986) calls reality. By *backward* and *forward* we are referring to temporality, past, present, and future. To experience an experience is to experience it simultaneously in these four ways and to ask questions pointing each way. (p. 417)

They observe, "Experience is messy, and so is experiential research" (p. 417). A person's experience involves inward and outward conditions and reaches into the past, present, and future. Its expression is complex in real life and in research.

Through The Stories We Are: An Essay on Self-Creation, Randall (1995) provides great insight into the meaning of personal experience. He asserts, "...We transform the *events* of our lives into *experiences* to the extent we weave them into stories" (p. 21). Randall describes four levels in the stories that people live and tell. The first, existence, or the "outside story" (p. 48) signifies what happened to a person in the past. The second, experience, or the "inside story" (p. 49) signifies a person's impressions and memories of what happened and prognostications about the future. The third, expression, or the "inside-out" story (p. 54) signifies versions of experience that a person expresses to others. The fourth, impression, or the "outside-in" (p. 56) story signifies what is told to a person about himself or herself by others. According to Randall, each of these stories interacts within a person's life. About the inside story of experience, he states:

> Whereas the whole story is the objective or outside story, then, the inner story is the *inside* story: the story of my life as I have internalized or digested it, the "real, inmost story" (Sacks, 1985, 105), the subjective story that I alone can tell. The inside story is what I *make* of the outside story; indeed, it is all I *can* make of the outside story, all I can *know* of it. (p. 50)

Randall further asserts this about a person's experience:

> Because the inside story of my life is *my* creation, then, and thus uniquely *my* possession, it is more easily separable than is the whole story from the story of the cosmos. It is what makes me an individual....This is because it is "told" not from some objective, all-knowing, impersonal perspective, according to which reality might be viewed as all of one piece, but from my own perspective....It is the totality of everything *I* know, think, feel, remember, believe, and hope about *my* self. (pp. 51-52)

The "inside story" can only be made, known, and told by an individual. While the "inside story" of experience is central to the story of one's life, all the levels are linked:

> In general, if the outside story is what happens to me, then the inside story is what I *make* of what happens to me and what I tell to myself. The inside-

> out story is what I tell (and show) to *others* of what I make of what happens to me, while the outside-in story is what others make of me on their own, with or (usually) without my consent. (pp. 57-58)

Through the experience of a woman who has a disability, the "outside story" could be connected with what happens related to disability and other intersections in her life, and the "inside story" with what the woman makes of them. The "inside-out" story could be connected with what she tells various people about her experiences in various contexts through her own voice. The "outside-in" story could be connected with how other people perceive her as a woman with a disability based on their own constructions of disability and ability. All of these levels interact as she lives and tells her own story. Based on the anthropological and constructivist perspectives, experience can be defined as the stories that women live and tell.

"Looking-glass self" sociological perspective on experience

Cooley's "looking-glass self," which he described in the early part of the 20th century, still provides insight into how people interact and see themselves. According to Cooley, every individual is "a member of a social whole" (1922/1956a, p. 35). He states, "Certainly everything that I say or think is influenced by what others have said or thought, and, in one way or another, sends out an influence of its own in turn" (Cooley, 1909/1956b, p. 4). His views on consciousness are also relevant to how women with disabilities see themselves and people with whom they interact. Self-consciousness is "what I think of myself"; social consciousness is "what I think of other people"; and public consciousness is "a collective view of the foregoing as organized in a communicating group" (Cooley, 1909/1956b, p. 12). The influence of one on the

other cannot be underestimated. Cooley emphasizes the significance of how an individual describes herself or himself, using pronouns, "I," "me," "mine," and "myself" and asserts:

> Ordinarily it will be found that in not more than ten cases in a hundred does "I" have reference to the body of the person speaking. It refers chiefly to opinions, purposes, desires, claims, and the like, concerning matters that involve no thought of the body. (Cooley, 1922/1956a, p. 176)

How a woman sees and perceives that other people see her appearance in social interaction may extend well beyond but begin with her physical body. Cooley's constructions of the looking-glass self are particularly relevant to a study of persons who have disabilities. As he explains:

> In a very large and interesting class of cases the social reference takes the form of a somewhat definite imagination of how one's self–that is any idea he appropriates–appears in a particular mind, and the kind of self-feeling one has is determined by the attitude toward this attributed to that other mind. A social self of this sort might be called the reflected or looking-glass self:
>
> "Each to each a looking-glass
> Reflects the other that doth pass."
>
> As we see our face, figure, and dress in the glass, and are interested in them because they are ours, and pleased or otherwise with them according as they do or do not answer to what we should like them to be; so in imagination we perceive in another's mind some thought of our appearance, manners, aims, deeds, character, friends, and so on, and are variously affected by it. (Cooley, 1922/1956a, pp. 183-184)

One's perceptions of another's perceptions do affect her or his own self-perceptions. How a woman sees herself is influenced by how she believes people with whom she interacts see her. One's own reflection reveals more than could ever be revealed at the surface level of any situation or interaction. Cooley goes on to explain:

> A self-idea of this sort seems to have three principal elements: the imagination of our appearance to the other person; the imagination of his

> judgment of that appearance, and some sort of self-feeling, such as pride or mortification. The comparison with a looking-glass hardly suggests the second element, the imagined judgment, which is quite essential. The thing that moves us to pride or shame is not the mere mechanical reflection of ourselves, but an imputed sentiment, the imagined effect of this reflection upon another's mind. This is evident from the fact that the character and weight of that other, in whose mind we see ourselves, makes all the difference with our feeling. We are ashamed to seem evasive in the presence of a straightforward man, cowardly in the presence of a brave one, gross in the eyes of a refined one, and so on. We always imagine, and in imagining share, the judgments of the other mind. (Cooley, 1922/1956a, pp. 184-185)

Self-reflection is influenced by the reflections of others, which are received and perceived through interaction. Cooley supports his views about the looking glass through the example of young children who recognize linkages in their actions and people's responses. He stresses that those in an individual's primary group are those of closest connection, which he defines as:

> Perhaps the simplest way of describing this wholeness is by saying that it is a "we"; it involves the sort of sympathy and mutual identification for which "we" is the natural expression. One lives in the feeling of the whole and finds the chief aims of his will in that feeling. (Cooley, 1909/1956b, p. 23)

How people identify themselves with a "primary group" (Cooley, 1909/1956b, p. 23), such as family members, varies. Common experiences often create associations in which identity is invested in a group, which he describes as:

> The group self or "we" is simply an "I" which includes other persons. One identifies himself with a group and speaks of the common will, opinion, service, or the like in terms of "we" and "us." The sense of it is stimulated by co-operation within and opposition without. (Cooley, 1922/1956a, p. 209)

What Cooley calls "self-reverence" (1922/1956a, p. 241) is impacted by interactions in which an individual identifies and involves him/herself. "Self-reverence" can facilitate resistance to people and influences what a person sees as incongruent with who he or she is. How an individual sees her/himself

is greatly influenced by how one perceives she or he is beheld in the "looking-glass self," "social whole," "primary group," and "group self."

Societal perspectives and disability experience

Definitions of disability, founded on constructions of normality, ability, and capacity, are pervasive in our culture and are influenced by both the medical and rehabilitation models (DeJong, 1983, Hannaford, 1985; Wendell, 1989; Zola, 1983). In attempting to establish universal definitions of disability, the World Health Organization and United Nation definitions reflect the assumption that disability must be defined according to standards of abnormality and normality (Albrecht, 1992; Higgins, 1992, Scheer & Groce, 1988; Wendell, 1992; Whyte & Ingstad, 1995, Wright, 1983). Throughout history and throughout our culture, the human experience of people with disabilities has been interpreted by standards of normalcy, which are idealistic rather than realistic in relation to gender, ability, and other aspects of experience (Ferguson et al., 1992a, 1992b; Higgins, 1992; Murphy, 1990; Wendell, 1989).

Wright's (1983) pioneering theory and conceptualizations have greatly influenced disability and rehabilitation concepts. Her work began to be noted in the 1940's and the 1950's through her collaborations with Barker, Dembo, and others regarding persons' adjustment to physical disability. Wright's Physical Disability: A Psychological Approach was first published in 1959, and the second edition appeared in 1983 as Physical Disability–A Psychosocial Approach. These books reflected her emphasis on the social environments in the lives of people with disabilities. Wright's (1983, 1988) greatest influence can be found both in rehabilitation research and rehabilitation counselor education

through such theoretical concepts as "spread" (1983, p. 61), "requirement of mourning" (1983, p. 78), and "coping-versus-succumbing frameworks" (1983, p. 194). Through her work, she also sought "to contribute knowledge and understanding that will lead to constructive views of life with a disability" (1983, p. xi). Her theorizing predominantly focused on the interactions between people with disabilities and people without disabilities, emphasizing self-esteem and the role of gratifications and grievances in relationships and perspectives. These concepts expanded the knowledge base on the experiences of people with disabilities and served as responses to earlier theorists who tended to emphasize the negative aspects of the disability experience (Wright, 1983, 1988). Even though some of her concepts occasionally resulted in the stereotyping of certain behaviors and experiences, Wright effectively explored a great deal of phenomena that had previously been unexamined. The "value-laden beliefs and principles" (1983, p. xi), which guided her work include the importance of the right to respect for individuals with disabilities and the promotion of their collaboration with providers and practitioners to facilitate effective practice and research. Many of her concepts continue to provoke questions regarding the individual experiences of people with disabilities. She states:

> I do not wish to imply that all ends well in the lives of persons with disabilities, but it should be emphasized that satisfactions and triumphs, not only sorrows and difficulties, are well represented. This is important because of the all too frequent tendency to view the lives of people with disabilities in primarily tragic terms. People with disabilities resist, if not resent, such a pervasive negative view, not only because it belies the facts, but also because of their efforts to cope with the problems they face. (1983, p. 4)

Wright included the experiences of women in her work without specific attention to them. In the foreword to Deegan and Brooks' Women and Disability:

The Double Handicap, Sherr and Wright (1985) conclude:

> Despite our long professional involvement in the field of rehabilitation psychology and our appreciation of a feminist viewpoint, we had been remarkably unaware of the unique issues of women with disabilities....The importance of this consciousness-raising applies to persons involved in making public policy and to the academic and professional rehabilitation communities. It applies to women and men with disabilities. It applies to society as a whole. (p. xi)

Some of Wright's theoretical conceptualizations tend to make it appear that all people with disabilities have certain kinds of experiences. Such "taken for granted" definitions of disability have heavily influenced the experiences of women with disabilities.

By contrast, in this study, while definitions of disability experiences are recognized as socially constructed entities (Ferguson et al., 1992a, 1992b; Gliedman & Roth, 1980; Higgins, 1992; Thomas, 1982), a basic definition is provided to make generally clear what is meant by disability. According to the 1990 Americans with Disabilities Act (e.g., Section 504 of the 1973 Rehabilitation Act), a disability can be defined as a physical or mental impairment that substantially limits one or more major life activities, a record of such as an impairment, or is regarded as having such an impairment (Rubin & Roessler, 1995; Treanor, 1993). As previously mentioned, in the Americans with Disabilities Act, no specifics about the nature of impairment are given other than it must limit one or more major life activities.

Hegemonic constructions of disability

It is important to recognize the societal constructions of disability, which are both pervasive and hegemonic. Hegemony can be understood as dominance,

and Gramsci's theory of hegemony can be used to understand the experiences of women with physical disabilities (Glick Schiller, 1992; Gramsci, 1971; Morrow & Torres, 1995). In his work, Gramsci (1971) discussed the nature of the social order and the domination of classes over others. Thus, his theory is useful in explaining the construction of disability in a culture with "taken for granted" definitions of normality and abnormality, as well as disability and ability (Ferguson et al., 1992a, 1992b; Hannaford, 1985; Higgins, 1992; Wendell, 1989). Hegemonic constructions of disability influence the experiences of people with disabilities, even if such constructions are rejected by these same persons (Abberley, 1987; Asch & Fine, 1988; Fine & Asch, 1985; Hannaford, 1985). Regarding hegemonic construction and its influence on people's experiences, Glick Schiller (1992) explains:

> The concept of hegemony gives us the language with which to investigate the manner in which dominant classes or sectors of society use culture to obtain consent from subordinated populations (Hall 1988; Williams 1977)....Hegemonic processes are the means by which subordinated populations participate in cultural constructions that contribute to their continuing subordination (Hall 1988; Williams 1977). Hegemony is built on daily practice and commonsense categories by which we understand the world. Hegemonic processes frame the way in which we understand our experience and so shape the experience itself. (p. 248)

Thus, to better understand the experiences of the women in the study, particular pervasive hegemonic constructions were examined. Such constructions included racism, sexism, classism, and ableism, which are hegemonically constructed and invisible and affect the lives of women with disabilities. The relationships of these hegemonic constructions to the study can be found through an examination of the dominant definitions of disability and models of care.

Dominant models of disability, health, and value

The dominant culture's medical and rehabilitation models of disability tend to focus on the cause, control, and cure of physical impairment (Abberley, 1987; DeJong, 1983; Gill, Kirschner, & Panko Reis, 1994; Higgins, 1992; Longmore, 1995; Murphy, 1990; Wendell, 1989; Zola, 1983). This emphasis on cure often detracts from the actual experience of individuals with disabilities. Moreover, such an emphasis on control not only gives authority to people who are seen as experts but reinforces an unreal expectation by others that bodies can be controlled or cured, creating conflict for individuals with disabilities (Higgins, 1992; Longmore, 1995; Murphy, 1990; Wendell, 1989). Both the medical and rehabilitation models are situated within a framework based on a desired control and cure. Wendell (1989) recognizes disability as "socially constructed from biological reality" (p. 107) and believes:

> The pernicious myth that it is possible to avoid almost all pain by controlling the body gives the fear of pain greater power than it should have and blames the victims of unavoidable pain. The fear of pain is also expressed or displaced as a fear of people in pain, which often isolates those with painful disabilities. All this is unnecessary. People in pain and knowledge *of* pain could be fully integrated into our culture, to everyone's benefit. (p. 115)

Such an integration has yet to occur since people's experiences with disability often conflict with the medical model's emphasis on cure and control (Longmore, 1995; Wendell, 1989). Reflecting on disability as part of the human experience, Murphy (1990) says of his own disability experience, "There's no cure for life" (p. 229). Further, while adequate health care should never be neglected in the absence of a cure, in the experiences of women with disabilities, Gill et al. (1994) observe:

> Women with disabilities–members of two large and frequently neglected communities–often get the worst of both worlds. As women, they may experience economic depression, abridged choices, and discrimination in many settings, including health service facilities. As people with disabilities, they deal with blocked access to schools, jobs, relationships, leadership power, transportation, and the built environment. Both women and people with disabilities have experienced repeated violations of their rights to self-determination in a historically paternalistic society. Furthermore, both communities have been neglected in medical research, professional training, health policy, and the development of health service delivery. (p. 357)

They also acknowledge the influence of feminist and disability rights movements on those disabled women who are speaking out about and receiving better treatment aimed at living with rather than finding a cure for disability. According to Gill et al., additional barriers that need to be addressed include: (a) facilitating action based on a female rather than male experience with disability, (b) accessing health care services and facilities, (c) recognizing and intervening in the lives of women affected by violence and abuse, (d) dealing with stress and mental health issues often influenced by dominating and discriminating attitudes about the lives of women with disabilities, (e) decision making in reproductive health, and (f) influencing policy issues related to decision making about the provision of quality-of-life services.

While women with disabilities may acknowledge certain societal barriers, they may also resist these barriers through their lived experiences and the recounting of their own personal stories (Asch & Fine, 1988; Browne et al., 1985; Fine & Asch, 1985, 1988; Hillyer, 1993; Lonsdale, 1990; Morris, 1991; Saxton & Howe, 1987b; Wendell, 1989; Willmuth & Holcomb, 1993). The relevance of such stories and experiences has been largely overlooked in the literature on disability. As Gill (1994) notes, "I believe disability is a marginalized status that society assigns to people who are different enough from majority

cultural standards to be judged abnormal or defective in mind or body" (p. 44). She adds, "You know you have a 'real' disability when you know society will label and marginalize you once your difference shows" (p. 46). About experience, she asserts, "Nondisabled people, no matter how much they love us, do not know the inside experience of being disabled" (p. 47). She is quick to point out, as are others, that even in the most ideal of accessible and tolerant cultures, an individual would still experience disability even if it were not devalued (Gill, 1994; Higgins, 1992; Longmore, 1995; Wendell, 1989; Zola, 1982). By contrast, Longmore (1995) notes:

> Some people with disabilities have been affirming the validity of values drawn from their own experience. Those values are markedly different from, and even opposed to, nondisabled majority values. They declare that they prize not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community. This values-formation takes disability as the starting point. It uses the disability experience as the source of values and norms. (p. 9)

Thus, studies of the experiences of women with disabilities can provide needed additions to existing literature on the dominant models of disability, health, and value.

Feminist standpoint perspective on experience

Standpoint epistemology can give attention to the experiences shared by women with physical disabilities, which "provide a unique angle of vision on self, community, and society–and theories that interpret these experiences" (Collins, 1991, p. 22). Factors, such as age, ethnicity, type of disability with accompanying limitations, class, and interactions with others, result in a diversity of experiences. Women with physical disabilities as a group may have

shared experiences and perspectives, but within these shared experiences, individually constructed, self-defined standpoints must be explored. Primarily, feminist theory and research focus on the epistemology and experiences of women in cultures dominated by men. Commenting on cultural explanation and experience in Toward a New Psychology of Women, Miller (1986) observes:

> Our understanding of all of life has been underdeveloped and distorted because our past explanations have been created by only one half of the human species. (p. xi)

Here, it is important to note that all women's experiences are not the experiences of all women. Gender constructions may create similarities, but race, class, and disability create differences (Andersen & Collins, 1992; Asch & Fine, 1988; Collins, 1991; Deegan & Brooks, 1985; Fine & Asch, 1985; Hannaford, 1985; hooks, 1984, 1989; Morris, 1991). In their book, Race, Class, and Gender: An Anthology, Andersen and Collins (1992) emphasize the following:

> Race, class, and gender are interlocking categories of experience that affect all aspects of human life. We want readers to conceptualize them as interactive systems, not just as separate features of experience or variables in sociological equations. While race, class, and gender can be seen as different axes of social structure, individual persons experience them simultaneously. The term *double jeopardy* has, for example, been used to describe the oppression of women of color by race as well as gender. However, we do not think of race and gender oppression in additive terms, an implication of phrases such as *double and triple jeopardy*. Rather, race, class, and gender are part of the whole fabric of experience for all groups, not just women and people of color (p. xii).

Often women with disabilities have been described as having double handicaps (Deegan & Brooks, 1985). Yet, all women experience life from standpoints that, only recently, have begun to be studied through such works as Gilligan's In a Different Voice (1982), Belenky et al.'s Women's Ways of Knowing (1986), Aptheker's Tapestries of Life (1989), and Collins' Black

Feminist Thought (1991). For example, Collins (1991) conceptualizes a standpoint theory of African American women that could also be associated with women who have disabilities. The theory's core themes include a "legacy of struggle" (p. 23), "the interdependence of experience and consciousness" (p. 24), and a "unique angle of vision" (p. 22) that may be suppressed by dominant groups but through which women can create resistance and action. Self-defining a standpoint is very important and can in itself be a rejection of dominant views. As Audre Lorde's observation quoted by Collins suggests, "It is axiomatic that if we do not define ourselves for ourselves, we will be defined by others–for their use and to our detriment" (p. 26). Through standpoint epistemology, women's experience, knowledge, and actions can be examined concretely and theoretically. About the unique experience of every individual, Collins states, "Each individual has a unique personal biography made up of concrete experiences, values, motivations, and emotions. No two individuals occupy the same social space; thus no two biographies are identical" (p. 227). In "Toward a Feminist Theory of Disability," Wendell (1989) makes these statements about standpoints:

> I do not presume to speak for disabled women. Like everyone who is disabled, I have a particular standpoint determined in part by both my physical condition and my social situation. My own disability may be temporary, it could get better or worse. My disability is usually invisible (except when I use a walking stick). I am a white university professor who has adequate medical and long-term disability insurance; that makes me very privileged among the disabled. I write what I can see from my standpoint. Because I do not want simply to describe my own experience but to understand it in a much larger context, I must venture beyond what I know first-hand. I rely on others to correct my mistakes and fill in those parts of the picture I cannot see. (p. 106)

She believes that social oppression may be common among people with different disabilities. About those experiences, she observes:

> Even when your experience is recognized by medicine, it is often re-described in ways that are inaccurate from your standpoint. The objectively observable condition of your body may be used to determine the severity of your pain, for instance, regardless of your own reports of it....
>
> When you are forced to realize that other people have more social authority than you do to describe your experience of your own body, your confidence in yourself and your relationship to reality is radically undermined. What can you know if you cannot know that you are experiencing suffering or joy; what can you communicate to people who don't believe you know even this? Most people will censor what they tell or say nothing rather than expose themselves repeatedly to such deeply felt invalidation. They are silenced by fear and confusion. The process is familiar from our understanding of how women are silenced in and by patriarchal culture. (pp. 120-121)

Standpoint epistemology gives researchers and women with disabilities a place from which to explore and understand experiences. While asserting that many women with disabilities are silenced and oppressed within the medical culture, Wendell stresses the importance of understanding her and other women's standpoints. People speak for, to, or about women with disabilities from viewpoints which are often far removed from their real experiences. Only a woman knows how she experiences disability, how she expresses herself, and how she experiences being peripheralized by people who do not understand (Fine & Asch, 1985; Hall et al., 1994; hooks, 1989, 1990). No two experiences will ever be lived or told exactly alike because no two women are exactly alike, regardless of disability.

Perspectives upon identity and voice

Identity and interaction

Experiences are the inner stories that women with disabilities claim as their own. At the heart of any life story is the person's identity. Identities are constructed through interactions with self and others (Denzin, 1992). As Kerby's (1991) definition of self notes,

> By *self* I mean the distinct individual that we usually take ourselves to be, an individual, therefore, that also knows itself to be. Associated with this selfhood are modes of address such as *I, me, myself, we*. Selfhood also traditionally entails a degree of identity, of self-identity over time. This self-identity involves believing or otherwise experiencing oneself to be, at least roughly, the same throughout a temporal span. (p. 4)

In this discussion, self-identity means experience of self. Randall believes, "In a sense, my inside story amounts to my *self*" (p. 52).

Experiences involve the stories that people live through interaction. This entire discussion of women's experiences with disability is framed by the interpretive interactionism based upon the work of Denzin (1989, 1992) and is drawn from the symbolic interactionist theory of Blumer (1969). Denzin (1989) focuses on epiphanic experiences and defines an epiphany as a "moment of problematic experience that illuminates personal character, and often signifies a turning point in a person's life" (p. 141). Regarding interaction, identity, and experiences, he states:

> The central object to be negotiated in interaction is personal identity, or the self-meanings of the person (Stone 1962; Strauss 1959; Couch *et al.* (eds) 1986a, b: xxiii)....The meanings of identity lie in the interaction process and emerge and shift as persons establish and negotiate the task at hand (Couch *et al.* (eds) 1986a, b: xxiii). The situations of interaction may be routinized, ritualized, or highly problematic. In them consequential experience occurs. Epiphanic experiences rupture routines and lives and

> provoke radical redefinitions of the self. In moments of epiphany, people redefine themselves. Epiphanies are connected to turning-point experiences (Strauss 1959). Interpretive interactionists study epiphanic experiences. The interactionist locates epiphanies in those interactional situations in which personal troubles become public issues (Denzin 1989b: 18). In this way the personal is connected to the structural, through biographical and interactional experiences. (1992, pp. 26-27)

The relationship between a person's identity and interaction are closely connected and must be explored further in the experiences of women with disabilities. As Randall (1995) points out, "inside stories" of experience are deeply influenced by interactions:

> The acts of telling our inside-out stories to others and of hearing their outside-in ones of us are "events" in our outside story, which in turn can become "experiences" in our inside story. Furthermore, it is often not until we tell somebody else what we are feeling that we realize that that in fact is what we *are* feeling. Similarly, many of us write in order to find out what we think. It is the act of going inside-out that frequently reveals to us what is going on inside....both the inside-out and outside-in stories directly influence the unfolding of our outside story: by affecting the range of options and opportunities that are open to us in our everyday lives and relationships. (p. 60)

The "inside story" of experience is influenced by the existence of opportunities, self-expressions, and impressions of others through interactions. Interactions of women with disabilities vary greatly according to context, which include those with self, family members, friends, educators, doctors, various professionals, acquaintances, and strangers.

Frequently, disability experience has been considered monolithic, with little consideration for intersections of gender, race, class, and other aspects of a person's unique experience (Asch & Fine, 1988; Fine & Asch, 1985, 1988; Leal-Idrogo et al., 1996; Payne, 1993, 1996). In "Disabled Women: Sexism Without the Pedestal," Fine and Asch (1985) assert, "The combined forces of a hostile economy, a discriminatory society, and negative self-image contribute to

a systematic *rolelessness* for disabled women. There is no avenue for self-affirmation" (p. 9). Societal conditions and contradictions can have great impact on the identities of women with disabilities (Asch & Fine, 1988; Fine & Asch, 1985; Hillyer, 1993; Phillips, 1988; Thomas, 1982; Wendell, 1989). Most of the stories of interactions in the lives of women with disabilities are included in anthologies, autobiographies, and other works and have little, if any, theoretical base. Voices and accounts of women themselves have been largely absent from research literature (Asch & Fine, 1988; Browne et al., 1985; Campling, 1981; Deegan & Brooks, 1985; Duffy, 1981; Ferguson et al., 1992b; Fine & Asch, 1985, 1988; Hillyer, 1993; Keith, 1996; Lonsdale, 1990; Morris, 1991; Saxton & Howe, 1987b; Shaw, 1994; Wendell, 1989; Willmuth & Holcomb, 1993).

Experiences silenced through interaction

Women's experiences have often been silenced, and women's identities have often been made invisible (Asch & Fine, 1988; Belenky et al., 1986; Jack, 1991; Taylor, Gilligan, & Sullivan, 1995; Wendell, 1989). Wendell observes:

> In the split between the public and the private worlds, women (and children) have been relegated to the private, and so have the disabled, the sick and the old (and mostly women take care of them). The public world is the world of strength, the positive (valued) body, performance and production, the able-bodied and youth. Weakness, illness, rest and recovery, pain, death and the negative (de-valued) body are private, generally hidden, and often neglected. Coming into the public world with illness, pain, or a de-valued body, we encounter resistance to mixing the two worlds; the split is vividly revealed. Much of our experience goes underground, because there is no socially acceptable way of expressing it and having our physical and psychological experience acknowledged and shared. A few close friends may share it, but there is a strong impulse to protect them from it too, because it seems so private, so unacceptable. I found that, after a couple of years of illness, even answering the question,

> "How are you?" became a difficult, conflict-ridden business. I don't want to alienate my friends from my experience, but I don't want to risk their discomfort and rejection by telling them what they don't want to know.
>
> Disabled people learn that many, perhaps most, able-bodied people do not want to know about suffering caused by the body. Visibly disabled women report that curiosity about medical diagnoses, physical appearances and the sexual and intimate aspects of disability is more common than willingness to listen and try to understand the experience of disability (Matthews, 1983). (p. 111)

According to Wendell, women with disabilities find it difficult to voice their experiences because they are not sure what to share and whether people want to hear what they have to say. In their literature review regarding the experiences of women who have disabilities, Asch and Fine (1988) emphasize the following:

> Women with disabilities traditionally have been ignored not only by those concerned about disability but also by those examining women's experiences. Even the feminist scholars to whom we owe great intellectual and political debts have perpetuated this neglect. The popular view of women with disabilities has been one mixed with repugnance. Perceiving disabled women as childlike, helpless, and victimized, non-disabled feminists have severed them from the sisterhood in an effort to advance more powerful, competent, and appealing female icons. (pp. 3-4)

Even though there may be conflict about how other people see women with disabilities and the mixed messages in society, works written by and about women with disabilities tell stories of unique and common experience. As Thomas (1982) asserts,

> The discovery (and that is not too strong a word) by women who are disabled of the pressures that shape their consciousness and their roles is another example of how many of the most penetrating studies of the experience of disablement come not from concerned professionals but from the conjunction of personal reflections enlarged by ideologies embedded in the mainstream of social thought. (p. 184)

Experiences shared through interaction

The experiences or stories that women reveal through identity and interactions must be told by women through their own voices. In the introduction to Gwyneth Ferguson Matthews' Voices From the Shadows: Women With Disabilities Speak Out, Israel and McPherson (1983) stress:

> Only by being very vocal, and a visible part of the community, can the disabled bring about a transformation in our society that will ultimately embrace and welcome those who, at first glance, don't seem to fit in. (p. 21)

In additional commentary on the process of creating the research with other women with disabilities for the book and the resulting reactions, Matthews (1983) recalls:

> In July 1981, the International Year of Disabled Persons, I was approached by a representative of the Nova Scotia government who asked if I would be interested in researching and writing a paper and brochure on the special problems faced by disabled women. She felt that I, a paraplegic for seventeen years, would be able to identify more closely with potential respondents than would an able-bodied woman....
>
> I found the forty-five women I interviewed very willing to discuss their difficulties, but one admitted, "I wouldn't have opened up if you'd come in tottering on spike heels." Another added, "You can really understand what I'm saying. You've been there."
>
> For five months I talked to women from all social, economic, and educational backgrounds; women with eighteen different disabilities....
>
> That seventy-four page effort was completed in December, 1981. I passed it on to the government and awaited publication.
>
> In March, 1982, I learned that the government was unwilling to publish. "Too depressing," I was told. Also, "Too much sex." Since I'd been hired to explore problems, I wasn't surprised by the first comment; what did they expect?" (pp. 9-10)

The Women's Educational Press eventually published the book, which informally explores Matthews' and other women's experiences regarding adjustment, education, relationships, marriage, family, institutionalism, labeling, work, and assistance, all connected with identity. Through the experiences of eight women, Morris (1991) analyzes prejudices that women with disabilities encounter and the pride that they develop. These works demonstrate that women with disabilities experience self in similar relationships and roles as other women. Even though the book does utilize the narratives of women with disabilities, more attention is given to disability-oriented theoretical development and research. In Women and Disability: The Experience of Physical Disability Among Women (1990), Lonsdale interviewed 21 women and, while incorporating some narrative, tends to summarize the experiences of women with disabilities regarding the prevalence of disability, the social context of disability, self-image and sexuality, dependency, employment, the financial consequences of disability, discrimination and civil rights, independence, and self-determination. The life experiences of women can be found in anthologies, such as Saxton and Howe's (1987b) With Wings, Browne et al.'s (1985) With the Power of Each Breath, and Keith's (1996) What Happened to You?, and research-based work, such as that found in Fine and Asch's (1988) Women with Disabilities: Essays in Psychology, Culture, and Politics. Mairs (1987, 1993) and Stewart (1989) write about their personal experiences with disability, while Frank's (1988) and Phillips' (1988, 1990) studies utilize oral narratives to understand the experiences of women with disabilities. Significant studies from the 1980's focused on the experiences of women with disabilities but with little theoretical grounding. In Images of Ourselves: Women With Disabilities Talking (1981), Campling asked each woman to write about her experiences as a

woman with a disability, but these women were not interviewed. Duffy's groundbreaking ...All Things Are Possible (1981) was developed from interviews with disabled women regarding sexuality issues, and Atkins (1982) prompted vital discussion in the field of rehabilitation about the needs of African Americans and also about women with disabilities. Her paper, "Women as Members of Special Populations in Rehabilitation," made a strong contribution to the Switzer Seminar on Women and Rehabilitation of Disabled Persons and continues to be relevant years later. Atkins observes:

> Contemporary American society is faced with the compelling challenge of assisting women, as members of special populations, to maximize their potential in order that increased participation in all aspects of society becomes a reality. Although it has been estimated that females represent 53% of the American population, women have traditionally not voiced their opinions and have been reluctant to speak on their own behalf. Women's roles have, however, recently undergone rapid changes and females have received meaningful public attention. (p. 38)

Atkins went on to note that while many Americans have not recognized that all people do not think and live in their same manner, the women's movement has advanced awareness about and participation of women.

More recently, Hillyer has contributed Feminism and Disability (1993), speaking from the standpoint of a mother of child with a disability. Women With Disabilities: Found Voices (Willmuth & Holcomb, 1993), which was also published as Volume XIV of Women and Therapy, is a collection of essays covering a variety of the experiences of women with disabilities. One study in the collection, "Found Voices: Women, Disability and Cultural Transformation" (Lisi, 1993) explores the cultural consequences of disability. Interestingly, there are no attempts in any of the essays to theoretically define or describe voice. For the study, the author interviewed four women with disabilities and two

mothers; and she also shared her own experience. Drawing upon the work of Gilligan, Lisi states:

> The voices of those experiencing disability as a part of their own whole and dynamic reality represent not so much the recovery of lost words as the emergence of words and voices that were silenced in past generations. For those of us whose experience of womanhood in America is shaped in contexts that somehow mark us as different or alien to those who surround us, the initial finding of voice may be a more solitary task. (pp. 196-197)

Women with disabilities must tell their own stories to reveal how their identities and interactions are constructed through their experiences.

Voice as a metaphor for identity construction

Examination of certain general explanations about the use of voice as a metaphor for personal identity and power relations is essential (Davis, 1994; Lakoff & Johnson, 1980; Reinharz, 1994). About metaphors, Lakoff and Johnson note:

> *The essence of metaphor is understanding and experiencing one kind of thing in terms of another.* (p. 5)

They emphasize:

> The most important claim we have made so far is that metaphor is not just a matter of language, that is, of mere words. We shall argue that, on the contrary, *human thought processes* are largely metaphorical. (p. 6)

Metaphors represent meanings but are less often defined in the literature. Discussions of voice are found throughout literature in various disciplines with little attention given to definition. As Reinharz (1994) comments:

> Today's dominant metaphors for power relations are voice and silence. Surprisingly, however, these words are rarely defined....This continuous drawing on, and yet not defining, the metaphor of voice is not a shortcoming; rather it is a clue to its deep cultural acceptance. (p. 180)

Understanding voice as a metaphor allows us to explore its meaning at a deeper level, while study of the metaphor of voice enables us to gain rich insights into the lives of all women. Voice can be understood as a metaphor for women's personal identity constructions in relation to disability, decision making, participation and power in social contexts, and issues of oppression and discrimination (Asch & Fine, 1988; Blumer, 1969; Denzin, 1992; Ferguson et al., 1992a, 1992b; Fine & Asch, 1985, 1988; Hahn, 1983, 1990; Hannaford, 1985; Higgins, 1992; Thomas, 1982). Again, in no way does one woman's experience speak for all women; but there may be common experiences that all share.

Disability and decision-making experiences

Voice can be understood as a metaphor for personal identity in relation to disability and to decision-making experiences. As previously discussed, many women are silenced by cultural ideals and personal interactions when talking about their experiences (Asch & Fine, 1988; Wendell, 1989). As Saxton and Howe (1987a) point out:

> Ours is a culture that emphasizes cure, or, short of that, immediate relief from symptoms, so that we can carry on with our busy lives. Unfortunately, in our cultural denial of the reality of chronic illness and disability, we frequently silence the voices of those who cannot deny it. (p. 1)

Therefore, how a woman identifies herself related to disability may reveal a great deal about her perspective and experience (Duffy, 1981; Hannaford, 1985; Mairs, 1987; Wendell, 1989). About her experiences as a child and an adult, Harilyn Rousso (1985) says, "My disability, with my different walk and talk and my involuntary movements, having been with me all of my life, was part of

me, part of my identity" (p. 24). Interestingly, she also reflects on the silence of her parents about certain issues in her life that affected her identity:

> While I was growing up, my parents and I never talked about sex, dating, marriage, children. Not even the familiar warning not to get pregnant. I took the silence to mean that these things were beyond the scope of possibility for me. So I focussed [sic] on school and career, carefully avoiding boy-girl relationships, which only made me feel different. Not until I was established in my career, in my late 20's, did I begin to seriously consider the possibility of a social and sexual life. (p. 28)

Neither she nor her parents were able to voice issues that were important to her identity development. Grealy (1994) has experienced great frustrations with her identity because of the disfigurement of her face caused by the removal of cancer as a young girl. After many years of corrective surgeries and experiences of all kinds, she realizes:

> Without another operation to hang all my hopes on, I was completely on my own. And now something inside me started to miss me. A part of me, one that had always been there, organically *knew* I was whole. It was as if this part had known it was necessary to wait so long, to wait until the impatient din around it had quieted down, until the other internal voices had grown exhausted and hoarse before it could begin to speak, before I would begin to listen. (p. 221)

Sometimes women with disabilities find it difficult to listen to their own voices because of dominant culture ideals and difficult interactions (Grealy, 1994; Saxton & Howe, 1987a). Disability does not inscribe but does influence experience and identity construction. Morris (1991) and others also believe that disability can become a source of individual and collective pride and power (Browne et al., 1985; Gill, 1994; Longmore, 1995; Medgyesi, 1992; Saxton & Howe, 1987b; Shaw, 1994).

Power and participation experiences

Voice can be understood as a metaphor for power and participation in social contexts of interaction. Reinharz (1994) asserts that voice can be a metaphor for power and powerlessness and that people may experience both in situations. According to Reinharz, the analysis of voice

> can help us to understand the experience of groups and their members whom researchers frequently have labeled oppressed. Beginning with the assumption that voice is a central concept for people interested in empowerment and diversity, I argue that voice is a metaphor that can help oppressed groups gain a stronger position in society. (p. 180)

While rarely defined, voice seems to be a universal metaphor that often reflects power in resistance to oppression (hooks, 1989; Reinharz, 1994). Being listened to and being heard seem to be strong reflections of individual and collective power in various contexts (Cantor & Bernay, 1992; Delpit, 1988; Gill, 1994; Medgyesi, 1992; Reinharz, 1994; Saxton, 1987; Wendell, 1987). As discussed previously, the medical model and emphasis on the professional as the expert tend to silence the voices of individuals with disabilities (Gill et al., 1994; Higgins, 1992; Wendell, 1989). About her experiences with doctors as a young child, Saxton writes:

> In all my hospital experiences, the saddest part was always the same. All those people trying so hard to help me: the nurses, the doctors, the volunteers, the Shriners. All of them hoping for me to get better and do well, all wanting to be kind and useful, all feeling how important helping me was, yet never did any one of them ask me what it was like for me. They never asked me what I wanted for myself. They never asked me if I wanted their help.
>
> The surgery I had was very successful. Doctors I see now still comment on the skilled work. But I do not feel entirely grateful. I feel, instead, a remote anger stored beneath my coping pattern of complacent understanding. People do the best they can to help in meaningful ways, I

> know. I just wish all disabled children would say to their helpers: "Before you do anything else, just listen to me." (p. 55)

Saxton's experiences are relevant not only for children but for adults who go unheard.

Sociopolitical models also have influenced perspectives and research about interactions among people with and without disabilities. Gill et al. (1994), point out:

> The notion of disability as individual tragedy or deficiency has been under attack for the past decade by disability scholars and activists alike. They assert that the *traditional medical model* of disability distorts reality by emphasizing one facet of the disability experience–the medical–while neglecting the more crucial social components. They argue that much of what we know as disability is culturally derived, particularly the limitations we associate with disability. These proponents of the new *sociopolitical model* of disability argue that disability is not contained within a person but derives, instead, from the interaction between that person and society. (Hahn, 1985) Heartily embracing this perspective, people with disabilities increasingly speak of overcoming not their physical, sensory, or cognitive limitations but job discrimination, disability bigotry, and thoughtlessly inaccessible structures. Like women, they point out that the negative images assigned to them are social fabrications–stereotypes–not natural facts of biology. From this perspective, being disabled no more renders a person tragic, weak, or dependent than being a woman makes a person innately passive, low achieving, or domestic! (p. 358)

In "Damaged Goods: Oral Narratives of the Experience of Disability in American Culture," Phillips (1990) reveals one woman's perspective about negative images and interactions:

> For Bonnie, negative terminology and images not only reflect but also reinforce condescending attitudes toward disabled persons. Such words and images effectively penetrate the cultural consciousness, predicting social interactions. [41, 42] (p. 851)

Bonnie and Kate, another woman in the study, experience conflict in interaction with nondisabled peers and service providers. Attempts by others to help them and to assess their capabilities, based upon impressions, hinder the women in

meeting certain goals in education and employment. In the study, Phillips concludes:

> My informants' narratives reveal the existence, and perhaps even the preponderance in American society, of patterned interactions between disabled and nondisabled persons. Their stories illustrate that many of their experiences are predicated on the cultural notion that disabled people are, in effect, damaged goods. (1) They illustrate the prevalence in the popular media of language and images which perpetuate the notion of the defectiveness of persons with disabilities. (2) They note the underlying message, imbedded in both the medical and the rehabilitation models, of the essential wrongness of their bodies. And, (3) they affirm the transformational and liberating effects on their self-images of those philosophies which demonstrate not their deviance, but their social minority status, and which strongly disavow the status-quo notion of disabled-as-damaged-goods. (p. 855)

In an interview study (Frank, 1988), Diane DeVries, a woman born with "limb deficiencies," appears to accept her identity and as such, "has taken on the role of militant and example, using her visibility strategically to work toward social goals for the disabled and nondisabled, alike" (p. 108). Through her interactions, she has chosen to be visible, which she perceives as self-empowering for her and for other people with disabilities. Her self-identity and presentation resist cultural norms through interaction.

Being asked and being heard reflect the possession of power and control in people's lives. According to Medgyesi in No More B. S.: A Realistic Survival Guide for Disability Rights Activists (1992), power can mean, "Having people listen to what you say" (p. 22) and control can mean, "Being able to say how you want things done" (p. 22). The National Director of the Developmental Disability Council and a person with cerebral palsy, Bob Williams (as cited in Medgyesi, 1992) says, "SPEAK UP FOR WHAT YOU KNOW IS RIGHT AND SPEAK AS ONE UNITED VOICE. REMEMBER–WE HAVE POWER IN OUR HEARTS AND IN EACH OTHER. WE MUST BREAK THE SILENCE" (p. 1). Speaking up

reflects power and shatters silence. Activist Laura Hershey (1993) reflects on using her voice as a woman with disability:

> Some of my selves want to speak of fear, anger, self-doubt, sadness, and other emotions previously censored for the sake of survival. Therapy for me has meant hearing and understanding those other voices. To my surprise, opening these voices has often yielded strength, even as they revealed vulnerability. And, contrary to what I half expected, I am not becoming apolitical by focusing on my more personal, emotional self. Rather, my politics are deepening. I become more passionate and committed as I speak from a medley of true voices. For example, my anger over incidents of discrimination and exclusion now resonates from within. My emotional self is no longer an awkward stranger, but a source of power.
>
> I am allowing all my voices to come out, and I am thereby continuing to come out. (pp. 16-17)

For this woman, speaking from her own multiple voices within her contexts of interaction is an example of the power and shattering of silence some experience when "speaking up."

Issues of discrimination and oppression

Voice is often affected by issues of oppression and discrimination. Paternalistic views of disability and dependence have influenced how people with disabilities are perceived and how they participate in their worlds (Gill et al., 1994; Hahn, 1983, 1990; Hannaford, 1989; Higgins, 1992; Hillyer, 1993; Wright, 1983). According to Higgins (1992), "servicing" increases dependence and passivity rather than active participation and interdependence:

> Through servicing people with disabilities, we handicap them. Through servicing we individualize disability, locating the challenges disabled people experience within their "flawed" selves. Those who participate in servicing are unequal, and we provide unequal services to disabled people. Professionals dominate to the detriment of disabled people, especially to the detriment of those who challenge the professionals' dominance. With an emphasis on organizational survival, servicing

> agencies may serve those most easily assisted, retain others who appropriately could develop a more independent way of life, and refrain from disrupting or making uncomfortable the larger community on which the agencies depend. Consequently, servicing transforms disabled people into passive individuals who are unlike the rest of us. It preserves our social practices and arrangements that hamper disabled people....
>
> Disabled people are not flawed individuals, but citizens with varying characteristics who have the right to make their lives in a world that will include them. (p. 186)

"Servicing" prohibits the full participation of individuals with disabilities in society and passively and actively silences their voices. In Living Outside Inside. A Disabled Woman's Experience. Towards a Social and Political Perspective. (1985), Hannaford supports this view:

> Normality and abnormality are socially defined. It also has to be a relative concept; we are all normal/abnormal to the social norm in varying degrees. Disability can and sometimes does interfere with the practical running of a life, but it is the social reaction and non-action which causes disablement. There is no such thing as *the disabled*, there are just people. (p. 10)

She reflects:

> I realize that a lot of what I have said will be unpopular, or that I can be dismissed as bitter and twisted. Dismiss me if you will, as society has dismissed the feelings and protests of ethnic groups, women and gays for centuries. Historically it has been proven that powerless groups are not given recognition until they demand and fight for it. Likewise I am not asking for my rights and humanity, to be given a place in this society, which like it or not, I belong to, I demand it. (p. 12)

Efforts to deal with discrimination and to enhance the full participation of people within society have tended to be politically based (Hahn, 1983, 1984, 1990; Longmore, 1995; Scotch, 1990; Shapiro, 1993). As Lonsdale (1990) observes:

> Women with disabilities, therefore, stand to gain considerably from a politics of disability that will liberate them from these fetters. Such a politics of disability, however, must be one which hears the voices of women, and acknowledges and deals with the particular oppression that women with disabilities experience. (pp. 156-157)

Women with disabilities across the country have supported, participated in, and been affected by the disability movement, but it is unclear how this movement and civil rights legislation, such as the Americans with Disabilities Act, are specifically affecting the experiences of women with disabilities (Shapiro, 1993, Shaw, 1994). Thus, experiences are the stories that women live through identity and interaction.

Variations in interactions

In this discussion, it is not possible to include all the variations in women's personal and professional interactions. About individuals' interactions and experiences, Higgins (1992) emphasizes:

> Through our interactions with one another and ourselves, we experience disability. Disabilities do not determine our experiences. We create them as we encounter the opportunities and obstacles of our larger world. People with disabilities make much more complex, varied, and changing experiences of disability than imagined by nondisabled people. Some may make it the cherished, "natural," (almost) taken-for-granted center of their lives, which bewilders most people without disabilities. However we experience disability, each of our experiences is a partial experience, not the one, "true experience." (p. 251)

As Wendell (1989), Thomas (1982), Gill (1994), and Longmore (1995) state and others imply or discuss, people with disabilities are often marginalized in interactions because of attitudinal and physical barriers related to disability. In The Experience of Handicap (1982), Thomas cites Berger and Luckmann's social constructivist explanations linking disability and marginality:

> Disability is not only a matter of medical and administrative definition, it is a personal one of how each person with an impairment defines him- or herself. Both official and subjective definitions (and the social and personal consequences of such definitions) may place an individual in a position where taken-for-granted identities are subject to transformation. Berger and Luckmann's (1971) view of marginality introduces the idea that

> a person whose normality of social identity is fragile and negotiable may occupy a position which is uncertain, ambiguous and not fully institutionalized, being at a distance from what most people would regard as society's core institutions and values. To some extent this is the position of disabled people, for though they are not separate from society they appear to occupy a marginal position, uneasily situated between a rigid dichotomous social classification and undifferentiated "normality." (pp. 4-5)

Marginality is constructed and situated in relation to the constructed norms of society. In some instances (Bruun, 1995; Wright, 1983), people with disabilities may be seen as brave or as heroes and welcomed into the culture, but this is rare. Even when people do consider themselves part of a society or a culture, they may experience marginality. Recently, people with disabilities have had much greater access to physical opportunities; but social and economic barriers still influence marginalization and marginality experiences for women with disabilities (Asch & Fine, 1988; Gill et al., 1994; Longmore, 1995). The construction of voice is shaped in contexts of interaction.

Conceptualizations of voice and identity construction

In this discussion of voice, the major focus is on feminist conceptualizations of voice. A historical review shows that women's voices have been silenced for centuries. Reinharz (1994) observes:

> Whereas in contemporary society, voice is a metaphor for freedom and power, in earlier times it had a more literal meaning. In essence, people without power were not allowed to speak. People with power, by contrast, could speak and could control the right of others to speak. Evidence for this pattern can be found in many dominant texts of our culture. (p. 181)

Women's voices have been suppressed throughout the canons of biblical and literature texts (Reinharz, 1994; Woolf, 1929/1957). In her seminal treatise,

A Room of One's Own, Virginia Woolf (1929/1957) describes how the voices of women writers have been silenced in literature throughout history. About the struggle, Reinharz (1994) says, "The history of women's efforts to liberate themselves encompasses the history of women's struggle to seize the right to speak and to be heard" (p. 181).

In this discussion, voice is a metaphor for the personal identity constructions of women within relationship (Brown & Gilligan, 1992; Gilligan, 1982, 1993; Gilligan et al., 1990; Taylor et al., 1995), in knowledge (Belenky et al., 1986; Haraway, 1988), by expression (Reinharz, 1994), and as transformation (Delpit, 1988; Fine, 1992, 1994; Foster, 1995; hooks, 1984; 1989; 1990; Lorde, 1984; Sparkes, 1994).

Gilligan: voice within relationship

Through the feminist movement and feminist theory (Olesen, 1994), attention has been given to the metaphor of voice. Carol Gilligan's study (1982) of differences in moral reasoning and responsibility reflected in the different voice brought the metaphor to the forefront of feminist scholarship. Gilligan developed three studies that relied on the use of interviews in a college student study, an abortion decision study, and a rights and responsibility study. Gilligan says this about voice:

> The different voice I describe is characterized not by gender but theme. Its association with women is an empirical observation, and it is primarily through women's voices that I trace its development. But this association is not absolute, and the contrasts between male and female voices are presented here to highlight a distinction between two modes of thought and to focus a problem of interpretation rather than to represent a generalization about either sex. In tracing development, I point to the interplay of these voices within each sex and suggest that their convergence marks times of crisis and change. No claims are made about

> the origins of the differences described or their distribution in a wider population, across cultures, or through time. Clearly, these differences arise in a social context where factors of social status and power combine with reproductive biology to shape the experience of males and females and the relations between the sexes. My interest lies in the interaction of experience and thought, in different voices and the dialogues to which they give rise, in the way we listen to ourselves and to others, in the stories we tell about our lives. (p. 2)

It is fundamentally important to emphasize that Gilligan (1982, 1993) was not focused on the differences in men and women as such, but on differences in people's thought and experience and in how they talk and listen to the stories that are lived and told. Foundational to her work, Gilligan (1982) assumes, "That the way people talk about their lives is of significance, that the language they use and the connections they make reveal the world that they see and in which they act" (p. 2).

Her definitions and assumptions about voice are central to the focus in my research in that the ways women with disabilities talk about their lives are significant and that the language they use to describe themselves and their experiences does reveal the world in which they see and act. The physical, cultural, and relational aspects of their worlds must be explored and understood if we are to understand their actions and reflections about their experiences. Through that research, Gilligan (1982) concludes:

> As we have listened for centuries to the voices of men and the theories of development that their experience informs, so we have come more recently to notice not only the silence of women but the difficulty in hearing what they say when they speak. Yet in the different voice of women lies the truth of an ethic of care, the tie between relationship and responsibility, and the origins of aggression in the failure of connection. (p. 173)

According to Gilligan, the different voice is a metaphor for an ethic of care, connection, and responsibility. She brought attention not only to the importance of, but to the distinctions in women's and girls' voices. Since 1982, Gilligan and

her colleagues have continued to pursue research regarding voice of women in predominantly educational contexts (Brown & Gilligan, 1992; Gilligan, 1993; Gilligan et al., 1990; Taylor et al., 1995). In several of these works, voice is described in metaphorical language that lacks clarity regarding definition of voice. Translation of voice as a metaphor into utilization as a research construct is complex. Davis (1994) asserts that even though Gilligan's notion of voice has made an important contribution, it is difficult to investigate. In a study on the feminine voice, she and her colleagues find that voices are multiple and are constructed in different ways. Davis comments:

> It is my contention that "hearing" and analysing [sic] the confusion or ambivalence in women's narratives does not just require a more elaborated methodology. It would also entail some revision of the notion of voice itself. (p. 359)

In a preface to a 1993 edition of In a Different Voice, Gilligan's reflections on the response to her book provide some deeper understanding about her notion of voice that is relevant to my research with women who have physical disabilities. Drawing on the work of leading voice teachers, Gilligan's analysis has deepened to focus on how voice is expanded or constricted through relationships and how it is opened or impeded as a physical and psychological channel. In a new, simple way, Gilligan (1993) now emphasizes:

> By voice I mean voice....To have a voice is to be human. To have something to say is to be a person. But speaking depends on listening and being heard; it is an intensely relational act. When people ask me what I mean by voice and I think of the question more reflectively, I say that by voice I mean something like what people mean when they speak of the core of the self. Voice is natural and also cultural. It is composed of breath and sound, words, rhythm, and language. And voice is a powerful psychological instrument and channel, connecting inner and outer worlds. (p. xvi)

The core of the self of women with physical disabilities has often been made invisible because of the visibility of physical characteristics. Looking at the outside, assumptions have been made about the inside without really asking women about their experiences (Asch & Fine, 1988; Gill et al., 1994; Krotoski et al., 1996; Hannaford, 1985; Morris, 1991; Wendell, 1989).

The voices of women must be explored and understood within their relationships. Gilligan offers voice as a key for understanding psychological, social, and cultural order. In this order, she asserts that women have difficulty understanding their own voices in relation to how they are constructed by others and that when women give up their voices under such pressures, they give up making choices. Gilligan's (1993) reflections about the complexities of understanding voice are particularly significant to her own research and to mine:

> In listening to people's responses to *In a Different Voice*, I often hear the two-step process which I went through over and over again in the course of my writing: the process of listening to women and hearing something new, a different way of speaking, and then hearing how quickly this difference gets assimilated into old categories of thinking so that it loses its novelty and its message....When I hear my work being cast in terms of whether women and men are really (essentially) different or who is better than whom, I know that I have lost my voice, because these are not my questions. Instead, my questions are about our perceptions of reality and truth: how we know, how we hear, how we see, how we speak. My questions are about voice and relationship. And, my questions are about psychological processes and theory, particularly theories in which men's experience stands for all of human experience–theories which eclipse the lives of women and shut out women's voices. (pp. xii-xiii)

Her evolving research purpose is not to compare the difference in men's and women's voice, but it is to explore women's experiences and to hear their voices. In disability research, much of the work would almost appear genderless (Asch & Fine, 1988; Deegan & Brooks, 1985; Fine & Asch, 1985, 1988; Morris,

1991) because of the emphasis on disability with little attention given to influences of gender and other constructions, such as ethnic background and class. The experiences of women with disabilities have been marginalized by the experiences of those considered able-bodied (Hannaford, 1985; Wendell, 1989). Gilligan's (1982, 1993) conceptualization of voice is significant to my work because of her emphasis on separation, on creation, and on maintenance through boundaries within relationships. How women with physical disabilities define margins in their lives in relationship with individuals, social networks, communities, and environments (Hall et al., 1994) brings knowledge that is yet to be explored through the voices of women with disabilities. The importance of hearing and understanding a woman's voice about her experiences cannot be underestimated. Gilligan's (1993) concerns about how researchers investigate gender difference has significance also for understanding experiences of women with disabilities:

> I find the question of whether gender differences are biologically determined or socially constructed to be deeply disturbing. This way of posing the question implies that people, women and men alike, are either genetically determined or a product of socialization–that there is no voice–and without voice, there is no possibility for resistance, for creativity, or for a change whose wellsprings are psychological. (p. xix)

Through voice, Gilligan emphasizes possibilities that are real in women's lives through interactions.

Voices of women with disabilities must be brought to the forefront in any discussion about disability experience. One of the reasons that women with disabilities have been silenced so often is because someone is speaking about disability to them or for them. In a qualitative study based on open-ended interviews with 31 women, "Wellness Models and Sexuality Among Women With Physical Disabilities," greater attention is given to models of wellness and

five major thematic domains than the voices of the women themselves (Nosek, et al., 1993). The women's voices seem muted in the thematic construction. Too often, rather than women telling their stories, stories are told about them. Unless women with disabilities can hear their voices in research, their stories are not being told. Women with disabilities should not have to fit their voices to any construction of disability but should fulfill their voices through their own constructions of experience. In "Ethics of Care, Women's Perspectives and the Status of the Mainstream Rehabilitation Ethical Analysis," Gatens-Robinson and Tarvydas (1992) discuss the significance of care and relationship and how women have been silenced through universalized disability-related meanings and medical models. In her extensive work, Gilligan has made a great contribution to feminist scholarship by exploring the "different voice" (1982) as a metaphor representing care, responsibility, and relationship. Her use of the metaphor of voice has created a powerful legacy for women and others to be heard.

Belenky, Clinchy, Goldberger, and Tarule: voice in knowledge

The work of Belenky et al, Women's Ways of Knowing: The Development of Self, Voice, and Mind (1986), has made a great contribution to feminist scholarship. Along with Gilligan, they place emphasis upon the dichotomy of silence versus expression. In their work, they do not define exactly what they mean by voice but describe it as a metaphor for women's development as constructed by the women themselves. In their interview study with 135 women ages 16 to 65, they find that women utilized metaphors of voice in their descriptions of their intellectual development, or ways of knowing.

Belenky et al. reveal:

> What we had not anticipated was that "voice" was more than an academic shorthand for a person's point of view. Well after we were into our interviews with women, we became aware that it is a metaphor that can apply to many aspects of women's experience and development. In describing their lives, women commonly talked about voice and silence: "speaking up," "speaking out," "being silenced," "not being heard," "really listening," "really talking," "words as weapons," "feeling deaf and dumb," "having no words," "saying what you mean," "listening to be heard," and so on in an endless variety of connotations all having to do with sense of mind, self-worth, and feelings of isolation from or connection to others. We found that women repeatedly used the metaphor of voice to depict their intellectual and ethical development; and that the development of a sense of voice, mind, and self were intricately intertwined. (p. 18)

This implies the importance of dialogue and interaction, and voice and silence are recognized as relevant metaphors.

Women's ways of knowing and development of voice are described through epistemological categories. Through "silence" (Belenky et al., 1986, p. 24), women listen to others and are not able to speak or be heard. Through "received knowledge" (p. 36), women listen to others for direction and knowledge and are silent. Through "subjective knowledge" (p. 54), women begin to speak from their own experiences and to be heard by others. The women begin to appreciate differences and see that there are many opinions. At times they may find it difficult to listen to others as they are focusing on acknowledging and expressing their own opinions. Through "procedural knowledge" (p. 93), women focus on understanding various experiences and opinions. By "connected knowing" (p. 112), they learn to understand the experiences of others through empathy; and by "separate knowing" (p. 103) they learn to use procedures for analyzing, evaluating, and communicating about other's experience and knowledge. Through "constructed knowledge" (p. 134), women understand that knowledge is constructed in context and they are

involved in dialogue. In "constructed knowledge," Belenky et al. point out that how women express their voices varies according to interaction and dialogue. Generally, self-confidence and speaking one's voice are related. Even though the focus of Belenky et al.'s work is on women's ways of knowing, it reveals a great deal about ways of voicing.

In the framework that Belenky et al. (1986) present, there seems to be more emphasis placed upon the knowing of women who have achieved higher education. How women who are of "invisible colleges" (p. 12) develop their voices and minds is not clear. In Talking Back, hooks (1989) discusses her experiences and her coming to voice as well as a different interpretation of silence by those who may seem invisible in some contexts:

> This emphasis on women's silence may be an accurate remembering of what has taken place in the households of women from WASP backgrounds in the United States, but in black communities (and diverse ethnic communities), women have not been silent. Their voices can be heard. Certainly for black women, our struggle has not been to emerge from silence into speech but to change the nature and direction of our speech, to make a speech that compels listeners, one that is heard. (p. 6)

By citing experiences of some women as symbolic for all women, voices are lost and experiences never told or understood. Abell and Sommers (1991) developed a significant study, "Counseling Incest Survivors: The Metaphor of Voice and Growth," utilizing the framework of the Belenky et al. study. In their study, they discuss a support group for women who had been sexually abused as children. Through the therapeutic process, women were able to voice their experiences in a supportive context. Abell and Sommers say the metaphor of voice "acts as a symbol to encompass the changing ability to bring words or voice to what has hitherto been inexpressible within the totality of past experience" (p. 68). In addition to participating in the support group, the women

participated in interviews in which they talked about gaining a voice. In their conceptualizations of voice, Abell and Sommers recognize the foundational elements of knowing what one wants to say, saying it, and being heard. Voice is constructed in knowledge by women of diverse experiences.

Reinharz: voice by expression

In her work, "Toward an Ethnography of Voice and Silence," Reinharz (1994) emphasizes that voice is recognized as a "megametaphor":

> Since the time of Timothy, voice and silence have referred both to actual speech and to a metaphor for power and powerlessness. Voice, in particular, has become a kind of megametaphor representing presence, power, participation, protest, and identity. (p. 183)

Reinharz defines voice as, "Having the ability, the means, and the right to express oneself, one's mind, and one's will" (p. 180). While she recognizes that if people do not have the means, the ability, or the rights, they are silenced, Reinharz emphasizes that voice must not be seen as merely a metaphor for development or silence alone but as a metaphor associated with identity. Not only can we understand how women come to know what they want to say, say it, and be heard in a process of coming to voice (Abell & Sommers, 1991; Belenky et al., 1986; Gilligan, 1982, 1993; hooks, 1989, 1990), but we can understand how they experience presence, power, participation, protest, and identity (Reinharz, 1994). Through a brief ethnography of voice, Reinharz traces women's history of struggle and liberation to speak and be heard. According to Reinharz, Lorde (1984), Belenky et al., Cantor and Bernay (1992), there are strong currents between women's fears, silence, risks, power, and speech. Lorde asserts:

> But primarily for us all, it is necessary to teach by living and speaking those truths which we believe and know beyond understanding. Because in this way alone we can survive, by taking part in a process of life that is creative and continuing, that is growth. (p. 43)

She adds:

> We can learn to work and speak when we are afraid in the same way we have learned to work and speak when we are tired. For we have been socialized to respect fear more than our own needs for language and definition, and while we wait in silence for that final luxury of fearlessness, the weight of that silence will choke us.
>
> The fact that we are here and that I speak these words is an attempt to break that silence and bridge some of those differences between us, for it is not difference which immobilizes us, but silence. And there are so many silences to be broken. (p. 44)

Drawing upon historical and feminist studies, Reinharz asserts that women have been made invisible and must be made visible and that they also must be heard. In research that explores women's diverse experiences, Reinharz recommends that we hear and listen to women's diverse voices that have been suppressed. In order to do this, we must be willing to share time with them and to avoid speaking for and about them.

hooks: voice as resistance and transformation

Throughout her work, hooks (1984, 1989, 1990) conceptualizes voice as a metaphor for resistance and transformation through dialogue (Delpit, 1988; Freire, 1970/1993, Greene, 1990). As a writer (1989), hooks identifies voice with expression through writing but goes far beyond that experience. hooks conceptualizes coming to voice through speaking out and being heard as an act of resistance. She emphasizes the process of coming to voice, the liberatory

voice, the importance of understanding that a person has multiple voices from which to speak and that no woman's voice speaks for all women's voices:

> Feminist focus on finding a voice may seem clichéd at times, especially when the insistence is that women share a common speech or that all women have something meaningful to say at all times. However, for women within oppressed groups who have contained so many feelings–despair, rage, anguish–who do not speak, as poet Audre Lorde writes, "for fear our words will not be heard nor welcomed," coming to voice is an act of resistance. Speaking becomes both a way to engage in active self-transformation and a rite of passage where one moves from being object to being subject. Only as subjects can we speak. As objects, we remain voiceless–our beings defined and interpreted by others. (1989, p. 12)

Voice cannot be given to people (Delpit, 1988; Fine, 1994; Foster, 1995; Sparkes, 1994; Tierney, 1995); but people must be given the power and space to establish their voices through dialogue with their own selves and other people in daily life, through research, and practice. In true, transformative dialogue, people must speak for themselves and be heard. If people's constructions of their lives are unheard, they are inaudible even if and while they are speaking. Regarding research, Tierney observes:

> Thus, the researcher's task is not to discover the "true" interpretation, for none exists; instead, the challenge is to uncover the multiple voices at work in society that have been silenced. (p. 99)

Voices cannot be self-transformed if dominated and repressed by hegemonic constructions of voice that marginalize people's experiences. Tierney notes:

> But also, many of our voices are denied or overlooked because they are subsumed by the hegemonic voice of the norm. I am not suggesting that we develop voices in our narratives simply so that we have a taxonomy of difference....Without bringing into question the notion of difference itself–how it is arranged and configured, and whose interests exist within the norm–we will forever doom voices such as Robert's to the border zones of our society. (p. 109)

Certainly, audience must be considered and brought into the dialogue if transformation is to take place in our world (Fine, 1994; Greene, 1990; Hall et al., 1994; Sparkes, 1994; Tierney, 1995). Frequently, people have not been asked questions in which they were able to talk about their experiences or say all that they wanted through multiple voices (Foster, 1995; Hall et al., 1994). In an autobiographical piece, Laura Hershey (1993), a woman with a physical disability, reveals:

> Some of my selves want to speak of fear, anger, self-doubt, sadness, and other emotions previously censored for the sake of survival. Therapy for me has meant hearing and understanding those other voices. To my surprise, opening these voices has often yielded strength, even as they revealed vulnerability. (p. 17)

hooks (1989), Fine (1994), Foster (1995), and others emphasize that as long as women are spoken for, they are oppressed.

Women with disabilities can speak about their experiences and actually transform knowledge when they are heard (Wendell, 1989). hooks (1989) describes the process as

> coming to voice—on moving from silence into speech as revolutionary gesture. Once again, the idea of finding one's voice or having a voice assumes a primacy in talk, discourse, writing, and action. As a metaphor for self-transformation, it has been especially relevant for groups of women who have previously never had a public voice. (p. 12)

In "Marginality as Site of Resistance," hooks (1990) establishes that marginality signifies repression and resistance. In her view, marginality is valued as a site from which to resist in which people refuse to take on the norm-constructed definitions of themselves:

> Understanding marginality as position and place of resistance is crucial for oppressed, exploited, colonized people. If we only view the margin as sign, marking the condition of our pain and deprivation, then a certain hopelessness and despair, a deep nihilism penetrates in a destructive way the very ground of our being....I want to say that these margins have been

> both sites of repression and sites of resistance. And since we are well able to name the nature of that repression, we know better the margins as site of deprivation. We are more silent when it comes to speaking of the margin as site of resistance. We are more often silenced when it comes to speaking of the margin as site of resistance. (p. 342)

hooks asserts that margins can be places of resistance where people define and speak for themselves. Conceptions of marginality are directly concerned with issues of voice (Freire, 1970/1993; hooks, 1984, 1989, 1990; Prilleltensky & Gonick, 1994; Reinharz, 1994). It is critical to understand that conceptualizations of marginality allow us to question and resist the very nature of the norms, whether regarding ethnicity, disability, or other social constructions. The disability rights movement in this country resists the norms that have tended to define people's experience as deviant, disabled, and devalued (Hahn, 1983, 1990; Hannaford, 1985). In the margins of resistance, they speak to issues in which they are oppressed and discriminated against, that are often controlled by the power of others. Greene (1990) emphasizes that transformation and dialogue must be brought into the world deliberately:

> It is to work for responsiveness to principles of equity, principles of equality, principles of freedom, which still can be named within contexts of caring and concern. They have to be **chosen**, as suggested, by living human beings against their own life worlds and in the light of their lives with others, able to express, to call, to say, to sing. And, using their imaginations, tapping their courage, to transform. (p. 17)

Experiences of coming to voice and speaking from the margins can become transformative expressions in the lives of women with physical disabilities.

Perspectives on marginality

Prior to the 1920's, little research was done on marginality. Park's essay "Human Migration and the Marginal Man," published in 1928 and in On Social Control and Collective Behavior (1967), has been recognized for its seminal influence on the sociological study of marginality. His research focused on the migration experiences of people. Stonequist (1937/1961) extended that research through The Marginal Man, in which he explored the experiences of people from a variety of cultural backgrounds. In 1948, Barker presented a conceptualization of marginal status and experience. With its validity and importance established, attention will be given to interactionist, political, feminist, and critical conceptualizations of marginality. Major emphasis will be placed on Ferguson's (1990) and hooks' (1984, 1989, 1990) conceptualizations of marginality as relevant to the experiences of women with physical disabilities. Hall et al.'s (1994) conceptualizations of margins, marginalization, and marginality are particularly important for research design and methodology regarding the experiences of women with physical disabilities.

Definitions of marginality connected with disability

As a conceptualization, marginality has been discussed in various ways related to the experiences of persons with disabilities. One of the most prevalent and traditional manners focuses upon marginal status between physical "normality" and "abnormality" (Barker, 1948, Fewell, 1991; Phillips, 1988).

Even though Barker (1948) does not cite influences on his work, his thoughts about marginal status in people with disabilities appear to be

influenced by the work of Park (1967) and Stonequist (1937/1961). In "The Social Psychology of Physical Disability," Barker develops an explanation about the social status positions and situations of children and adults with disabilities that could be described as "underprivileged," "ambiguous and marginal," and "involves new, unknown social conditions" (p. 31). Regarding marginal status, Barker claims:

> The physically disabled are analogous to a sociological class inasmuch as some physically disabled persons are able to enter the ranks of, and become accepted as, normal persons, and many of them share common activities and satisfactions with their normal contemporaries. In other words, the demarcation between physical normality and disability is not definite; the distinction between what a particular disabled person can and cannot do is uncertain. This means that most physically disabled persons have a marginal status between the physically normal and the physically helpless. (p. 32)

Barker (1948) makes the distinction that people with disabilities can be recognized as a social class. Certainly, there are difficulties in referring to individuals who have varying experiences with physical disabilities as the physically disabled, but he presents an important perspective by dealing with social issues. Marginality conditions evolve around a person's uncertain physical ability status that could impact personal freedom, impose restrictions, and influence other people's perceptions:

> Very often the dual requirements of such overlapping minority and majority positions lead to conflicting behavior tendencies. For example, in his role as a child, the appropriate behavior for an adolescent may be lively activity and expressiveness; in his role as an adult, however, he may be expected to exhibit sedentary behavior and self-control. Such different behaviors cannot be carried out simultaneously. While such overlapping situations persist, conflict with resulting inhibition or vacillation of behavior and with heightened tension and emotionality is inevitable. Such marginal positions cannot usually be maintained for long periods of time and the person who is caught in such a conflict will usually make an effort to escape into one or the other of the overlapping situations. (p. 33)

People might try to adjust to marginal situations by managing their own perceptions, through recognition or rejection of disability status, identification with other people with disabilities, or retreat from others (Fewell, 1991; Hahn, 1984; Phillips, 1988). Barker recognizes certain tensions for people with disabilities related to constant adjustment of perceptions, behaviors, and interactions in various situations, while recognizing that every person has unique experiences. In his opinion, the degree of marginality depends on the nature of disabilities. He states that those disabilities which are invisible, along with fluctuating limitations, create greater degrees of marginality. He stresses:

> It is much more important, however, to help the disabled person to define the limits of his world of free actions, i.e., to make a clear dividing line between the activities which are open to him and those which are closed. (p. 37)

Barker adds:

> The disabled person must know what he is up against. This involves knowing the areas in which opportunities lie as well as those from which he is excluded. (p. 38)

According to these views, the primary responsibility for defining and adjusting to limits and dealing with exclusion falls upon the person with a disability. Regarding a person's physical and social marginality experiences from a physical deviance-oriented perspective, Barker concludes:

> Some aspects of the social-psychological situation of physically handicapped persons in American culture are clear. Their underprivileged and marginal position, with consequent frustration and conflict, make the incidence of maladjustment understandable. Their isolation, and the fact that their underprivileged position is rooted in their own inferiority as well as in the prejudice of others make frequent intrapunitive and withdrawing adjustments understandable, also. Amelioration of the social-psychological position of the physically disabled appears possible in some degree by providing legal safe-guards to employment and to suitable education. However, such provisions cannot remove all the restrictions upon the physically deviant in a world constructed for the physically

> normal. The ultimate adjustment must involve changes in the value systems of the physically disabled person. (p. 38)

According to Barker, the responsibility to make changes is on both the person with a physical disability and society. Much later, Murphy, Scheer, Murphy, and Mack (1988) define this in-between status as liminality. Barker's propositions about the marginal statuses of people with physical disabilities tend to center on normality/abnormality statuses. Conflicts within the person result from tensions in the marginal status, affecting the responses of self and others to disability. Meyerson (1990), editor of the classic 1948 Journal of Social Issues, recognizes this paradigm about disability:

> To epitomize the dominant paradigm in 1948: The locus of disability problems was viewed as being in the bodies of the people categorized as "disabled." In our culture, it was the unfortunate but realistic destiny of most of these people to live deprived, marginal, and devalued lives in a material and social world designed for the able-bodied. The solution to the problem-was to adjust these people by helping them accept what "fate" and the existing system had consigned to them. (pp. 14-15)

Meyerson also attributes the origin of the minority group status of people with disabilities to these works in the 1940's and 1950's, which Barker recognized and he encouraged nondiscrimination in education and employment of people with disabilities. Forty years later, Meyerson points out that much progress had been made in understanding disability and the experiences of people with disabilities; but there is more progress to be made.

Deviance and marginality

Much of the major study about interaction between people with and without disabilities has been founded on works such as Goffman's Stigma (1963),

Davis' "Deviance Disavowal" (1961), Wright's Physical Disability–A Psychosocial Approach (1983), and Murphy's The Body Silent (1990). In a study recognized by Murphy as one of the best in exploring interaction between people with and without disabilities, Davis discusses interaction between people with and without disabilities. Interaction is threatened by focusing exclusively on the disability, interrupting interactional and conversational boundaries, being uncertain about abilities and disabilities, and sensing ambiguity about capacity in certain kinds of activities. Through deviance disavowal, the person with the disability tries to normalize interaction through various strategies, with or without success. Davis also emphasizes the important point that people have difficulty voicing their feeling and thoughts in awkward interactions. Thomas (1982) and Wright emphasize the importance of research about interactions, but stress that they will always vary according to the nature of relationships and encounters. Thomas observes:

> That this does occur is not deniable, but as an image of interaction it neglects the disabled person as a skilled co-manager of interactions and also neglects the vitally important point that the majority of our *significant* relationships are not of the casual, ephemeral kind, but are with people with whom intimacy, friendship and trust are built up over time. Disabled people have a wealth of experience to bring to new relationships and while we can be uneasy at a first meeting, our greatest allies will be disabled people themselves who appreciate our feelings and can help us through any awkward phase. (pp. 59-60)

Roles and responses vary in interactions with family members, friends, acquaintances, professionals, and others; and identity is created within interactions. As Davis suggests, interaction and identity presentation are not passive but active. Davis' and Goffman's (1963) works tend to focus more on individual defectiveness and deviance that influence life experiences and research (Wright, 1983).

Interaction and marginality

Interaction is the crucible for the ways women experience disability, which may be influenced by conditions of marginality. Hall et al. (1994) clarify the position that the process of marginalization is not oppression, alienation, stigmatization, or segregation but may involve these processes and provide useful insights for exploring experiences. In "Disability and Ethnicity in Conflict: A Study in Transformation," Phillips (1988) describes a marginalization process in the life of Margaret, a young girl who had polio at the age of 7. She experienced stages of marginality in which she felt distanced from her community through lack of involvement in dance traditions and by negative perceptions about her capacity for gendered roles in marriage and motherhood. Because of this, she retreated and withdrew from all community activities. Through "renegotiation" (p. 209), she established her own identity through playing the piano and identifying with her ethnicity and community; and in "emergence" (p. 211), she fully established her identity. Lived experiences of women with disabilities are given little theoretical attention in the literature regarding experiences of marginality (Asch & Fine, 1988; Deegan & Brooks, 1985; Fine & Asch, 1988; Hillyer, 1993; Morris, 1994a; Phillips, 1988; Whyte & Ingstad, 1995). Investigating experiences, or inner stories, of marginality in the lives of women with disabilities can bring their identities and interactions to the center of relevant research. Particularly, in the disability-related research and practice, too much attention has been given to notions of abnormality and normality, capacity and limitations, and definitions and constructions of disability that do not speak to or from lived experiences (Asch & Fine, 1988; Ferguson, 1990; Ferguson et al., 1992a, 1992b; Fine & Asch, 1985, 1988; Hahn, 1983,

1984, 1990; Hannaford, 1985; Higgins, 1992; Hillyer, 1993; Lonsdale, 1990; Lorde, 1984; Malterud, 1993; Morris, 1991; Wendell, 1989; Wright, 1983). People enter margins in relation to invisible centers, or norms (Ferguson, 1990). How margins are experienced varies.

Feminist, critical conceptualizations of marginality

From this review of literature, it could seem that hooks (1984, 1989, 1990), Ferguson (1990), and Hall et al. (1994) do not trace their perspectives about marginality to traditional, sociological conceptualizations but to political conceptualizations of marginality. These conceptualizations of marginality also draw on feminist, critical, and interpretive frameworks (Ferguson et al., 1992a, 1992b; Hall et al., 1994; hooks, 1984, 1989, 1990).

hooks' conceptualizations of marginality

hooks (1984, 1989, 1990) centers on conceptualizations of oppression and resistance to discuss marginality but frequently does not formally cite the theory and literature by which her work is influenced. Throughout her works, she does acknowledge Freire's work as having impacted hers; but generally she does not cite influences upon her work in the traditional sense. In spite of this, her conceptualizations are strongly stated and worthy of focus in this research because of their relevance regarding lived theories and experiences of women. In Feminist Theory: From Margin to Center (1984), she states:

> To be in the margin is to be part of the whole but outside the main body....We could enter that world but we could not live there. We had always to return to the margin, to cross the tracks, to shacks and abandoned houses on the edge of town....

> Living as we did–on the edge–we developed a particular way of seeing reality. We looked both from the outside in and from the inside out. We focused our attention on the center as well as on the margin. We understood both. This mode of seeing reminded us of the existence of a whole universe, a main body made up of both margin and center. Our survival depended on an ongoing public awareness of the separation between margin and center and an ongoing private acknowledgment that we were a necessary, vital part of that whole.
>
> This sense of wholeness, impressed upon our consciousness by the structure of our daily lives, provided us an oppositional world view–a mode of seeing unknown to most of our oppressors, that sustained us, aided us in our struggle to transcend poverty and despair, strengthened our sense of self and our solidarity. (p. ix)

hooks' conceptualization of marginality experience reflects understanding about the social construction of the symbolic universe and the constructions of norms that push certain people and experiences into the margins (Berger & Luckmann, 1966/1967). She recognizes importantly the knowledge and position of the person in the margins. Margins, marginalization, and marginality must be explored from the perspectives of people with experience rather than from those with expertise about them. Physical disabilities can be understood as medical categorizations resulting from impairments to a specific organ or body system that limits activity, but how disability affects people is constructed by them and is influenced by the world in which they live (Hahn, 1983, 1990; Higgins, 1992; Rubin & Roessler, 1995; Scheer & Groce, 1988; Thomas, 1982; Whyte & Ingstad, 1995; Wright, 1983). In fact, abnormality and normality and disability and ability are among the most pervasive categorizations in the symbolic universe (Berger & Luckmann, 1966/1967). In other categorizations, such as gender, ethnicity, and age, constructions revolve around norms, with a range of valuing and devaluing responses. The notion of abnormality and normality seems foundational to all of them.

The Americans with Disabilities Act of 1990 established the rights of people with disabilities to equal access in all areas of public life, but there are many struggles with which people with disabilities are faced (Asch & Fine, 1988; Hershey, 1993; Lisi, 1993; Shapiro, 1993; Treanor, 1993). As Ferguson (1990) points out, we must understand that people's positions and experiences in the margins are highly influenced by invisible, mythical, powerful norms (Lorde, 1984).

Ferguson's conceptualizations of marginality

Ferguson (1990) does not deny the dominance of the center but suggests that people must resist definitions that are created and controlled by it. About marginalized groups, he observes:

> As historically marginalized groups insist on their own identity, the deeper, structural invisibility of the so-called center becomes harder to sustain. The power of the center depends on a relatively unchallenged authority. If that authority breaks down, then there remains no point relative to which others can be defined as marginal. (p. 10)

Certainly, Ferguson challenges the conceptualizations of universality and authority (Berger & Luckmann, 1966/1967) that deny and devalue diverse identities and experiences. Regarding resistance of marginalization, Ferguson asserts:

> We must do this in the face of the omnipresent center, the invisible center which claims universality without ever defining itself, and which exiles to its margins those who cannot or will not pay allegiance to the standards which it sets or the limits which it imposes. (p. 13)

Only individuals themselves can truly define their experiences related to physical disability. Disability must be understood from the perspective of the

person who is living in the world that focuses on ability as a categorization that defines value and influences capacity and activity (Hannaford, 1985; Shaw, 1994; Thomas, 1982; Whyte & Ingstad, 1995).

Hall, Stevens, and Meleis' conceptualizations of marginality

Experiences of marginality among people with disabilities can be explored effectively through the sociopolitical model of disability which is resistant to the medical model of disability (Gill et al., 1994; Hahn, 1983, 1984, 1990; Longmore, 1995). First, it is important to distinguish between the meanings of margins, marginalization, and marginality drawn from the work of Hall et al.:

> Marginalization is a concept emerging from a focus on the characteristics, functions, and meanings of margins–that is, borders or edges. *Margins* are defined as the peripheral, boundary-determining aspects of persons, social networks, communities, and environments. Margins are established in several ways: in contrast to a central point, according to the separations they maintain between the internal and external, or as distinctions between the self and others. From this perspective, persons are viewed as relatively different from the norm or as cast out to varying degrees from the societal "center" to its periphery. *Marginalization* is defined as the process through which persons are peripheralized on the basis of their identities, associations, experiences, and environments. *Marginality* is therefore defined as the condition of being peripheralized on these bases. (1994, pp. 24-25)

Clearly, people with disabilities have been marginalized by others based on identity, association, experience, and environment. According to Hall et al.'s conceptualizations, voice is described as "the language and forms of expression characterizing marginalized subcultures" (p. 31). Voice implies possibilities of being silenced and misunderstood as well as the possibility for expression. If other people speak of and construct the experiences about and for women with disabilities, they remain marginalized. Women who know

disability in their lives are often least heard because of the overpowering voices of those who know about disability.

The places or margins from which women speak and the voices through which they tell their stories are important. Only individuals themselves can truly define their experiences related to physical disability and define and deal with conditions of marginality. About living on the margins as a woman with a disability, Snow (as cited in Pearpoint, 1990) says:

> The margin may be a dangerous place, but at least there you know who you are, and you are not constantly facing disapproval and discomfort....
>
> Living on the edge of chaos changes the people who survive it. You become very aware of the value of things ordinary citizens take for granted; things like having your opinions listened to, having a chance to make a mistake, to be forgiven and to have a chance to try again; things like having friends and family who celebrate holidays with you and who will tell their friends that you are looking for a job. Living on the margin either burns you out and kills you, or it turns you into a dreamer, someone who really knows what sort of change will help and who can just about taste it; someone who is prepared to do anything to bring about change. If these dreamers are liberated, if they are brought back into the arms of society, they become the architects of the new community; a community that has a new capacity to support everyone's needs and interactions. (pp. 123-125)

Hahn (1983, 1984, 1990) has written powerfully for the last several years from a political science perspective regarding the experiences of people with disabilities. He emphasizes:

> From a sociopolitical perspective, which regards disability as a generic concept that may evoke biased or discriminatory reactions from others and which concentrates on effects rather than causes, there appears to be a pressing need to acquire an aggregate measure of the experiences which unite or divide people with disabilities. Unlike other minority groups which are defined genetically or by preference, disabled people have not been able to gain a sense of their own cultural values and common interests. (1984, p. 363)

According to Gill et al. (1994), Hahn (1990), Shapiro (1993), and Longmore (1995), people with disabilities have increasingly identified themselves as a group to confront oppression. Hahn (1990) points out that people with disabilities have often been separated by specific characteristics and a sense of stigma. Zola (1993) asserts that disability experience must be viewed as continuous, fluid, and holistic by all people and researchers if we are truly to understand the nature of disability experience. He states:

> Having a disability is not a fixed status, but rather a continually changing, evolving, and interactive process. It is not something that one is or is not, but instead is a set of characteristics everyone shares to varying degrees and in varying forms and combinations. (p. 30)

In the last several years, the disability rights movement has gained much greater strength as a result of the coming together of people through shared identity and interaction (Shapiro, 1993; Shaw, 1994). No doubt it has been important for people with disabilities to come together collectively to develop strength and power in individual and collective interaction, but disability experience itself does not make people alike in identity or interaction. Shapiro notes:

> I also discovered a unique movement that had much to teach other social and civil rights movements. The disability movement is a mosaic movement for the 1990s. Diversity is its central characteristic. No one leader or organization can claim to speak for all disabled people. It is accepted, as a matter of course, that members of the disability cause will hold shades of belief and not hew to an overriding orthodoxy. All social crusades are made up of people with complex and varying opinions. But today the black civil rights and feminist movements, in particular, are perceived as struggling with such diversity of thought and weakened by challenges to traditional thinking. The result is to diminish our appreciation of the enormous change each cause has brought about. Without one highly visible leader, the disability movement has gone largely unnoticed by nondisabled people. But by its acceptance of differences, the campaign for disability rights has forged a powerful coalition of millions of people with disabilities, their families, and those that work with them. (p. 11)

Conditions of marginality have had direct bearing on the creation of the disability movement.

Marginality, dialogue, and women with disabilities

The experience of marginality cannot be understood without exploring the nature of oppression, liberation, and dialogue. In this discussion, we will focus upon the seminal work of Paulo Freire's Pedagogy of the Oppressed (1970/1993), which has great relevance to the experiences of women with disabilities and will be explored throughout this discussion. Freire asserts that people who are oppressed are treated as objects, as those known and acted upon, and people who are oppressors are in control as those who know and act. Historically, people with disabilities have been literally treated as objects in the Western culture by medical professionals and by others perceived as having all the knowledge and being the experts about disability (Gill et al., 1994; Gliedman & Roth, 1980; Stubbins, 1984; Wendell, 1989). Rarely, in research and practice, are the voices of women with disabilities, who have knowledge and experience, engaged in dialogue (Asch & Fine, 1988; Fine & Asch, 1985; Gill et al., 1994; Hannaford, 1985; Leal-Idrogo et al., 1996; Wendell, 1989). According to Freire, humanization is "the people's vocation" (p. 25). Throughout history, people with disabilities have been treated as less than human. Because of the dehumanization process, oppressors recognize themselves as people and others as things. As Freire asserts:

> This, then, is the great humanistic and historical task of the oppressed: to liberate themselves and their oppressors as well....Only power that springs from the weakness of the oppressed will be sufficiently strong to free both. Any attempt to "soften" the power of the oppressor in deference to the weakness of the oppressed almost always manifests itself in the form of

> false generosity; indeed, the attempt never goes beyond this....True generosity consists precisely in fighting to destroy the causes which nourish false charity. False charity constrains the fearful and subdued, the "rejects of life," to extend their trembling hands. True generosity lies in striving so that these hands–whether of individuals or entire peoples–need be extended less and less in supplication, so that more and more they become human hands which work and, working, transform the world. (pp. 26-27)

False generosity keeps people in their places, and charity efforts that create pity have been resisted in the Western culture by people within the disability rights movement (Hahn, 1983, 1990; Scotch, 1990; Shapiro, 1993; Treanor, 1993). True generosity equalizes opportunity among people with and without disabilities. Even though people with disabilities may reject or resist other people's perceptions of them, conflict is created within individuals and within groups. Freire observes that people who are oppressed internalize the consciousness of the oppressor and experience conflict in making choices, speaking out, and transforming the world in which they live. Freire describes prescription as one of the basic elements between oppressor and oppressed, which represents the oppressor's dominance of choice on the oppressed. Certainly, people with disabilities have been given prescriptions that may not have reflected their choices. Freire describes the pedagogy of the oppressed as:

> A pedagogy which must be forged with, not *for*, the oppressed (whether individuals or peoples) in the incessant struggle to regain their humanity. This pedagogy makes oppression and its causes objects of reflection by the oppressed, and from that reflection will come their necessary engagement in the struggle for their liberation. And in the struggle this pedagogy will be made and remade. (p. 30)

Stages of the pedagogy include the first, in which the oppressed unveil oppression and commit to transformation, and the second, in which oppression is transformed. Through praxis, which includes reflection and action, people are

transformed and liberated. Dialogue is necessary in praxis and liberation with, rather than for, the oppressed. In the education of oppressors, banking is utilized in which teachers fill the students' minds with knowledge that they deem appropriate. In his discussion of that kind of education, Freire describes the marginality experience of the oppressed:

> For the more the oppressed can be led to adapt to that situation, the more easily they can be dominated. To achieve this end, the oppressors use the banking concept of education in conjunction with a paternalistic social action apparatus, within which the oppressed receive the euphemistic title of "welfare recipients." They are treated as individual cases, as marginal persons who deviate from the general configuration of a "good, organized, and just" society. The oppressed are regarded as the pathology of the healthy society, which must therefore adjust these "incompetent and lazy" folk to its own patterns by changing their mentality. These marginals need to be "integrated," "incorporated" into the healthy society that they have "forsaken."
>
> The truth is, however, that the oppressed are not "marginals," are not people living "outside" society. They have always been "inside"–inside the structure which made them "beings for others." The solution is not to "integrate" them into the structure of oppression, but to transform that structure so that they can become "beings for themselves." (p. 55)

Throughout his work, Hahn (1983, 1990) speaks to the dangers of paternalism and viewing the pathology of disability within a person rather than as interaction between the person and the environment. Through a type of "banking" education regarding causes, control and effects of disability, people have been stereotyped and discriminated against within Western culture. Historically, they have been seen as inherently pathological and not acceptable for integration into society and have not been seen as complete, capable beings and thus often treated as "welfare recipients" on the edges of society. About their situation, Hahn (1983) explains:

> By allowing others to seize the principal initiative in promoting disability policies and programs, disabled persons may have missed a rare opportunity to dispel the aura of paternalism which has permeated

> relationships between disabled and nondisabled segments of the population. Disabled persons often have not been permitted to speak for themselves. (p. 43)

In the last 20 years, through legislation and activities of all kinds, we have seen how people with disabilities have developed "conscientizacao" (Freire, 1970/1993, p. 18), or learned to perceive social, political, and economic contradictions and have spoken about them. The pedagogy and the dialogue must continue in the face of oppression and opposition in the fight for freedom, full humanity, and liberation (Shapiro, 1993). According to Freire, people can transform the world through their words, which involve reflection and action in their situations. Certainly, people with disabilities must make decisions and deal with limits to their freedom influenced by a number of factors, which Freire calls "limit-situations" (p. 80). About the vocation of all people, Freire asserts:

> In order to achieve humanization, which presupposes the elimination of dehumanizing oppression, it is absolutely necessary to surmount the limit-situations in which people are reduced to things. (p. 84)

Throughout history, people with disabilities have been reduced to things and have been marginalized and silenced (Gliedman & Roth, 1980; Hannaford, 1985; Rubin & Roessler, 1995; Shapiro, 1993). Through generative themes, Freire (1970/1993) indicates that the realities people perceive can be explored in their thoughts and language. About the nature of such a group's silence, Freire suggests:

> A group which does not concretely express a generative thematics–a fact which might appear to imply the nonexistence of themes–is, on the contrary, suggesting a very dramatic theme: *the theme of silence*. The theme of silence suggests a structure of mutism in face of the overwhelming force of the limit-situations.
>
> I must re-emphasize that the generative theme cannot be found in people, divorced from reality; nor yet in reality, divorced from people; much less in "no man's land." It can only be apprehended in the human-world

> relationship. To investigate the generative theme is to investigate people's thinking about reality and people's action upon reality, which is their praxis. For precisely this reason, the methodology proposed requires that the investigators and the people (who would normally be considered objects of that investigation) should act as *co-investigators*. The more active an attitude men and women take in regard to the exploration of their thematics, the more they deepen their critical awareness of reality and, in spelling out those thematics, take possession of that reality. (p. 87)

Freire's recognition of the theme of silence, of the human-world relationship, and of the need for people to coinvestigate thinking and acting is most relevant to the experiences and personal identity constructions of voice by women with physical disabilities. Transformative dialogue requires love, humility, faith in people, hope, and critical thinking with, rather than for or about, people. Because of the physical, attitudinal, social, and psychological limit-situations they have faced, people with disabilities have often been silenced. Until recently, discussion of their limit-situations by other people has only contributed to the silence of the people with disabilities rather than causing them to speak out. The phenomena of voice and marginality must be discussed in human-world relationships in order to be realistic and relevant. The researcher is not the creator or controller of research, and the women are not objects of research; but they are, rather, coinvestigators through research that strives to increase awareness of reality and self-awareness and genuine dialogue, as envisioned by Freire. In her book, Living Outside Inside. A Disabled Woman's Experience. Towards a Social and Political Perspective., Hannaford (1985) describes her experience with marginality:

> I finally left that place of hidden pain and despair and got back into the mainstream of life, but with a difference; I was now "disabled". I was entering the world of "normal" and "abnormal", and I was soon to find that I was firmly on the side of the "abnormal" divide. It is a strange and frightening experience to leave hospital "different" from when you went in. I somehow expected the world to have changed because my experience of it had, but it was just the same, it was I who had changed. Hospital was

> horrible, but at least you had a place in it, everybody was ill, but out there you were on your own. Life somehow became relegated in the mind as "then" and "now". (p. 9)

Sociological and political conceptualizations are applicable to experiences of women with disabilities.

The interpretive paradigm, voice, marginality, and narrative

Narrative as inquiry

Through the expression of her voice, only a woman with a disability can tell her stories of experience and describe the influences of situations and people in her life. Therefore, research methodology must access the narratives of women with disabilities. Exploring the intersections of disability, race, class, and gender through her words is essential to understanding a woman's inner experience (Asch & Fine, 1988; Fine & Asch, 1985; Gill et al., 1994; Krotoski et al., 1996; Leal-Idrogo et al., 1996; Morris, 1994a; Payne, 1996). Such research can make an important contribution to disability, feminist, and other scholarship through exploration of the phenomena of voice and marginality in the experiences of women with physical disabilities. Through narrative, we can hear the stories of women's lives.

In this discussion, narrative is defined as both story and inquiry (Clandinin & Connelly, 1994, Hall et al; 1994, Hatch & Wisniewski, 1995; Lincoln & Guba, 1985; Polkinghorne, 1995). Clandinin & Connelly (1994) establish this understanding:

> Narrative names the structured quality of experience to be studied, and it names the patterns of inquiry for its study. To preserve this distinction, we use the reasonably well-established device of calling the phenomenon

> *story* and the inquiry *narrative*. Thus we say that people by nature lead storied lives and tell stories of those lives, whereas narrative researchers describe such lives, collect and tell stories of them, and write narratives of experience. (p. 416)

Understanding the purposes and partnership of narrative (Mishler, 1986; Polkinghorne, 1995) is important as well as understanding the perspectives and power dynamics in the narrative (Clifford & Marcus, 1986; Fine, 1994; Foster, 1995; Hall et al., 1994; hooks, 1989).

Through an interpretive paradigm, it must be established that the stories people tell are constructed interpretations of their experiences, and the interpretations of the research from those are just that (Denzin, 1992; Ferguson et al.,1992a, 1992b; Guba & Lincoln, 1994; Randall, 1995). About this type of constructivist inquiry, Guba and Lincoln (1994) assert:

> The aim of inquiry is *understanding and reconstruction* of the constructions that people (including the inquirer) initially hold, aiming toward consensus but still open to new interpretations as information and sophistication improve....Advocacy and activism are also key concepts in this view. The inquirer is cast in the role of participant and facilitator in this process. (p. 113)

Interpretations shift and change and are not definitive or static regarding experience according to the interpretivist paradigm (Denzin, 1989, 1992; Ferguson et al., 1992a, 1992b; Guba & Lincoln, 1994; LeCompte & Preissle, 1993).

Through narrative, participants and researchers are involved in "living, telling, reliving, and retelling our own stories" (Clandinin & Connelly, 1994, p. 418). As Hahn (1983, 1984, 1990) has pointed out, in some research, the attitudes about experiences with disability of researchers are more obvious than those of the people studied. The use of narrative inquiry, in which the voices of both the researcher and the participants are distinct, facilitates actual

understanding of experiences for them and the audience (Clandinin & Connelly, 1994; Fine, 1994; Hall et al., 1994; Hatch & Wisniewski, 1995; Personal Narratives Group, 1989).

Narrative as story

About the telling of the story, Hall et al. (1994) emphasizes:

> Marginalized people often tell through stories, theorize through narratives. Eliciting and analyzing narratives, therefore, provide a channel of communication between the marginalized and the community as a whole. Such inquiry not only constitutes research, but also functions as mediation. Telling one's story without the language constraints inherent in questionnaires and structured interviews is empowering for marginalized persons, because it overcomes the invisibility and silencing they are so familiar with. Most narratives not only relate actual experiences, but also convey interpretive reflections on those experiences. Narratives therefore represent processes of self-inquiry that allow for the sharing of power in research and practice. (p. 38)

Through narratives, people can express their inside stories (Randall, 1995). Such telling can be empowering to them and increase knowledge and understanding of their experiences (Mishler, 1986; Weiss, 1994). The study of experience is foundational to our understanding of unique human beings. For many years, women's voices were silenced and their stories remained untold. It is essential to explore how women construct their identities in the midst of interactions. Only as she tells her own story can the experiences of a woman be revealed.

Concluding thoughts: voice and marginality in the experiences of three women who have physical disabilities

The conceptualizations of marginality as described by Ferguson (1990), Hall et al. (1994), and hooks (1984, 1990) and the conceptualizations of voice as described by Gilligan (1982, 1993), Belenky et al. (1986), Reinharz (1994) and hooks (1989) were used as powerful frameworks for my research exploring the experiences of women with physical disabilities. Through this research, the women's perspectives from their standpoints and contexts of interaction were explored: "The invisible made visible. Our bodies. Our stories. The silenced insisting on Voice. In our own words." (Wade, 1995, p. 39). By utilizing the concept of voice, it was possible to understand how they identified themselves, how they came to know what they wanted to say, how and what they said, and how they were heard as women who have physical disabilities. By utilizing the concept of marginality, it was possible to explore if, and how, women with disabilities experienced marginalization as a process in which they were peripheralized on the basis of their experiences and identity and if, and how, they experienced margins or boundaries related to disability and other aspects of their lives.

CHAPTER III

METHODOLOGY

Introduction

In this chapter, the methodology and research process for this study are explained. A brief review of the project framework, the research questions, and interview guide construction are included. My personal perspective as a researcher and the community nomination process through which the three women were identified, selected, and agreed to participate are presented, followed by a brief description of each of the women. Finally, the four phases of the inductive process used in this project are outlined.

Research question development

The research questions evolved as a result of an extensive, multidisciplinary review of feminist, critical, multicultural, educational, anthropological, disability, and rehabilitation literature. The methodology, in connection with the research purpose, design, and questions, was developed within the framework of an interpretive paradigm. Data analysis and interpretations were also guided by this framework, grounded in feminist and critical theories. The interview guide for the project was developed and refined over a 2-year period. The study focused on the following research questions:

1. How are the phenomena of voice and marginality experienced by three women with physical disabilities?

2. How is disability and its related health and medical issues experienced by the women?
3. What is the nature of the women's interactions with professionals, family, friends, and other people with and without disabilities?
4. What have been the significant events and experiences in the lives of the three women?
5. How do the women construct personal identities in relation to disability, decision making, participation and power in social contexts, and issues of discrimination and oppression?
6. Do margins become sites of repression or resistance in their experiences? If so, how? What situations, if any, are identified by each woman in which she has encountered physical, attitudinal, interactional, and other barriers?
7. How do the intersections of race, class, and gender affect the experiences of marginality among these women with physical disabilities; and how is voice affected by those experiences?
8. How is voice affected by experiences of marginality in different contexts of interaction? Under what circumstances do the women believe that their voices have been heard, been silenced, and/or affected change?

The research questions were established at the beginning of the study; however, my thinking about them has evolved throughout the data collection and analyses processes. Thus, questions two, three, and four sought specific information about each woman's experiences; while questions one, five, six, seven, and eight were intended to identify how the phenomena of voice and marginality operated in each woman's experiences.

Interview guide development

The interview guide was developed to access information regarding each woman's experience as a person in the first interview, her construction of life experiences in the second interview, and her experiences in society in the third interview (see Appendix C). For the second interview, I asked each woman to develop a "construction of life experiences" (Adler, 1927/1992; Clandinin & Connelly, 1994). While not imposing any structure on these constructions, I did provide a few general "demographic" and "construction of life experiences" prompts to aid the women in these constructions (see Appendix C). When we met for the interview, I tape recorded each woman as she shared her construction. Each woman gave me her written construction. For the third interview, each woman was asked about her societal experiences, particularly those connected with voice and marginality, within her contexts of interaction.

During the interview process, I made slight modifications in the interview guide. In the first interview, I realized that the later questions regarding family experience could be asked in the second interview. And, after Hope mentioned her motto in the second interview, I decided to ask the other two women about their mottos. In the third interview, I also decided to ask each woman how disability has affected her daily life and perception of her mission. During the interview process, I believed that the women's narratives would inform my questions regarding the phenomena of voice and marginality in their experiences. Further, as a part of this process, a woman interviewed me, and I prepared my "construction of life experiences." During the interview process, this method allowed me to reflect on my own thoughts and experiences and to recognize similarities and differences in my own experiences and those of the

women in my study. Bracketing my own interpretations enabled me to identify them initially and to revisit them during the analysis process. What I learned will be discussed in connection with the study's conclusion and implications (Chapter V).

Researcher perspective and participation

As a woman with cerebral palsy and as a researcher, I have engaged in this study as part of my lifework. The genesis of the research questions can be found in my own experiences. Questions about social categories of race, class, and gender in relation to the individual and collective experiences of people with disabilities first emerged in my own life in a Memphis rehabilitation hospital during the 1970's. Through this study, my goal has been to construct a multitheoretical framework and research design to explore the phenomena of voice and marginality through the experiences of women with disabilities (Hall et al., 1994; Reinharz, 1994). hooks' Teaching to Transgress (1994) speaks to the importance of theory, foundational to real life and to research:

> I came to theory because I was hurting–the pain within me was so intense that I could not go on living. I came to theory desperate, wanting to comprehend–to grasp what was happening around and within me. Most importantly, I wanted to make the hurt go away. I saw in theory then a location for healing. (p. 59)

Reflecting on her words, I can hear a welcome, if little emphasized, purpose for theory, which connects with my experience and to those of other women. hooks' words led me through and beyond my experiences:

> When our lived experience of theorizing is fundamentally linked to processes of self-recovery, of collective liberation, no gap exists between theory and practice. Indeed, what such experience makes more evident is

> the bond between the two–that ultimately reciprocal process wherein one enables the other.
>
> Theory is not inherently healing, liberatory, or revolutionary. It fulfills this function only when we ask that it do so and direct our theorizing towards this end. When I was a child, I certainly did not describe the processes of thought and critique I engaged in as "theorizing." Yet, as I suggested in *Feminist Theory: From Margin to Center*, the possession of a term does not bring a process or practice into being; concurrently one may practice theorizing without ever knowing/possessing the term, just as we can live and act in feminist resistance without ever using the word "feminism." (pp. 61-62)

I, too, at an early age, began theorizing without the terms and have now come to a new place of exploration with other women who have disabilities. Now, as a result of graduate studies and work experience in rehabilitation counseling, I am able to state that I see my disability as <u>some of</u> rather than <u>the sum of</u> who I am. My self-perception continues to evolve as an always shifting and changing personal construction. Along with the women who participated with me in this study, I am no more static in my identity or experience than any other human being. Thus, this research sought to understand how the women constructed their identities in connection with the phenomena of voice and marginality.

Participant perspectives and participation

Research and personal and professional experiences have convinced me that the voices of women with disabilities have been marginalized and even silenced. Despite autobiographical works, and limited theoretical work, more research is needed to explore and to amplify the voices of women with disabilities, individually and collectively (Asch & Fine, 1988; Atkins, 1982; Browne et al., 1985; Danek, 1992; Deegan, 1985; Fine & Asch, 1988; Rousso,

1985; Willmuth & Holcomb, 1993). Without closely examining the experiences of these women, research and practice fails to include and examine realities from which all women construct real-life meanings.

Three women agreed to participate in this research project. A community nomination process suggested in the work of Foster (1995) and Ladson-Billings (1994) was conducted to gain what anthropologists term an "emic" or insider's perspective on a particular issue or issues. Personal involvement in the disability community and in religious organizations focusing on cross-cultural exchanges resulted in my initial interaction with individuals in the Jamesville area. Relationships and activities provided access to these women with physical disabilities, whom I had not known previously.

Participant descriptions

The three women whom I asked and who agreed to participate in the study were identified as able to provide the "insider" perspective I sought. Because of my familiarity with and activity in the community, I was also perceived by these woman as having an "insider" perspective. We were not previously acquainted until meeting through our community activities. Even though each of the women and I had interacted briefly at these activities, we had not talked to any extent about personal experiences, including those with disability, which affected their lives at different times. None of the women were congenitally disabled. Two of the three women, Hope and Victoria, were actively involved in the disability community, which may have influenced their perceptions of themselves related to disability. One of the women, Samantha, was actively involved in racial reconciliation efforts, which may have influenced how she perceived herself

related to race. As with Wolcott's (1990) study of one person, in this study, I attempted to learn all I could about voice and marginality through these three women's lives. From the interview data analysis and interpretation, much has emerged regarding the women's experiences and the phenomena of voice and marginality. Thus, each of the women had a unique standpoint that informed this study.

Hope Smith

Hope Smith is a White, 34-year-old woman who was first diagnosed at age 21 with multiple sclerosis, a disease of the central nervous system in which the myelin sheath, or nerve fibers, is damaged or destroyed. Because the ability of the nerves to conduct electrical impulses to and from the brain is disrupted, she experiences symptoms such as weakness, numbness, impaired sensation, unstable equilibrium and mobility, and heat sensitivity. She is a wife, a mother, and an active person in her community and church. One year ago, Hope was appointed to the Jamesville Advisory Council, which advocates for people with disabilities, advises the city administration, and participates in community awareness on relevant disability issues. Initially, we met through participation on this council.

Victoria Greene

Victoria Greene is a White, 46-year-old woman who at age 35 began experiencing symptoms of olivopontocerebellar atrophy, a degenerative coordination disorder that affects her speech, manual dexterity, and walking.

After working in restaurant management for several years in a northern state, she currently receives Social Security Disability Insurance and Medicare and lives with her mother and father in Wood County. She is a public awareness coordinator for a local technology center for people with disabilities. Victoria participates actively in the disability community and is involved with councils related to compliance with the Americans with Disabilities Act, disability awareness, and women's health issues. We became acquainted through these disability community activities.

Samantha Johnson

Samantha Johnson is a Black, 52-year-old woman who was first diagnosed with polio that resulted in paralysis at age 9. After surgeries and rehabilitation, she learned to walk again; but scoliosis weakened the capacity of her legs, hips, and back and affected her appearance. Several years ago, she began to experience symptoms of postpolio syndrome with lessening physical strength and increasing pain. Samantha and her husband have grown children and grandchildren. She has been employed with mental health organizations for more than 28 years and has worked as a data entry technician at a community mental health center for many years. An active member in her family, community, and church, she has recently been involved in a cross-cultural, racial reconciliation group in which I also participated.

Narrative research benefits

The methodology was designed to access the narratives of the women through the use of interviews. Qualitative research interviews provide avenues through which people can tell their stories (Clandinin & Connelly, 1994; Mishler, 1986; Riessman, 1987; Weiss, 1994). In Research Interviewing: Context and Narrative, Mishler (1986) describes an interview "as a discourse between speakers and on the ways that the meanings of questions and responses are contextually grounded and jointly constructed by interviewer and respondent" (pp. 33-34). About participation, he states:

> The effort to empower respondents and the study of their responses as narratives are closely linked....As we shall see, various attempts to restructure the interviewee-interviewer relationship so as to empower respondents are designed to encourage them to find and speak in their own "voices." It is not surprising that when the interview situation is opened up in this way, when the balance of power is shifted, respondents are likely to tell "stories." In sum, interviewing practices that empower respondents also produce narrative accounts. There is, however, an additional implication of empowerment. Through their narratives people may be moved beyond the text to the possibilities of action. That is, to be empowered is not only to speak in one's own voice and to tell one's own story, but to apply the understanding arrived at to action in accord with one's own interests. (pp. 118-119)

Narrative research further increases understanding and knowledge among participants, researchers, and inquirers (Hall et al., 1994; hooks, 1989; Mishler, 1986; Reinharz, 1992, 1994; Weiss, 1994).

Research phases

The study involved four phases of qualitative research. In Phase I, the literature review and pilot study were developed and refined as part of my

comprehensive examination. During Phase II, the women agreed to participate in the interview study; and approval was gained from the Institutional Review Board, (The University of Tennessee, Knoxville) to implement the research process (see Appendix D). Data were collected through Phase III, with analyses and constructions of data interpretations completed in Phase IV.

Phase I–development of rationale and present research

Phase I consisted of an extensive literature review and synthesis regarding the phenomena of voice and marginality and a pilot study conducted during my doctoral comprehensive examination process. Synthesis of the related literature was presented in chapter II.

The purpose of the pilot interview during Phase I was to explore the phenomena of voice and marginality through the experiences of one woman who had a physical disability. The woman and I met for two rather than the one interview session I had anticipated. As suggested by Mishler (1986) and Weiss (1994), data were collected and analyzed, utilizing the framework of the interview guide. The pilot interview and interview guide were developed for my doctoral comprehensive examination, and the results do not appear in this dissertation (see Appendix A). The research questions for this present study emerged from my long-term research interests and results of the pilot interview process and an extensive review of the literature. Based on the pilot interview process, I developed an initial interview guide for the study; and I projected that three interviews would be necessary with each woman (see Appendix B).

Phase II–community nomination and legitimization processes

During Phase II, the community nomination and research legitimization processes occurred. After approval was received from the Institutional Review Board at the The University of Tennessee, Knoxville, I presented the research project prospectus and reviewed the methodology with the doctoral committee. With their recommendations and those of women in the community who have disabilities, I reviewed, refined, and expanded the interview guide for the study (see Appendix C).

Phase III–data collection

At the beginning of Phase III, the three women and I discussed the project in greater depth; and after they agreed to participate, the informed consent forms were signed (see Appendix D). Three interviews of 2 to 3 hours each with each woman were audiotaped. The number and time-length projections of the interviews were based on the interview guide framework and the understanding that more than three semistructured interview sessions would likely produce diminishing returns (Weiss, 1994).

When we discussed appropriate places and times to arrange the interviews, each woman suggested meeting in her home. During the interviews, I made only minimal notes; but during audiotape transcribing and transcript reviewing, I recorded detailed notes and thoughts. The first interview with each woman was transcribed as soon after its completion as possible in preparation for subsequent interviews and data analysis. Before meeting with each woman, I recorded a few notes on the guides, which were sometimes used as prompts,

during the second and third interviews. Questions about the women's mottos, missions, and daily experience with disabilities were added during the interviewing process.

To begin the second interviews, I quoted a statement that each woman made when we met the first time. In the second interview, Hope mentioned her motto, which we discussed; and I later asked Victoria and Samantha about theirs. As requested, each woman completed her construction of life experiences; and we discussed them during the second and third interviews. For her construction, Hope prepared and chose to read her written statement. After she finished, I asked several questions; and she further described her experiences. She told me that she wanted to recopy her statement and gave me a revised version the following December, which varied from what was recorded in the second interview. Victoria prepared her construction by focusing on and typing her response on the demographic sheet (see Appendix C). During the interview, she did not want to read her construction. With her permission, I reviewed and asked questions about her construction. Samantha listed specific information on the demographic sheet and prepared a written statement for her construction. Citing information on her demographic sheet, I asked several questions to which she responded during the second and third interviews. During the data collection and analysis, I continually reviewed and analyzed the women's oral and written constructions of life experiences.

Before we met for the interviews, I asked each woman if she could provide me with medical information about her disabilities, specifically mentioning medical records. The women gave me written and oral information about their disabilities, but none of them were able to obtain records from their doctors. Hope gave me several brochures from the M.S. Society that had been helpful to

her. Victoria gave me information she collected through various sources, including the National Organization for Rare Disorders, the National Ataxia Foundation, and information her sister obtained on Medline. Samantha did not have any information which she could locate, but gave me the address for the Polio Connection of America to which I wrote and received information. Because the women described significant work experiences, it became unnecessary to obtain any kind of written documentation regarding their vocational histories, which I originally anticipated. Since the focus of this research was the construction of identity through the participants' lived experiences and knowledge, the technique of triangulation was not employed.

Phase IV–data analysis

Interview data were analyzed throughout the interviewing and writing processes, but Phase IV included extensive analytic induction, systematic comparison; and typological analysis for grouping data and developing categories and themes (LeCompte & Preissle, 1993; Mishler, 1986; Weiss, 1994; Yin, 1994). Aligned with the research purpose, questions, and interview guide framework, these strategies elicited particular experiences and reflections connected with voice and marginality from the women's narratives. Resulting interpretations from the analysis were based on multiple readings of the transcripts and extensive review of the women's constructions of life experience. As I was initially transcribing, I recorded thoughts and questions about the interviews. After working through some initial analytic induction and typology development, I decided that it was necessary to review the tapes for accuracy. After completing the review process, I continued with the analytic

induction, typological analysis, and systematic comparison of the interview data (LeCompte & Preissle, 1993; Mishler, 1986; Weiss, 1994; Yin, 1994). Transcripts were printed and organized in notebooks for each woman.

Early in the analysis process, I began to develop a framework linking the review of literature and the research questions with what was emerging in the data regarding each woman's voice, or identity construction, and experiences of marginality. After recording some general notes regarding conceptualizations, I began to reread and code each woman's interview transcripts. After reviewing and revised the coding from each woman's interviews, I began focusing specifically on generative categories emerging from the three women's experiences. Gradually, I developed a generative model from the analysis process, with themes coded "mirror," "mouth" (voice) and "margin." With those themes, I reviewed and labeled the women's transcript excerpts.

From those initial themes, I began to construct a single illustrative case study incorporating all of the women's experiences. I refined an analytic strategy for outlining, coding, and merging the data into one illustrative case study with three major themes. To distinguish the women's individual identity constructions and to clarify the themes that emerged from the analysis examining the phenomena of voice and marginality in their experiences, it was decided that individual case studies should be written. During Phase IV, each woman reviewed her transcripts as well as my initial interpretations of the data (see Chapter IV and Appendix E). With this feedback from the women, the case studies were completed focusing on the themes of each woman's personal identity description, personal identity construction, and personal identity location.

CHAPTER IV

DATA PRESENTATION, DISCUSSION, AND FINDINGS

Introduction

My study centered on three women's constructions of their identities in relation to the phenomena of voice and marginality. The chapter includes each woman's case study. The research questions guided the data analysis process, and the resulting interpretations rest within a metatheoretical framework in which the following major themes emerged from the women's experiences in their contexts of interactions:

Theme 1:

Personal Identity Descriptions–how each woman sees herself.

Theme 2:

Personal Identity Constructions–how each woman defines herself.

Theme 3:

Personal Identity Locations–how each woman positions herself.

These themes were created with rather than for the women who participated in the study. The categories from which the themes derived were not predetermined prior to the interviews but developed as a result of the data analyses. In the data presentation, each theme will be explained in connection with concomitant theoretical constructs and then illustrated in relation to the data. The research findings cannot be generalized to the experiences of all women with disabilities but are particularized to the individual experiences of the three women in this study (Clandinin & Connelly, 1994; Dembo, 1974, 1977, 1984). Emerging between and within each woman's story (Randall, 1995), the

themes demonstrate how Hope, Victoria, and Samantha see (personal identity description), define (personal identity construction), and position themselves (personal identity location) within their contexts of interaction. The data suggest that how each woman sees, defines, and positions herself has and continues to develop and evolve. Therefore, the data analysis must be viewed as one interpretation of the experiences of these women, which can be useful in examining the role of voice and marginality in the identity constructions of women with disabilities.

Theme 1: personal identity description

This theme examines how each woman sees herself within her contexts of interaction. The theoretical framework within which to view this theme is symbolic, interpretivist interactionism (Denzin, 1989, 1992, 1994; Ferguson et al., 1992a, 1992b; Guba & Lincoln, 1994). Cooley's (1922/1956a) looking-glass self and Collins' (1991) standpoint conceptualizations also provide lenses for understanding the personal identity descriptions of each woman. The **personal identity description** theme illustrates how each woman sees herself through subcategories identified as her individual profile, personal picture, and standpoint. In her **individual profile**, each woman begins to introduce a self-description that continues to develop throughout the interviews. Each woman mentions particular involvements and initially characterizes herself through certain realities and roles in her life. With her **personal pictures**, each woman discusses significant relationships, which Cooley called primary groups (1909/1956b). Through her **standpoint,** each woman describes experiences in relation to disability, decision making, participation

and power, and issues of discrimination and oppression within her individual contexts of interaction. These standpoints (Collins, 1991) and experiences (Clandinin & Connelly, 1994) have impacted how each woman constructs her voice.

Theme 2: personal identity construction

This theme examines how each woman defines herself within her contexts of interaction. In this study, voice has been defined as a metaphor which represents a woman's personal identity construction in knowledge, by expression, within relationship, and as transformation (Belenky et al., 1986; Gilligan, 1982, 1993; hooks, 1989; Reinharz, 1994). Thus, each woman "named" a dominant aspect of her voice in her contexts of interaction, which correlated with knowledge, expression, and relationship, which has become transformative. The **personal identity construction** theme investigates how each woman has come to define herself through subcategories distinguished as her early foundations, changing orientations, and evolving developments. The significant family; school; and related activities, attitudes, and associations are each woman's **early foundations** (Adler, 1927/1992; Clandinin & Connelly, 1994). Each woman's **changing orientations** are affected by her diagnosis process, experiences with disability, perspectives, and mottos for living. Each woman's **evolving developments** include relevant factors and features of her voice construction developed through and within her contexts of interaction (Belenky et al., 1986; Gilligan, 1982, 1993; hooks, 1989; Reinharz, 1994). From the beginning to the end of the interviews, Hope, Victoria, and Samantha spoke distinctly about their voices. Phrases such as "I say/said," "I

tell/told them," and I explain" illustrated their use of "voice"; while other phrases, found in their individual interviews and constructions of life experiences, refer to their specific identities, interactions, and interests. As suggested by the data, each woman's realities have impacted her identity and interests; while her narrative identifies where she has centered her attention within her contexts of interaction.

Theme 3: personal identity location

This theme examines where each woman positions herself within her contexts of interaction. The **personal identity location** theme explores how each woman positions herself through subcategories identified as her ongoing involvements, significant dialogues, and personal impacts. Her **ongoing involvements** occur within personal and public spaces (Ferguson, 1990; hooks, 1990). Shared understandings and serious issues regarding situations reflect her **significant dialogues** (Freire, 1970/1993). Each woman's **personal impacts** are those that she identifies as influential within her contexts of interaction. As the data suggest, the locations within which each woman places herself can incorporate margins or boundaries and become sites of repression, resistance, and transformation (Ferguson, 1990; Hall et al., 1994, hooks, 1990; Wendell, 1989). Sites of repression are those within the margins where each woman perceives that her voice has not been heard or is silenced. Sites of resistance are those within the margins, through which each woman articulates her opinions regarding the issues that affect her. Sites of transformation are those in which each woman recognizes the impact of her voice coming through the margins (Greene, 1990; hooks, 1984, 1989, 1990).

The thematic analysis was drawn from the stories and statements found within each woman's narrative and her construction of life experiences and provide a glimpse of who she is and what she has experienced within her contexts of interaction. A discussion of each woman's story follows in the order in which she was interviewed.

Hope's story

Hope, a White female, was born in March 1962 and has always resided in Jamesville, a southern city located in the Appalachians. She is a tall woman with blond hair and blue eyes. The "baby girl" of seven children, she considers herself one of ten because her sister's three children lived with the family. Her father was a painter and her mother a homemaker, and she describes them as hard workers. They did not have a washer and dryer, and she remembers her mother singing hymns and never complaining while she washed clothes. Her parents have always lived in the same house, which had one bathroom and two bedrooms when she was growing up.

Hope remembers her early years with her family as fun, noting that friends always wanted to play at their house. She calls the fun they had "priceless" and attributes her attitude to her background. Hope loved playing sports, particularly softball, and was active in school and church activities. Her best friend from childhood and she are still very close. Immediately after high school graduation, Hope and her husband David were married. After two years, Leslie was born; and Hope describes their daughter, now a high school student, as "such a joy to us."

Hope went to nursing assistant school and was the president of her class. When Leslie was about a year old, Hope began to experience numbness in her hands and feet. She visited several doctors, but no one could tell her what was wrong. Based on information in her nursing school textbooks, she began to suspect that she had multiple sclerosis. Her brother-in-law also obtained information from a woman with the M.S. Society. Hope talked with her, and the woman referred her to Dr. Shepherd, who confirmed the diagnosis six weeks later. Her doctor gave her the name Hope because of her positive outlook.

Hope became a private duty nursing assistant at a nursing home. When she experienced increasing trouble with her balance, her doctor eventually recommended that she not continue with her job. She was not eligible for Social Security Disability Insurance (SSDI) because she had not earned enough income hours. David is an electrician, and his insurance has generally covered most of her medications. No longer able to participate in many of her previous activities, Hope discovered that she enjoyed tole painting, which has proven to be both a creative outlet and financial asset.

When initially asked to describe herself, Hope replied that she was a wife and mother, active in church and community activities. She explained, "I have M.S., but it doesn't have me" and "It's <u>in</u> my life, but it's <u>not</u> my life" (emphasis added by researcher). With her involvement and responsibilities, she stressed, "I don't have time to let the M.S. slow me down."

Once diagnosed, Hope was hesitant to interact with people with M.S. because she had known a woman who had what she perceived as a bad attitude. She was also afraid of the unknown and did not want to interact with people who had limitations of varying types. Gaining and sharing knowledge through experiences, she now talks often with people who have M.S. and their

family members. Nominated by her physical therapist, she is an active participant with the Jamesville Advisory Council for the Handicapped. Since the time of the interviews, she has been working with a friend, who has a visual impairment, in his vending business, which is supported by federal vocational rehabilitation funds.

Theme 1: Hope's personal identity description

Hope's individual profile

The personal identity description theme emerged in Hope's narrative and revealed how she sees herself as an active participant within her contexts. Hope's response to the first interview question, "If you were to tell yourself who you really are, how would you do that?" (Belenky et al., 1986, p. 231) showed that she sees herself primarily as a mother and wife. Hope's individual profile reflected how she sees herself through those roles. She also named her involvement as a care group leader in her Sunday School class and as a participant in disability-related community groups, such as the Jamesville Advisory Council for the Handicapped and the Center for Independent Living. She did not mention specifically her experience with multiple sclerosis until later in the first interview. As Cooley (1922/1956a) has suggested, her descriptions do not emphasize physical as much as social characteristics. Hope's individual profile is not linked or dictated by M.S. or her appearance, rather she has developed a looking-glass self (Cooley, 1922/1956a) through which she perceives and interprets her own and other people's judgments of her. Comments about her physical appearance by others are often very different from her own thoughts, which she has not generally expressed:

> They say things like that, "You're so young, what are you doin' in that thing?" (av) And I don't really, I'm not thinkin' nothing mean, but, I'll just smile and say somethin', "I've got M.S." or, you know, but I'm thinkin', "Oh, brother, anybody could, you don't have to be a certain age to be in a wheelchair, or have a disability."

She described herself as "optimistic and real positive." Hope's personal identity description is rooted in her relationships, roles, and the responsibilities within her immediate and larger contexts of interaction.

Hope's personal pictures

Another aspect of Hope's personal identity description is her personal pictures that include the individuals with whom she is most involved, which Cooley labeled a "primary group" (1909/1956b, p. 23). Hope called David her best friend, adding that they do "everything together" with their daughter. Hope was deeply aware of how David and Leslie have always shared her experiences: "It was like he had M.S. My daughter had M.S. too because they went through all this, these things with me." She recognizes that "As far as David and Leslie go, whatever I do affects them. Even if I fall down, it affects them." Hope also acknowledged what her husband and daughter do for her as "beyond the call of duty." She remarked that David describes these activities as "no big deal," believing that she would do the same for him. While her family has seemed mindful of what Hope can and cannot do, she has felt sadness and frustration when unable to play the role and perform the responsibilities of a wife and mother in ways that she would like (Asch & Fine, 1988; Fine & Asch, 1985). Her feelings emerged in this incident with Leslie:

> Well, then it come down to where school was just a day or so away and she got this blue, blue, I don't know, attitude goin' on. And I asked her, I said, "Aren't you excited?" I said, "What's wrong?" And she said something that just killed me. She said, "Well, Mom, who's gonna hold

> your hand?" I said, "What do you mean?" She said, "Well, when you go to the store and you do this and do that," she said, "Who's gonna hold your hand?" That's why she was upset because, I don't know, she probably, had thought in her mind, she had this picture of me stumblin' and carryin' on without her. But I had to assure her that me and her Aunt Cindy were gonna have, "We're gonna go shoppin', (e, av) and do all this stuff and have a good time," and she felt better.

Emotional tensions have lingered for Hope through the years regarding her role with her daughter. Hope's personal pictures revealed that her life is centered around her husband and her daughter and she has been very involved with their activities. Included in her personal pictures are her parents and her family, whom she described as "dysfunctional" in a "Jeff Foxworthy sort of way." Her family's love for humor and fun have continued into adulthood. Hope and her sister Cindy have always been very close. Another significant person she mentioned is her doctor, to whom she has referred many people. Soon after she was diagnosed, she was concerned about whether it would be too much trouble for her family and friends to deal with her wheelchair or if they would be embarrassed. Instead, she found that "I don't feel really like anything's different."

Hope's standpoint

Hope's personal identity description is also revealed through her standpoint (Collins, 1991) that represents her interpretations of experience within her contexts of interaction. This analysis includes her individual perspective and focuses on particular experiences regarding disability, decision making, participation and power, and issues of discrimination and oppression. Reported here are important aspects from Hope's standpoint regarding these experiences.

Disability:

Hope has been keenly aware that individuals focused on her appearance while verbally and nonverbally interacting with her (Davis, 1961; Goffman, 1963; Murphy, 1990; Thomas, 1982; Wright, 1983). She observed:

> You know if somebody just is starin' at you, and I think, "Hello, what's the problem?" (av) If they don't verbally say, "What's, why are you walkin' with a cane?" or "Why are you in a wheelchair?" or somethin' like that, they just stare at you, or maybe it's just like they can't figure out why somebody so beautiful (chuckle in voice) as me and young (bc) is in a wheelchair. That's it. (iw) (bl)

In her mind, she has internally resisted stigmatizing reactions by reflecting on how she sees herself. She also mentioned people smiling at her as if to say, "Bless her heart," which she sometimes resisted in her thoughts with, "What are you smilin' at? I ain't happy today." When people have looked at her as if to say, "Oh bless her heart," her sister has often commented, "Why does everybody smile at you and they don't smile at me?" Hope has used her external interactions with people to educate them about disability and her experience with it. She recognized that individuals have different views about what is "someone else's business," but she made it "her business" to educate people:

> People are ignorant to the fact, they don't know about different disabilities and until like you're educated about different disabilities, you don't know what. People have different expectations for anybody (e) and they don't know what expectations they can have for a person with a disability. I think people with disabilities need to educate people more.

In these encounters, she sees herself from the standpoint of an educator, "I'm ready to tell 'em." Hope admitted that it "drives me crazy" when people say, "You don't look sick." In response to this comment, she has explained that M.S. is a disability rather than a sickness. Hope believed that "Until you help them,

educate them, they don't know" and answering "appearance-oriented"questions is one avenue through which Hope educates.

Decision making:

When Hope has been to some physicians, including those who have treated her eyes and malignant melanoma, she has educated them about M.S. She stated, "I always end up educatin' the doctor" and described educating a physical therapist about her physical capacity:

> I was just goin' with the purpose of them showing me some exercises I could do at home to help maintain muscle, and that sort of thing and I ended up tellin' them. They were wantin' me to do this swim therapy that was so strenuous and everything. I knew, it's not because I don't have the will to do it or the want, to wanta do it. But I really (e) physically am unable to do what they wanted me to do....She said that I wasn't tryin' hard enough. And it wadn't that I didn't have the will, I just could not physically do that. Or I knew, (e) I had more knowledge than she did about a person with M.S.

When Hope returned the next day she noticed that the therapist had a book on her desk about M.S. and had adjusted her expectations. Other situations which have affected her include those in which people have made decisions about her participation in certain activities without asking. She believed this has been because they did not want to offend or inconvenience her, and she has also utilized these opportunities to educate.

Participation and power:

Hope has educated herself and individuals regarding her ability to participate within her contexts of interaction. She has learned to avoid heat, fatigue, stress, and certain conditions and activities to maximize her participation. After she was diagnosed, she was not able to participate in some

of the activities she had enjoyed since childhood, experienced a grieving process, and found new outlets for participation. She decided to utilize her athletic knowledge:

> Well, our team was in last place for a couple years, and then I started coachin' the team myself out of my wheelchair and we was in first place for the next two years. (bl)

Hope's knowledge has given her more power and positively affected her participation within her contexts of interaction. She has educated herself and her family and friends about what she can and cannot do and what she needs and does not need. What she knows has given her power in her experience, "The more you know, the more power I feel like I had over this (e) and it didn't have over me. I knew more about it....It made me feel a lot better." Hope has found people sometimes try to assist her in ways that are not always helpful and actually interfere:

> If I want to get my own wheelchair out of my Jeep they insist (e) on helpin' me and you know, I just tell 'em to knock theirself out. Go for it, you know, if they. (av, bl) I guess it's on my part too that I need to....Maybe it makes them feel better to help me. Maybe if there's some law somewhere that says that they are evil if they stand back and watch a poor little pitiful handicapped girl do it herself. (bl)

As Hope points out, people often not only assume what kind of assistance is needed but also what her personal experience is like. She does not always say what she is thinking. One example occurred when she fell at church one day and a person reacted, "Oh, Hope, that hurt me to see you fall." She was not hurt but was embarrassed and thought, "Here I am the one down here bruised." Looking at her experience from their perspectives, people have said to her, "Oh, if that was me, I don't know what I'd do. I'd just die," to which she responded:

> And I think, "No, you're just like me. You'd just do what I've done. I'm not no." (av)...They act like I'm some strong superwoman, that they wouldn't take it as good as me. But I'm just like they are. And I just had

> to, take it one day at a time. Step by step, baby steps too, you know. I didn't take no big, big people's steps, I took baby steps. (bl) Crawled a lot, did a lot of crawlin'. And you just have to find, find your way.

As suggested by the data, finding her own way has facilitated her power and participation within her contexts of interaction.

Gender:

Hope described disability effects in terms of the individual context rather than gender characteristics and in terms of what a person may or may not give up related to identity, work, and other factors. She suggested that women with disabilities may be offered assistance more quickly than men:

> Well, I really can't say that there's a difference. Personally, I don't know, it's like I was gonna tell you earlier, (iw) say that this was my brother instead of me. I don't know if it would cause a difference in what his job would be, there are different labor jobs. You know, well, not anymore. There are as many women electricians where my husband's workin' as there are men. But I'd say it just, (sigh sound) I don't know, it's a individual thing. I think it just depends on the person and their job and what they have and what they have to give up. (e)

More than focusing on gender as a specific characteristic, she believes "It's a individual thing" and "Just who you are."

Race:

Hope had little to say regarding racial background other than to mention the prejudice of some family members. She commented, "But I don't see where that comes into, that affects it any way. In any way." I decided not to pursue the topic any further. Experiences regarding race did not seem to be germane to Hope's personal identity description.

Class and personal financial situations:

When asked about her financial situation and how it has affected her experience, she responded, "I'd say that I'm very poor." About the same time she was diagnosed with M.S., she, David, and Leslie were involved in a car accident. After 16 years of marriage, they are completing payment of bills from that accident, and she says it is like they are "just startin' out." Her painting has helped to pay some of the bills. Her medications now cost approximately $1,000 a month and are covered by her husband's insurance.

Awareness and issues of discrimination and oppression:

As has been emphasized, Hope has used her experience to promote education about M.S. She had little exposure to people with disabilities and initially avoided them after she was diagnosed:

> I avoided people with M.S. because I was just, for one, I was ignorant about it....If I saw somebody with a cane, it just killed me thinking I might have to walk with a cane or I might be in a wheelchair. I was just afraid of the unknown. (e) That's what I mean by just educatin' myself.

As Hope stressed, one of the ways that she combats inaccurate perceptions of herself as a person with a disability is by projecting a positive attitude because, "I think your attitude (e) rubs off on people." She explained that she does not have a "pity committee" of people who try to do everything for her or feel sorry for her. As some instances illustrate, Hope has sensed less control regarding reactions to her, but she has chosen to educate people through her knowledge and attitude toward her disability.

Conclusion: Hope's personal identity description

How Hope sees herself emerged through her individual profile, personal pictures, and standpoint. Her background and experiences have strongly influenced her personal identity description. In the first interview, Hope quickly named her focal point as knowledge and began to indicate how her voice has developed. Throughout her interviews, she emphasized the importance of knowledge. Her words became a "text within a text" as she talked about specific aspects of her experience with M.S. and how she lives within her contexts of interaction. Hope sees herself as someone who shares knowledge: "If they want to know about M.S., I'm glad to tell 'em. If they don't know about it at all, you know, just educate 'em a little bit." In her personal identity description, elements of her voice construction began to appear through her emphasis on knowledge.

Theme 2: Hope's personal identity construction

Hope's early foundations

The personal identity construction theme emerged in how Hope defines herself as an educator within her contexts. She began to describe how she constructed her voice through her personal identity description by identifying her involvements and interests (Belenky et al., 1986; Rubin, 1983).

The personal identity construction is made up of the experiences which Hope perceives as significant in her past and present. As evidenced in her narrative, Hope's early foundations as a child and years "before disability" (Adler, 1927/1992) impacted her identity. When asked about her family's attitudes and beliefs, she mentioned being taken to church by her mother,

"the Christian attitude," and "the spirit of togetherness." Her earliest memories include family Christmas traditions. She remembered:

> When I was young, we were poor, our family was poor. The things we did, we had so much fun all the time. We had so much fun. And it was priceless. You know the fun that we made, just games we made up and did, you know it's priceless, it's a lot of fun....It's just the joy that you can get out of what we did...it couldn't be bought.

Hope also actively participated in and had a sense of belonging through sports, school, and church. In high school, she did not feel the need to be like everyone else, and said, "I didn't get pressured into anything." Hope described herself as content, which she attributes to the way she grew up:

> I'm content. I've always been content. Maybe it's from growing up in, whatever you had was what you had, and you gotta make the best outta the circumstances, and everything.

Thus, her definition of herself, as a woman who believes that "attitude is everything," is rooted in her childhood experiences.

Hope's changing orientations

How Hope's disability experience changed her orientations was influenced by her adjustments, turning points, and new activities (Asch & Fine, 1988; Ferguson et al., 1992a, 1992b; Fine & Asch, 1985; Higgins, 1992; Wendell, 1989; Wright, 1983). At the time Leslie became a year old, Hope began to notice numbness in her hands and feet, which doctors initially thought might be related to a corn on her toe or a pinched nerve. With no answers, she began to search for her own through nursing assistant textbooks and a book her brother-in-law obtained through the M.S. Society:

> It was just like I had written this book. It was just like, you know, things that I had been tellin' everybody. I thought, "I can't believe somebody else has actually experienced these things too." You know because nobody I

> knew (e) at the time (e) had heard of all these things. It was just like I'd written the book myself.

A woman with the M.S. Society suggested that she see Dr. Shepherd and within 6 weeks, he gave her a diagnosis of multiple sclerosis when an MRI showed scar tissue on her myelin sheath. Hope had suspected M.S., and her doctor was surprised by her response to his pronouncement:

> When my doctor finally said, "Hope, you have M.S." (av) I's like, "O.K." He said, "No, you don't understand, you have multiple sclerosis." I said, "O.K.," (av) (e) you know, "what I have has a name." (e) You know, it wadn't like a big shock to me. I was, actually I was relieved in a way, because it was like, "O.K., now, what, what do I need to do now?" "I have M.S. Okay, what do I need to do?" I was hopin' maybe there was some miracle cure (bl) that they could give me, but no, there's not and yet. (e) You know, it's just like, "O.K., now what do you want me to do?"

Having a diagnosis and knowing she wasn't "crazy," Hope wanted direction and continued to seek knowledge. She said that when she stopped feeling sorry for herself and started feeling better, people around her did so as well. Hope stated, "I think the positive outlook is like a medicine." Hope takes various medications to slow her symptoms, including occasional steroid dosages, and her husband administers a betaseron shot to her several times a week. She uses a walker, cane, and wheelchair, and emphasized that experiences vary:

> M.S. is not a fatal disease. But some of the cause and effect. Some of the things that M.S., just like the kidney infection. You know that can be fatal. Just different things like that. It's a disabling....I can't run, can't walk far, you know, walk big distances, even short distances. I have good days, bad days, good seconds (e) and bad seconds. (e) It's not, you know, you never know. M.S., in particular, is one of the really, the most mind-boggling diseases that there are because it's so different with each individual person.

Educating herself has helped Hope to deal with the unknowns, and learning what she can and cannot do has been important:

> But it's just like now, you know, I do what I can....There's a definition in a book I read for balance. And balance is doin' what you can, and doin' it, doin' it well, and askin' for help on the rest. And that, I live by that.

Another way that she has strengthened her capacity for certain tasks is by maintaining "banking hours" in which she rests and preserves her energy. In her construction of life experiences, she reflected:

> I have to say the emotional part is rougher than the physical part. It's a long hard road. But I'm a Christian and I believe God only allows things to happen for a reason. I don't know what the reason is and that's O.K. All I need to do is let people see God in me. I know he will take care of me!

Part of Hope's journey has been finding new hobbies such as painting to replace other activities. Hope emphasized throughout her interviews the importance of focusing on what she <u>could</u> rather than <u>could not</u> do:

> That's the key. Don't focus on all those things that you can't do. Focus on the things that, you know, "I can do this" (av) or "Maybe I can do this and I'll try, you know."

She also began to see that she could pursue and share knowledge (Dembo, 1974) with people who have similar experiences:

> I wanta help somebody. I just feel like that's one of my missions to help somebody, to make it easier, to make 'em feel better or somethin'. I don't want people to have to go through the gloom and doom and woe is me, and it's the end of the world. I want 'em to know, "Hey, it's not the end of the world." There's life after M.S. diagnosis.

She would like to write a book entitled, <u>I Have M.S., Now What?</u>, and it would be for people with M.S. "just to let 'em know what little things they can do that would help."

As Hope recalled particular experiences and thoughts throughout her narrative, she continued to emphasize knowledge and mentioned particular mottos, which reflect her orientation to life, "Raise cane, that's my motto....I coined that phrase, "Raise cane....I've just got a cane and I know how to use it."

(bl) Other mottos she mentioned seemed to reflect the activities and attitude important to her identity construction:

> There's several little phrases that I've got. Whatever's dealt you, it can make you bitter (e) or it can make you better. (e) You can be a whiner or you can be a shiner. You know? It speaks for itself. You can let things, tragedies turn into triumphs...Is the glass half full or half empty? It depends on what your perspective is, what you want, how you want to see it. If you're a whiner, you could say, "It's half empty, it's almost gone." You know? It's just how you look at things. Your attitude. Attitude is everything.

Hope's evolving voice development in knowledge

The personal identity construction theme emerged through Hope's definition of herself as one who educates people in her contexts of interaction. As evidenced from the data in the first interview, Hope has used knowledge to develop her voice within her contexts of interaction (Belenky et al.,1986). What she has learned is not always visible:

> "You look healthy." "You don't look sick." You know it's not like the flu. Got snot comin' out of your nose (chuckle in voice) and that kinda thing. (bl) And you're not coughin'. They can't see (e) the numbness in your feet, they can't see the fatigue, they can't see your equilibrium's bad, but it's there (e)....People expect things of you. Now, (e) the people that I'm acquainted with and that love me and are friends with me, I've taught 90 percent of them, what I can do and what I can't do. Now they know that I have limits to what I can and can't do, but until you help them, educate them, they don't know.

Two of her key phases include "Knowledge is the key" and "Knowledge is power." Sharing what she knows is important to her:

> I find it easier to talk to people...about their loved ones or friends with M.S. People will call and say, "My cousin or my sister or so and so has M.S." I tell them a little bit, why this person is feelin' this way, what they can expect as far as depression in a person just newly diagnosed.

Disability is not her only area of interest. Reflecting on her input to issues at a school her daughter once attended, she emphasized, "I just know what I know

and I can help with what I do know." She uses her voice to tell people what she knows from her experience, "I will gladly educate (bl) anybody. (chuckle in voice) You know, I don't know all there is to know. But what I do know, I'd be glad to tell everybody."

Conclusion: Hope's personal identity construction

How Hope defines herself, as suggested through her stories and statements, appears strongly influenced by her early foundations, changing orientations, and evolving developments. Through her experiences, Hope has come to define herself as an educator and utilizes her voice to share knowledge within her contexts of interaction. Her voice as an educator has gradually grown stronger within these contexts. Her personal identity construction in knowledge is important because it illustrates how she defines herself through her own experience and expertise (Clandinin & Connelly, 1994; Collins, 1991; Randall, 1995). Hope's voice in knowledge has become a voice of resistance and transformation in her contexts of interaction. How Hope defined herself is grounded in the personal identity locations within which she positions herself.

Theme 3: Hope's personal identity location

Hope's ongoing involvements

The personal identity location emerged in Hope's narrative to show how she positions herself as an involved individual within her contexts. Hope's ongoing involvements in her personal and public spaces affect how she sees and defines herself, and she concentrates most on using her voice in her own immediate family and community. When asked if she has felt invisible, she said

that she did as the "baby girl" growing up with older brothers and sisters. Even though she did not always get to do what she wanted, she admits that she was pampered by her parents. She went on to describe a current sense of invisibility associated with people's perception of her disability and explained that people sometimes seem afraid to ask whether she can participate in an activity, such as horseback riding with her Sunday School class, or assume that she cannot. Reinharz (1994) asserts that voice can be a metaphor for power and powerlessness, and that both can be experienced in a situation, as Hope has found. Among those she mentioned, one significant example focuses on family interactions:

> Well, I do get a little bit aggravated. Sometimes I'll think, "Now, why didn't they ask me to do that?" Or just like, you opened a whole can of worms. (av, bc) No, just like, at Thanksgiving when all the girls and the moms are clearin' off the table and doin'. It's got it's good points and bad points if they don't ask you to help. (bc) But, sometimes I think, "I feel like maybe I'm in the way" or something. I don't like to feel that way. I don't like that feelin' at all. But usually I'll just go in and watch football with the guys or somethin'.

Her use of the words, "a can or worms," indicates that these locations are places in which she has repressed some of her thoughts. At times she has expressed her feelings in the same situations:

> I'll say, "Well, just go on, don't ask me to help or and I won't." (av) and then they just look at me like I have four heads and I just go on with my way.
>
> That's at, like my family's Thanksgiving or Christmas or whatever the occasion is, if it's somebody's birthday. People are cleanin' up or doin' this or doin' that. It's just like they don't want to inconvenience me, (e) but that (e) in itself is an inconvenience to me.
>
> I wanta be included. And it's just like, now my sister, when I go to her house, she don't do this. (e) She's not like that. (e, hc) I go and watch her plant flowers or somethin'. She'll push my wheelchair and tell me exactly where I'm gonna sit and she'll say, "Now you sit there and watch

> me and you can hold on to this rake and do this and do that. You can do that." (e) And I'll say, "Okay." (e) I like that.

Feeling "in the way" is inconveniencing to Hope, and she likes being included. She resists intentional and unintentional exclusion by voicing her opinions. Hope stated that she feels most comfortable in locations where she is involved and is able to contribute through her participation (e.g., with the Jamesville Advisory Council). As she explained, "I can help other people and help myself at the same time."

Hope's significant dialogues

Hope's significant dialogues reflected how she has handled conditions of marginality in her personal identity locations (Freire, 1970/1993; Hall et al., 1994). Once Hope began to gain knowledge about M.S., she wanted to share what she was learning. She began to position herself as part of what Cooley called a "group self." According to Cooley (1922/1956a), "The sense of it is stimulated by co-operation within and opposition without" (p. 209) and produces a sense of solidarity. She has engaged in informal dialogue with people connected through her personal identity locations. One of her missions has been to share her experience with individuals just recently diagnosed and families, "I like to get a hold of 'em and say, you know, just give 'em some pointers." After avoiding support group involvement for several years, Hope took a friend to a meeting and decided to stay and participate with people of all ages and backgrounds. She said that the conversation focused on different resources and "there wasn't a word actually spoken that was about M.S." She felt an affinity with people who seemed like her:

> Everybody was just real normal and it was seein' everybody else with their walkers, canes, and electric mobility, whatever they had. Everybody that

> could walk, walked like me. I mean it felt real comfortable. (e) It wadn't like everybody was watching me walk (e) or everybody was watching each other. It was just like normal, it was like a bunch of people just like me....I don't know a real comfort zone...real comfortable like "Been there, done that, I know what you feeling" (av) (lc) or "I understand that." Real understanding.

As illustrated by her experience, "real understanding" can be found in the margins where individuals share common interests (Freire, 1970/1993).

Although the Americans with Disabilities Act established the rights of people with disabilities to equal access in all areas of public life, there are still many physical and attitudinal barriers (Shapiro, 1993; Treanor, 1993). In some personal identity locations, Hope has positioned herself to educate people about barriers which have prevented her and other individuals' participation (Freire, 1970/1993). In sites where she has been marginalized, responses from individuals have varied. Hope described one encounter:

> I thought, "I'm not gonna park in that handicapped spot so somebody maybe worse off than I am can park there." Well, so I parked in a quote unquote normal person's parking spot and when I got out of the car, I got just really, he chewed me up and spit me out because (e) he said, "Now if I parked in the handicapped place I would have got a ticket, but here you are takin' up my spot when you've gotta license plate and you should be parked in a handicapped spot." And so, I thought, "Uh, (sigh) so the moral to this story is, don't be nice, (av, hc) don't do no favors, if you've, you gotta handicapped sticker and it's yours and you're the one drivin', then you park in that handicapped spot." (hc)

She was "speechless" and silenced by the man's words and did not share her thoughts. During the first interview, Hope stated, "I think that's another taboo thing against people with disability. I think that parking is a huge way that society looks at people with disability."

The data suggest that for Hope, sites of repression, resistance, and transformation can occur within and through the margins she has experienced

(Ferguson, 1990; Hall et al., 1994, hooks, 1990; Wendell, 1989). In her words, she has "raised cane" about physically inaccessible locations. In one store, she explained to a manager that she could not look at clothes because the racks were too close together, and he implied that he had no control over higher management decisions. When she initially decided to complete a comment card, she said that he had the "audacity" to tell her to "put in a good word" for him. She complimented him and the store, but then asked, "Are you hearin' what I'm sayin'?" She went on to say, "You're missin' my point" and "It's not accessible." He implied that he understood because his mother was blind, to which she responded, "It's a disability, yes, but, that's comparin' apples and oranges." He reiterated that he could not change policy, she left frustrated, and has not returned. Hope wrote but received no response from the owner.

In another store, Hope's "raising cane" and "hollerin'" brought results:

> I sew and stuff like that. And I went into Cloth Kingdom, I love that store, and they've got little wood cut outs and stuff there. And I couldn't get up and down any of the aisles because my wheelchair was like a half inch too big, you know. And a half a inch, it might as well be a mile. Well, I went to the manager and I was very upset (e) and she knew I was very upset. (e) And, I told 'em that there were ADA laws now (e)....That the new buildins' were supposed to be accessible, you're supposed to get through every place in the buildin'.

When the store's inaccessibility communicated, "You're not welcome here," she acted on the belief that "The squeaky wheel gets the grease." She expressed her concerns and mentioned her involvement with the Jamesville Advisory Council for the Handicapped, which she believed might have had some impact:

> If you gotta gripe, you need to tell somebody about it because nothin's gonna get done if you just sit and go home and stew about and cry about it and whine....You gotta go straight to the head.

She exercised control by, "Being able to say how you want things done" (Medgyesi, 1992, p. 22). At the time, she believed that the manager was embarrassed because, "I wasn't bein' quiet about it." When she returned, she discovered a different scene with wider aisles and also noticed that one of the employees seemed happy. Hope commented, "This is great....I could get to every little thing." (av) Reflecting on that situation, she stated:

> I think people are willing to help if you just will, if you just kinda give 'em a gentle nudge or a push or whatever. (hc) Slap 'em up side the head, or whatever they need to, "Hello? Wake up, you know." (av)

Hope used her voice to point out how she was marginalized and people responded with changes. In some personal identity locations, Hope has found herself in positions where she spoke out because she believed it was necessary. With and without results, she has let her thoughts be known when she has been marginalized and restricted from full participation.

Hope's personal impacts

The important experiences in Hope's personal identity locations demonstrated where her voice appears transformative. When initially asked about a time when she expressed an idea or an opinion that was acknowledged and that made an impact, Hope laughed and talked about a closet her husband built. She went on to tell about how she led her daughter to the Lord when she was a child, just as her mother had done for her. Hope also recognized her impact in other ways, such as helping families deal with M.S., helping her brother-in-law get a job through a phone call, and by speaking up about inaccessible situations:

> Yes, I think that's a good example, for people other than myself with a disability....I know (e) that it would help other people 'cause I know a lot a

> ladies and men (e) like to sew and do, just different little craft projects and love to go places like that but can't. But now they can. (av)

As the data illustrate, Hope has constructed her voice or identity around knowledge and often helped people by positioning herself as an educator in her personal identity locations. How Hope sees herself and what she does is clearly stated in her mission and reflects how she views her personal impact. Along with helping people and writing a book, she mentioned:

> Well (p) my mission is my family, to provide a good home and be supportive for them and just be a good wife and mother. Outside of my family, I just wanta be a good person and be able to share with anybody that needs help through disability, just any kinda crisis. I just wanta be able to share knowledge about what's out there for the disabled people. Or first and foremost, (e) share God, with my friends and with people that don't know Him. (e)

Hope's mission is consistent with the personal identity description, construction, and location illustrated through her story.

Conclusion: Hope's personal identity location

How Hope positions herself emerges through her ongoing involvements, significant dialogues, and the personal impact of her voice in her interactions with others. In private and public spaces with individuals, she has experienced both repression and resistance. Her voice has become transformative in those locations where she has shared knowledge with people.

Victoria's story

Victoria, a White female, was born on December 6, 1949, in Fernwood, a small southern Appalachian city, which was developed during World War II. Victoria has blonde hair and green eyes and is thin with well-defined facial features. She is the oldest of four sisters and describes her family's experience as "normal" and middle class. Victoria's grandparents and other relatives lived in different areas of the country; and as a result, she and her sisters had little exposure to older people and "intergenerational activities." In her earlier years, she remembered being shy and introverted.

Victoria attended college in a midnorthern state, desiring a "clean break" because "I just did not want to continue being known for what I was in the past." Victoria and her boyfriend married and moved to a northeastern state where he attended graduate school. When she was unable to find a teaching job, she waitressed. After Victoria and her first husband divorced, she remarried and continued working as a supervisor/waitress in a restaurant for "18 years, 4 months, and 6 days."

For several years, Victoria experienced congestion in her throat which doctors attributed to allergies. With increasing difficulties and no answers, she underwent extensive testing at Yale. After 9 months, doctors told her she had olivopontocerebellar atrophy (OPCA) and added that there was nothing they could do for her and that she could expect difficulties with coordination that would affect her mobility, dexterity, and speech. Her ability to waitress was altered much sooner than the doctors projected, and her employers attempted to reduce her work hours. She persisted and continued working full-time to maintain insurance coverage, but was not surprised to be given a "pink slip"

and laid off because of her difficulty with various responsibilities. The following day she applied for Social Security Disability Insurance (SSDI) and was notified of her eligibility more quickly than usually occurs with this form of federal assistance.

Before she was laid off, she had turned to Easter Seals vocational rehabilitation counselors for vocational guidance. They directed her to and provided the financing for word-processing training. While receiving unemployment benefits and seeking new employment, she found that her typing speed did not meet expected rates, and that many jobs also required other tasks, such as answering the telephone, which she could not perform. Eventually she began receiving SSDI and paid for COBRA insurance until shortly before she began receiving Medicare assistance.

In the period during which she was laid off, her husband became increasingly distant and asked for a divorce. No longer able to maintain financial or physical responsibility for her house, Victoria returned to Fernwood to live with her parents, who built a new, more accessible condominium. She expresses appreciation of them as "great people" but states that she never expected to be depending on them for "minimal creature comforts."

Missing her friends and community and church activities, Victoria read, sewed, wrote letters, and volunteered with Recording for the Blind. She experienced a turning point when she attended a forum on health issues and expressed her opinions about comments made by the political candidates. As a result, Victoria became known for expressing herself and has often been asked for input on community health and disability issues. She was asked to serve on the local Planned Parenthood Board because of her interest in pro-choice issues and universal health insurance coverage and the county government's

Americans with Disabilities Act (ADA) Oversight committee because of her expertise on compliance issues.

After reading an article written about Victoria in a local paper, an associate of her father's mentioned her to the staff at the Ability Place, who contacted her. Following the interviews, Victoria was hired as the public awareness coordinator when the position became available. Victoria describes her work as fun, emphasizing that "I actually get paid to raise cane."

Theme 1: Victoria's personal identity description

Victoria's individual profile

The personal identity description theme emerged in Victoria's narrative and revealed how she sees herself as a person with a disability, a "social activist liberal," a participant in her community, and a family member. As Cooley (1922/1956a) has suggested, her descriptions emphasized social more than physical characteristics. Victoria's personal identity description is important because it differentiated how she once saw herself and how she now sees herself. Through her individual profile, Victoria clarified who she was and who she is now and described her experiences before and after disability affected her life. Her response to the first interview question, "If you were to tell yourself who you really are, how would you do that?" (Belenky et al., 1986, p. 231) revealed how she sees herself internally and externally:

> Well, (p) I'm a person with a disability. I don't feel I'm disabled or handicapped. But there are limits (e) to what I can and cannot do. And I'm an activist and I'm one of these people who don't mind speaking their mind, especially when I have nothing to lose....I'm a definite liberal (e) and proud (e) of it. But I'm not just a person with a disability. (av, e) I'm also a person who cares about a number of issues, whether it be women's health or the environment or children. But one thing I know I'm not anymore is a

> supervisor, slash, waitress, slash, cook, slash, you name it, I did it (av, e) in a restaurant, which is what I did for 20 years after college.

Differentiating between her involvements and interests in the present and those in the past marked significant changes in how she perceived and placed herself. When asked how she would describe herself to other people, she reiterated her initial response, "I adamantly feel that I'm not (e) disabled or handicapped. I am a person with a disability." (av) Calling herself a person with a disability rather than a disabled person underscored her personhood while acknowledging her disability-related limits. She identified her ideological standpoint as liberal with interests in several issues. Experiencing disability has been a process:

> Everyone goes through a sorrow period, or a grief period. And everyone (p) eventually, if they don't go crazy in the process, eventually says, "Ohhh, I am who I am." And I have to accept that. And if you don't, (p) you won't survive, without driving everyone around you absolutely nuts. Because they can only feel so sorry for you so long and then they can't deal with you either. So, you become isolated if you allow yourself to wallow in self-pity.

In her individual profile and her personal pictures, Victoria pointed out how her disability experiences affect her family and acknowledged the influence of their responses to her.

Victoria's personal pictures

In Victoria's personal pictures, the immediate people with whom she is involved and places where she has interacted have shifted because of signficant life changes connected with increasing disability limitations. From the past, Victoria includes several friends with whom she shared time and interests in the northeastern state in which she lived from 1972-1993 and with whom she has maintained contact. In her interviews, she also identified herself as "a lover

of kitties" and referred to her cat as "my real friend." She described her parents, with whom she lives, as "great people." Other family relationships were important to her personal identity description:

> I'm not married but I have some wonderful parents and I'm a sister to three sisters and I am an aunt to three nephews and a niece who was born two months ago. That's what I am. (vl, ll)

Her family has been involved in her disability experiences as illustrated in Victoria's description of her interactions with one nephew:

> My 4-year-old nephew hasn't truly figured me out, but when his sister was born in March and I did not go up there, (iw) help with the baby then, he wondered where I was. (vc) So at least he doesn't, at least he accepts me as part of the family, but we have gone to a couple of tourist stops where we use their wheelchairs and he has enjoyed sitting on my lap and pulling around. (vl) But he doesn't really understand, I think why I am the way I am. (vc)

She explained:

> Well, he's asked questions like, "Why do you walk so slowly, Victoria?" I say, "Well, Jay, some people walk quickly and some people don't." (e) (av) (vc) But he'll keep asking that question (vc) and he doesn't understand that there are people who (vl) are not as able as his mother.

Her environmental and social roles, locations, and questions have altered within her new contexts of interaction:

> Well, work in an industry where women are needed, like the restaurant industry. You don't run without women. (vc, lc) (iw) They are your waitresses, they are your cooks. (e) So I didn't have the experiences that these other women had and because I didn't have children, I didn't fit into the Sunday School, mother, teaching role. And because my balance and manual dexterity are such that I can't work effectively in the kitchen, I don't do social activities well. And it's just, "Where do I belong in this community?" (av)

She recognized that "I have problems at church finding my niche there" and has developed other outlets, including various disability community efforts. She said, "My real friends accept me as I am, and put up with my outspokenness."

(vc, lc) How she sees herself appeared associated with making her presence known through the expression of her voice or identity:

> The good fight is that someone has to stand up and say, "Hey, I matter" or "people with disabilities matter." That's the good fight....But the annoying part is you have to keep on doing it and you have to wear them down and you have to fight with them consistently. And you have to make a spectacle of yourself and you have to, and you have to do it, whereas when, before I had a disability, I never had (e) to do it. (e)

People with disabilities were also in her personal pictures, and she believed that her activities have impacted them, "Sure because I'm not just affecting me, I'm helpin' out other people as well....Or potentially other people as well." Specific examples of how this helping occurred will be offered later in the chapter.

Victoria's standpoint

How Victoria sees herself cast in relation to "outside" views emerged through her "inside" standpoint (Collins, 1991) on her experiences with disability, decision making, participation and power, and issues of discrimination and oppression. Two examples of this standpoint involved her contributions to society and differences in what her life once was and is now.

Disability:

Throughout her interviews, Victoria stressed societal conceptions of usefulness and how she sees herself and emphasized that "Society rates you on how much money you can earn; and if all you're doin' is drawin' from disability insurance, you're not of much use to anyone." Victoria described her standpoint on her situation:

> I guess not being able to support myself does get to me. But I'm still mobile enough to drive and work part-time and do a lot of volunteer work. So I feel like I'm somewhat useful. (e)

In our society, physical appearance continues to be a primary avenue for evaluating a person with a disability (Davis, 1961; Goffman, 1963; Murphy, 1990; Thomas, 1982; Wright, 1983). Based on her experiences, Victoria has found:

> They look at the disability first and assume that because of it, that either I've had it all my life or I didn't get good schooling because of it, or that somehow there's something mentally challenged as well as physically, especially (e) when I open my mouth (e) and sound like I do. Unless you keep on pluggin' away at that, at certain things, then you won't get what you want. (e)

She has resisted assumptions by letting people know how she sees herself, and expressing her voice is essential to this process:

> When I meet people, I have to open my mouth and say stuff to prove that I know something they might not know or I may know something that they know, (p) and they just need to know that I know it as well. And I never had to prove to everyone on such a regular basis that I am worthy of respect and that I have a brain in my head. (e)

Decision making:

After Victoria's limitations prevented her from working in the restaurant, she turned to vocational rehabilitation counselors:

> Losing my job was a significant experience, I guess. It meant having to admit that I was of no use to society anymore. It meant having to deal with voc rehab counselors at Easter Seals asking me what I wanted to do when I was asking, "Well you tell me what I can do." They were the experts I thought and they didn't have a clue.

Even though Victoria can no longer be involved in certain activities, she has found new ones and new abilities:

> That type of ability to see that programs are necessary, why they're necessary, and that the public sector should be responsible to this, that the

> private sector only looks at bottom line versus well-being of all its citizens. It's something I will stand up for. (sigh)

Victoria decided to develop expertise and to express her voice in discussions of women's health and disability-related issues.

Participation and power:

Victoria focuses on what she can do and recognizes her limitations and needs. Her participation in some activities has been affected by her disability:

> I don't care so much about not being able to waitress because I didn't really enjoy it anyway, it was a means to an end, but not being able to go hiking or swimming or water skiing or just being able to try out new things...walk long distances to, say, concerts in the park, or that's really limiting socially. (e) Or going to fairs or you know, just knowing I can't do that much walking at those things, limits one's ability to interact with other people. And that's very isolating. I do what I can (e) do, but I also have to accept my limits.

She has often been confronted with people's limited awareness of what she can and cannot do; and while she appreciates their intentions, they sometimes hinder rather than help her. She recognizes people's assumptions that she needs help while noting that they don't offer the same assistance to other people. Victoria stated that she misses her independence but also believes that, "Everyone is interdependent on everyone else. We are never independent totally." (e) Previously, she had little interaction with people with disabilities:

> If you told me 10 years ago I would be doing what I am now, I would have told you that you were nuts. I was like everyone else in America unable to speak to people with disabilities or to relate to them. I remember crying at a nursing home when my college sorority went to sing Christmas carols there. I had never seen old people unable to take care of themselves. Fernwood was so isolated and when I was growing up here, there were no old folks. I do remember going with the Future Teachers of America in junior high to Bryan Hall to see children with disabilities, and left saying that I could never teach those kids.

In her narrative, Victoria refers to how she used to be, how she is now, how she wants to be seen, and people with whom interactions are more awkward:

> People who want to pity me. Or people who just don't want to understand. (e) People who have a preconceived notion about disability and that you can't do anything.

Victoria seemed uncertain about how people really see her:

> I don't know. (vc) I hope they don't pity me. I obviously have it pretty good, materially living with my parents here. There are some advantages to this disorder in that I think before I speak now, mainly because I can't speak as quickly. Some people may want me on committees because I'm the token person with a disability (vc)....Sometimes they say words like, "You're courageous or brave" and I'm like, "No, I'm not. (e) You know I'm just like you." (av, vc) And so people say, "Oh, I could never do what you do if I had your disabilities" and I'm like, "Yeah, you would, if you wanted to remain sane, you would." (av, vc, lc)

She has exercised power by expressing her voice within her contexts of interaction and implies that people remember her not only for what she says but for how she looks, "Commissioners don't forget little blonde women with flowered canes (bl) coming in to tell them off." (bl)

Gender:

When Victoria was asked how she believed women with disabilities are seen, she responded, "I guess they see them as weak or not sufficient or uhm, but basically, I don't know." When asked, "How does that fit with how you see yourself?" she responded:

> I don't know. (vc) I really can't answer. I don't see it as a women issue though more women do have disabilities simply because they live longer. I guess society thinks that they should be quote "cared for."

As a woman, Victoria believed that her identifications were not "real strong" before disability affected her life and that disability could impact some women

more in relation to a husband, children, and a job. Based on her experiences, she expressed strong views regarding women and gender (Asch & Fine, 1988; Fine & Asch, 1985; Hillyer, 1993; Morris, 1991) related to her professional and personal experiences:

> (Ohh-type sound, p, sigh). I really hate feminists, who cry that being a woman is different than being a man. That they have to cry for respect because they're a woman (p, sigh)....or to work harder (e) because they're a woman. I guess because I worked as a waitress and as a supervisor in a restaurant that was predominantly run by women except maybe the manager and maybe a dishwasher....If a man or a manager ever degraded us as women, (e) he woulda lost half his, three quarters of his staff. He needed us. (e) So I never had that experience where I had to prove myself as a woman (e) over a man....So I really, I have a hard time dealing with feminism and disability, though I do find it annoying when doctors say, "Ohh, you're such a good girl." Or you know that, when they pat you on the shoulder or whatever it is that they, that kinda nonsense bothers me.

Victoria suggested that there is no difference in disability experience for men and women and cited common adjustment periods:

> Just disability is disability, no matter what sex it is. And trying to say that my experience is totally (e) different because I'm a woman (e) compared to a man. I think we all go through the grieving period, we all go through the "I can do this" period, we all go through an acceptance period and we all go through a "Hey, (e) I don't care."

Race:

Victoria described an affiliation between African American people and herself based on civil rights issues, which she asserts make a difference in interactions:

> Oh well, I'm White. And the funny thing is more Black people identify with my problems with civil rights than White people do. And that's meant new friendships and that's good, but it's....I think, oh, Black people go out of their way to be more courteous to me than they were before just because of the identity of being in a minority.

She perceived:

> Even though they can't relate to my disability as I can, or as others, people with disabilities can, they can relate to not being able to use the bathroom or use the water fountain and so.

Victoria has connected with African American individuals, not because of her racial background, but because of disability and civil rights issues.

Class and personal financial situations:

Victoria has received SSDI for a few years and receives state medical care coverage that can be applied toward medical necessities. She does not see a physician about her disability needs nor does she take any medications. About her situation, she stated:

> I mean here I am living with my parents. I mean, I never (e) expected to have to live with my parents in order to have comforts, creature comforts, (vl) minimal creature comforts.

As stated previously, she works as a public awareness coordinator for a nonprofit agency for which she is paid and continues to be eligible for SSDI.

Awareness and issues of discrimination and oppression:

According to Victoria, education through interaction and expression is important for dealing with discrimination and oppression and for increasing the public's general awareness of people with disabilities. At the end of the third interview, Victoria made what she called a "profound statement":

> The only way we can get rid of disability discrimination is to start by educating people when they're in school. That we are no different than anyone else. And that we deserve, (e) just by our very being, an education and a place at the society dinner table. Until we acknowledge that the only way this will happen is by getting kids with disabilities in the same room (e) with kids who don't (e) have disabilities, this will never (e) happen (e, qv) because you learn (e) your social skills and how to interact with people when you are young and until the school systems do that we

> probably will be having to do an awful lot of yelling and screaming and ranting.

This statement seems to reveal what Victoria believes is necessary to make a difference in society.

Conclusion: Victoria's personal identity description

How Victoria sees herself emerges through her individual profile, personal pictures, and standpoint as revealed in her interviews and constructions of life experiences. Victoria's past and present experiences also have influenced her personal identity description. She has formed her own views of her contributions to society and has encountered and resisted what she perceives to have been hegemonic views of disability (Glick Schiller, 1992; Gramsci, 1971; Morrow & Torres, 1995). In the first interview, Victoria described herself as an activist who expresses her voice on issues that concern her. Throughout her interviews, she emphasized the importance of expressing herself as a woman with a disability, and she discussed issues which have become important to her. She also described how she has become involved in her contexts of interaction. In Victoria's personal identity description, particular elements of her voice construction begin to appear through her emphasis on expression.

Theme 2: Victoria's personal identity construction

Victoria's early foundations

The personal identity construction theme emerged in Victoria's narrative to reveal how she defines herself as one who expresses her voice within her contexts of interaction (Reinharz, 1994). This definition illustrates how Victoria

would like her voice or identity to be understood by identifying herself as, "I'm an activist and I'm one of these people who don't mind speaking their mind, especially when I have nothing to lose." Victoria's personal identity construction appears to have been affected by her childhood and the years "before disability" (Adler, 1927/1992). The early foundations of her identity were formed in Fernwood, a small city established during World War II where she grew up and which she described as isolated. Community members formed clubs, a playhouse, an art center, and a symphony and did not have the need to go other places for entertainment. Her family was her primary source of interaction, which she described as:

> Oh, normal, (e) average, (e) boring. (e, ll) It was normal, (vc) no one had any problems. Except my second sister, who was cross-eyed, and she had to go in for a couple of operations, but they never corrected her cross-eyedness. And she finally, 5 years ago or so, she found a doctor who could pull her eyes apart, however, she still sees double. But she is married and has a really good career and she's very happy and has been able to overcome her cross-eyedness, and deals with it. And so, other than that, we were a normal family, kids'll, we fought in the car on vacations, (bl) and we went to see a lot of places when we were on vacation. And it was a normal, typical, middle-class family. (vc)

She characterized herself as, "quite shy, but I was a normal kid." She enjoyed learning to swim, ride a bike, play the piano and flute, and hike. As the oldest daughter, she "got stuck babysitting a lot (e) (lc) and hated it." Playing in the high school band was a significant activity for her.

Victoria described her teenage experience as "Not great. Isolating in many respects. Not having the gift of gab, not giggling (e) like teenage girls. It was isolating, (e) you know." She chose a college with a larger ratio of men to women and no religious service attendance requirements in the midnorthern region of the country and because "I wanted it as far away from home as I could

get" and "I wanted no part of anyone from my past, knowing me." Victoria enjoyed her college years, was involved in a sorority, and majored in history. After college, she moved to a northeastern state with her first husband and began waitressing when she could not find a teaching position. After working for many years, divorcing, remarrying, experiencing disability, and divorcing again, she returned to Fernwood.

Consistent with her family's attitudes and beliefs, treating people as valuable has influenced Victoria's interactions:

> We were raised as Unitarians, which means that we were different (vc) than any other religion around and did not deal with Bible school or deal with a lot of discussion about Jesus. We dealt more with how you treat people here on this earth as being of value rather than doing good so that you will get your just reward in heaven. I don't know if that has made my life any more different than anyone else's in terms of how I interact with people, but I certainly don't deal, dwell on what will happen to me after I die. (av, vc, lc)

In the third interview, she added, "I don't think a God is punishing me for some unstated sin I did in the past" and:

> I don't think that I have this disability for some purpose, (e) some divine (e) purpose. I don't think that, (sigh) I don't think that there's a God who predestined bad or good on people or has a will to make (e) people be disabled. And I don't think that he, or she or it comes down and picks on you and says, "You (e) are gonna be disabled and because of it, you will have a purpose (e) to be disabled. It is my divine plan." I don't buy this. (e) I'm sure other people feel that God willed (e) it on them. I don't believe that, so. (vc)

The woman Victoria appears to be now, that is, a woman with "a reputation for speaking out and making waves," contrasts with the shy child she described earlier. She stated, "It's because of my disability that I'm speaking out. And (p) if I didn't have the disability, I wouldn't even be there." (e)

Victoria's changing orientations

Victoria's diagnosis finally came after misdiagnoses and ineffective treatments over a period of several years. Because she had "voice problems," she said that she was asked several times, "Do you have any mental stress going on that sometimes trigger[s] this?" With increasing difficulties and no answers, she underwent extensive testing. In her words, she realized that she was a "basketcase" when several specialists came to her room at one time. When they gave her a diagnosis of olivopontocerebellar atrophy after nine months of testing, she thought, "At least I knew that the doctors knew I wasn't crazy." They also told her:

> "Well, we can't do anything for you." (av) So I walked out of the office and I said, "I don't care if they can't do anything for me as long as it has a name." (chuckle in voice)

She said, "I accepted that they couldn't do anything for it. I don't know why, but I accepted it very easily." (av) At the time, she asked the doctor about the progression of the disorder and later found that the condition progressed more rapidly than he had predicted:

> And I said to the doctor, "Well?" (av) He said, "Well, you're going to have manual problems and you're going to have balance and walking problems," and I said, "But I'm a waitress. (av) How long will this be?" (av) And he said, "(ina. filler) about 5 years." Well, it progressed much quicker and within 6 months I was having problems with manual dexterity and within 2 years I was out of a job. So, every case is different. People who inherit this seem to have it much worse.

Victoria described OPCA as a rare disorder that causes "cell degeneration in the olivo, which are nodules in the nerve endings" that are "dyin' off at warp speed" in the sections of the brain that deal with speech and coordination. Doctors "can't fix" the disorder, which affects people in different ways and at different paces.

Not being able to speak, write, or walk quickly has impacted her life. A "frustrating part" of the disorder for her is not being able to coordinate emotion and speaking. She stated that, "There are some advantages to this disorder in that I think before I speak now, mainly because I can't speak as quickly." She is no longer able to hike, swim, or play her flute but adds that she "can still enjoy music." She says, "Just choppin' up vegetables and preparin' a meal I can do, (av, e) but it takes forever." (av, e) She also mentioned that she can't waitress, take courses, or work in an office in which quick writing and speaking are required. Because of the limitations, she recognizes, "It's really hard (e) to think in terms of findin' employment in quote "the real world." She stressed, "It takes me longer to do everything...the biggest (e) annoyance is just (sigh) every single day, I can't be at the same pace as everyone else." When she is tired, her voice "gets worse," and her walking "gets slower." If she has planned to go out at night, she tries to take a nap to revive herself. Victoria "can still drive just as quickly as anyone else" and is committed to her work and community involvement. Her short-term goal is "just bein' able to do what I can, (e) as long as I can," and she stated, "I don't make long-term plans because I don't know how this disorder will progress."

Because of her limitations, she can no longer participate in some activities and has found others, some which she referred to as trade-offs. She provided this example:

> My parents own a cabin on Shale Lake and I rarely go out there with them. There are times when my sisters come and visit us and they think I should go. But it's hard to get in and out of the cabin and I can't swim anymore and the paths are full of rocks and tree, roots, and I don't always see them in time to catch myself and it's just not a fun place for me to be. So I will trade off that time to clean my room (vc) or write a letter, or read a book or whatever else here at home. And it's a trade-off but, sure I miss going there, but you do what you can do and you accept that, and you try and make it, good a time of it as you can....Well, you use your time according to

> your abilities. And what you use to be able to do, you find other things that you are able to do and you focus on what you are (e) able to do and try and enjoy that to the fullest extent.

Having left behind friends and activities in New Jersey, it took more than a year for Victoria to find new avenues for self-direction and expression. In her construction of life experience, she reflected, "Having to do the good fight is annoying but it has given my life more meaning than when I didn't have a disability." Her motto seems to illustrate her emphasis on expressing her voice:

> Raising cane is good for the soul. (av, laugh in voice) (bl) Treat people with respect and dignity and they will give that back to you. Uhm, hopefully.

Victoria said that her motto was influenced by her usage of two canes, her parents' usage of puns, and her belief in treating people with respect. She also uses her motto to explain to people what she does at the Ability Center, "And I say, 'I'm the public awareness coordinator, which means I actually get paid to raise cane.'" She described her role as:

> My job is to alert the press and the people that we serve about various disability issues. And where we stand on them. There have been several attacks on the, from Congress recently to curtail, programs that help people with disabilities. I don't mind telling congressmen off. (vs, av, e, bl)

Victoria's evolving voice development by expression

As an activist, Victoria has centered the construction of her voice in expression and involvement in issues which affect her life and the lives of other people with disabilities. In the beginning of her first interview, Victoria called herself an activist and asserted the importance of standing up and being counted. She identified a health forum in which she participated as a very influential experience and one through which she "got a reputation for speaking out and making waves." What she described as her turning point came through

interactions with "a bunch of Republican men who I told off at a health reform forum in Gloucester two years ago when I had insurance problems." She found herself thinking, "No, no, no" and expressing her views:

> Well, I basically shot down their theory that if people just ate right, exercised, didn't smoke, didn't drink, didn't do drugs, wore their seatbelt, or didn't inherit their disability, that they would be perfectly okay. (e) And that I was a person who had a disability and I wanted them to have a face to put with their asinine arguments and that I had insurance hassles and that I am unique to all the ones they were talking about and that they should seriously think about tightening up the COBRA laws and that Congress had let the insurance companies walk all over them way too long and only Congress could clean up the mess that they themselves had caused by their inaction. And I was remembered. (bl)

Aware of what she could no longer do, she entered a new arena:

> That got me started on this long road of "raising cane" and informing and educating people about disability issues. That was my biggest turning point because for the first year I was here again, I spent much time reading in my room and had little interaction with people other than to volunteer at Recording for the Blind, which I began 13 months after I moved down here.

Through the exercise of her voice, Victoria began to develop a new power both in her perspective and in her participation within her contexts of interaction:

> Now I do things just so I can hold my head up and say I am somebody despite my disabilities. That means speaking up, not taking no for an answer, but it is a lot of work that is somewhat annoying because people don't expect that I am of any worth to them at first glance. Having to do the good fight is annoying but it has given my life more meaning than when I didn't have a disability. "Raising cane" is good for the soul.

As her narrative illustrates, she is interested in the interactional and physical transformation of society and focuses on improving accessibility for people with disabilities, whether it involves awareness, education, buildings, or health insurance. She also has spoken out at political and community government meetings and in conversations with individuals. Because of her disorder, which she describes as making her "sound drunk," she thinks before she speaks and

plans what she is going to say at meetings. According to Victoria, not being married has influenced how she expresses her voice on issues which impact her life:

> I think someone has to be out there saying, pressing the issues. And who else to do it, but some crazy woman (bl) with a disability, who doesn't have a husband who will be embarrassed by what she's doing. (vl)

By speaking up, she has resisted conceptions of how people become disabled and what is relevant regarding their experiences. Through this process, she has discovered:

> It's so nice to be respected for my abilities, to say what a lot of people can't articulate nearly as much. And they don't have the life experiences; however, with the technology that we now have in this country for medical needs, more and more people will have disabilities and will have those needs.

Victoria's personal identity construction shows how she defines herself through her own experience and expertise and how she has resisted "outside" perceptions of her as a person with a disability and in the situations where she has been affected by those perceptions (Clandinin & Connelly, 1994; Collins, 1991; Randall, 1995).

Conclusion: Victoria's personal identity construction

How Victoria defines herself has been impacted by her early identity foundations, changing orientations, and her evolving development of voice. Victoria expresses her voice because people "need to know firsthand from someone who has a disability." Her voice construction in expression was illustrated throughout the interview process. Victoria's voice has become one of resistance and transformation in her contexts of interaction, particularly in the

community. How Victoria defines herself is grounded in personal identity locations.

Theme 3: Victoria's personal identity location

Victoria's ongoing involvements

The personal identity location emerged in Victoria's narrative to reveal how she positions herself as an activist within her contexts of interaction. Victoria believes that her relationship with her ex-husband altered as her disorder progressed and as he became more concerned about "lookin' out for number one." She described the experience:

> On the night before my divorce I met with my minister who said that she was so tired of hearing men's reasons for breaking up with their wives was because they weren't "intellectually stimulating" enough. She said that I could live though this, and when I watched my ex on the witness stand, I knew that that was not the man I married. She said that I was better than I thought I was and to not let him intimidate me. Now that I don't have a husband I can embarrass I am much freer to do and say things without having to deal with how it might affect his public image or ego.

Thus, her experience with her former husband illustrated sites of repression and resistance in her personal identity.

Victoria's ongoing involvements in personal and public spaces are primary contexts within which she sees, defines, and positions herself. Public spaces include those where she interacts with associates and acquaintances in community organizations and businesses. In the past, she found meaningful church projects with friends where she once lived:

> Making costumes, only because belonging to a group where you help out is so important to not only defining who you are, but also having true friends as a result is so important to human beings. No one ever can live independently truly.

Because she had a different professional and personal experience and identity as a woman, she felt uncomfortable in a women's church discussion group in which "a lot of it was, talking about how women are considered second-class citizens, (sigh) I just could not get into this." (sigh sound) (av, emp, sort of chuckle) Victoria stated that dealing with belonging has been "the hardest part," "feeling like you're not in the way, that you can contribute." She has focused on several issues that affect people with disabilities and believes that it is important for people with and without disabilities to interact:

> Speaking out also landed me on the board of Planned Parenthood because of opposition to health insurance companies paying for abortions as a reason why some wanted not to reform the health delivery system in this country. This involvement on this board is an outlet where I can be part of an entity that isn't disability related.

She emphasized:

> You can be in a community, but not part of a community.
> You can be (p) a-p-a-r-t (spelled) or a different word, part. (vc)

As the above data illustrate, sites of repression, resistance, and transformation have occurred within and through the margins that Victoria has experienced (Ferguson, 1990; Hall et al., 1994; hooks, 1990; Wendell, 1989).

Victoria's significant dialogues

Victoria's significant dialogues seem to illustrate how she has used relationships to handle situations of marginality:

> My relationships with people with disabilities is a true understanding of what it's like to be a person with a disability. (e) And I don't think even parents of kids with disabilities truly understand what their kids are going through. They talk a similar language with other parents and they know their frustrations, (e) but I don't think people really understand what it's like (e) to be disabled until you become so.

Victoria believes that sharing disability experience facilitates understanding and that time and energy do not have to be spent "proving that you have worth and demanding respect from people without disabilities." Victoria has met one other person with OPCA whom she described as "fighting for her dignity" through a National Organization of Rare Disorders (NORD) network. Victoria wrote to some other people but actually visited this woman in another state. Victoria characterized her as "fighting it, unlike some people that I wrote who were very depressed by it all." Through their association, Victoria and this woman are fighting the disorder together. According to Victoria, being involved in the "good fight" is how she has maintained her self-respect, identity, and worth.

Her interest in ADA-related issues has also facilitated understanding and dialogue with people in her community. In one example, at a candidate debate in an inaccessible auditorium, a man who used a cane offered to help her with some stairs. When they both sat on the first row, she discovered that the man had postpolio syndrome and was also a county commissioner. As a result of their interaction, he asked her to become involved with the ADA oversight committee he was organizing to address county accessibility. Once Victoria gained expertise, she began providing input in various situations, and "now they don't go anywhere without me, (vc) (ina. filler) because I'll look at things they won't look at." As illustrated by Victoria's experiences, true understanding is found in the margins where individuals share common understanding based on their experiences (Freire, 1970/1993). In the second interview, she explained what she meant by having "nothing to lose" in connection with her involvement in ADA issues:

> Well, with ADA, it's a law that is not being fulfilled and so if you stand up and be counted and you educate people about the law, you have nothing to lose because they haven't done anything. There's everything (e) to gain and the other thing that you gain is eventually someone has

> to listen to you and you will gain access to that building or that job or whatever and it's good to stand up and be counted. Too many people hide away and too many people commit themselves or their loved ones to institutions rather than fighting to maintain their dignity and their worth and that is good for the soul. (e) (bl)

When Victoria was asked about when she felt her voice was silenced, she responded, "Can't think of any. I get my way." (e) (vc) To illustrate, she told about talking with the major architect in charge of ADA at a government auditorium where she went to an event, and there were no handrails to facilitate her access. At his request, she agreed to meet with him about another project. She reflected, "I can be happy (e) in the fact that at least I know handrails are on the list."

Victoria's personal impacts

Within her contexts of interaction, Victoria concentrated most on using her voice in her community by expressing her opinions. She recognized her personal impact in those situations where she chose to speak out, such as those created by inaccessible buildings and/or services that affect not only her but other people with disabilities. Victoria has utilized her voice in her personal identity locations to "wake up" people:

> I'm always different. And my opinions are different because of my life experience. How does that affect what I say, how does it affect other people? Well, it might (iw) make them uncomfortable, but it might (e) wake them up. (e)

She recalled several examples, including this one:

> I went to a Democratic Women's Club meeting and the county executive was there and he talked about the budget and the great credit rating the county had and on and on. But he said, "I really want those chimes in the courthouse to ring and it'll cost us $30,000." (av) And this one woman said, "Oh, that would be so nice." (av) And I raised my hand and said, "We have

> ADA questions to deal with before you deal with chimes," (av, e) and I think (e) I finally woke them up that ADA is a law. (av, e, vc)

She told the group that they had ignored the deadlines for ADA requirements and wanted to know when the work of creating access for people with and without disabilities would begin. When asked why she thought she woke them up, she said, "I mean no one came to me afterwards, but they sure didn't dispute my ranting and raving." (vc) Victoria's voice, through expression, has become a voice of resistance and transformation within and through the margins of her personal identity locations (Greene, 1990; hooks, 1984, 1989, 1990). According to Victoria, she lets her presence be known:

> Well, it's hard to be invisible when you walk around with two canes with flowers on them. (e) People remember you. So I, invisible? Uh-huh. No. I'm too outspoken to be invisible.

When asked when she had expressed an idea or opinion that had an impact, Victoria replied, "The health forum, I've written some letters to the editor, and people have responded favorably." She mentioned a lecture she presented to students at a university and went on to assert:

> Just my presence at something has an impact on people, just because they don't think that people with disabilities should be involved. They don't know how to deal with people with disabilities so just having, being there is saying, "Hey, I can be a contributing member," has an impact whether it be at a League of Women Voter's discussion or a candidate thing has an impact.

She sees her position as one in which

> I really am (e) an outsider doing education for them, (e) trying to get them to understand, but that doesn't mean I'm an insider so, even though I'm there (sigh) doing something for them.

People with disability experience and interests have recognized Victoria's impact, including her boss at the Ability Place and people in the community with whom she has contact. About her experiences, Victoria reflected:

> Well, I don't focus on what I can't do (e) anymore and try and find things that I can do. And I don't give a damn about how I sound. (vc, lc) About how slowly I move. And people want my input. One other county commissioner who doesn't like to spend money asked me to be on the board of Cool Creek Home Health Care, which is a nonprofit to help people in their homes so they don't have to go into nursing homes. And he said, "Well, with all your perspective of disability issues, I thought you might be interested in this." And I said, "Oh, I'm stretched to the limit, but I'll help out where I can." (chuckle in voice)

When asked about her mission, she quickly replied, "I hate mission statements" and "I don't have a hidden agenda. (vc) Everyone knows (e) my agenda." (vl) She then added:

> They know if they see me coming, I'm going to talk two things: health care or disability or a woman's right to choose. And (vc) they know (e) this, (vc) and if they don't know it now, they'll soon learn. (bl) So, I don't have a main mission in life, (sigh, p) I guess I try and divorce between who and what I am and what my work is.

When asked to clarify, she continued:

> Divorce. Try to separate those two things. And if you're talking about my mission at work, then that's one thing. But if you're talking about my mission as a person, I don't have a mission. (e) I don't have an agenda. (e) I just try to live life without causing any harm to anyone (vc) and try and do some good along the way for my fellow human beings. And I think that's what everyone's mission in life should be. (e)

Victoria's words underscored her statements about how she has used her voice. By expressing herself, Victoria believes:

> There's everything (e) to gain and the other thing that you gain is eventually someone has to listen to you and you will gain access to that building or that job or whatever and it's good to stand up and be counted.

Conclusion: Victoria's personal location

How Victoria positions herself emerges through her ongoing involvements, significant dialogues, and the impact of her voice in a variety of situations. Her personal identity locations have been places where Victoria has experienced both repression and resistance. However, her voice has also become transformative as she has expressed her opinions and demonstrated her expertise to people within her contexts of interaction.

Samantha's story

Samantha, a Black female, was born and has lived in Jamesville, a southern city in the Appalachians, the majority of her life. She is a petite woman with brown eyes and grayish, black hair. Typically, she wears shirts and slacks or dresses that she has made.

Born on August 18, 1943, she is the older of two children, having a sister three years younger. When her parents divorced after she was 3 years old, Samantha was taken to another southern state to live with her father's parents. Early experiences with her grandparents greatly influenced her life.

When she was approximately 8 years old, Samantha came to Jamesville for the summer and, after contracting polio, did not return to her grandparents' home. She had what seemed to be a cold and suddenly became weaker. Unable to walk, she was taken by her mother and stepfather to the hospital and diagnosed with polio. Initially, she was not expected to live and now calls herself "a miracle child." After being paralyzed for a time, she learned to walk again and was in a children's hospital for surgeries and rehabilitation during a 3-year period.

Samantha participated in hospital and home-bound education and eventually continued with public education at a one-room schoolhouse. Samantha completed high school as 20th in her class of 200. People comment that she is smart, and she credits this to the one-on-one education she received. Samantha always wanted to be a nurse and worked toward that goal until she could not pass a physical examination during her senior year and was advised that she should choose another career. With vocational rehabilitation assistance, Samantha attended college for 2 years. When she became pregnant, she went to stay with her father in a northern city.

After her son was born, she returned to Jamesville and began to clean homes. At that time, Black women could not work in public places, such as department stores or restaurants. She again became pregnant, had a daughter, and continued working. Samantha and her husband married in 1967 and had one son. Upon completing vocational training, she began working at a local mental health institution as a pharmacy assistant and was eventually transferred to a community agency. Currently a data entry technician, she has worked for 28 years and hopes to retire within 2 1/2 years.

For many years, Samantha, John, and their children lived in homes with her grandmother, whom she called "my life," until her death. Depressed by the death of her grandmother and separations from her husband, Samantha contemplated but never attempted suicide. Living as a single parent with her children for several years, she worked at establishing open communication with them. Being connected to her children and grandchildren has continued to be important to Samantha. After one separation and a time of reflection, she and her husband reconciled and renewed their marriage vows after receiving

counseling. They had been married almost 30 years until his death after these interviews were completed.

Because of scoliosis, she has experienced pain, particularly in her hip, and eventually was diagnosed with postpolio syndrome as a middle-aged adult. For 8 years, doctors associated her symptoms of weakness with menopause, saying to her that she was "'bout that age."

Her activities have revolved around relationships at home, church, and work. Samantha was asked and became a deaconess in her church, fulfilling a life-long dream. She has taught Sunday School for many years and enjoys teenagers. Samantha has also related easily to coworkers, sharing many experiences and insights with them. A few years ago, Samantha asked God to reveal her purpose, and she believes that she has been and is a peacemaker.

Theme 1: Samantha's personal identity description

Samantha's individual profile

The personal identity description theme emerged in Samantha's narrative and revealed how she sees herself as a "people person" within her contexts. She disclosed how she sees herself through her own self-descriptions and as Cooley (1922/1956a) has suggested, they emphasize social rather than physical characteristics.

Her individual profile shows how she looks at her internal and external selves. Throughout her life, Samantha developed a looking-glass self (Cooley, 1922/1956a) particularly connected with having polio. During the interviews, she relayed several of her experiences with people's responses to her physical appearance and how she saw and now sees herself. Samantha's opening

response to the first interview question, "If you were to tell yourself who you really are, how would you do that?" (Belenky et al., 1986, p. 231) illustrated how she sees herself and her life, "I am a unique person (av, e) because of the incidents that have happened in my life. And it's that I'm just a miracle child." According to Samantha, how she sees herself as an adult is directly linked to her childhood experience with polio:

> By surviving and being able to do the things that I'm now doing, I can look back and say it was miraculous because, I just felt like God had a purpose for me in my life and to end it so early, I couldn't accomplish what He had for me to do and I just feel like I wouldn't be the person that I am today had I not had that experience. (av, e)

She began working in mental health organizations many years ago, and she has shared her insights and experiences with other individuals:

> It's just gone from one thing to another, but never took away my love for people. I'm not (e) a therapist, but you be in the field long enough, you know how to give advice, (e) you can come to me and don't have to pay ever. (e) (ss, bl)

When asked how she would describe herself to others, she stated:

> I'm me. (bl) I wouldn't. (av, e) I'm just what you see is what you get. I'm just me and that's it. I'm a people person.

Samantha's personal pictures

Samantha's personal pictures span her life and include several locations. These personal pictures have impacted how she sees herself. She believed that, "The Lord, has been with me, I guess from the time I entered into this world," and that her relationship with God has been significant:

> I'm just thankful for what has happened to me, how it has happened...how it has molded me as a person. And how it's still molding me 'cause I'm still growing, I'm still learning. The older I get, the more wise I've become. Thank God for that, 'cause I prayed for wisdom (e) and understanding along with it. I just thank God, you know, for what He's done. That's just

> my life and everytime I get tickled, I say, "Gosh, I'm talking more about God"...the older I get the more about God I seem to talk about, but that's my life. That's part of my life. Therefore, in order to speak of my life, I have to speak about the Lord. If anybody don't like to listen, then that's their problem. (ss, bl) I don't force my feelings off on anybody. (e) I just repeat what God has done for me and you know, people can see. I'm a visible (e) sign of what God can do.

Samantha's personal identity description includes the individuals with whom she has been most involved, those Cooley called a "primary group" (1909/1956b, p. 23). She has interacted in roles as a granddaughter, a daughter, a sister, a wife, and a mother and sees herself as, "A flowered pillow because I don't know, my family's so close-knit that each of us play a different role, and we just fill in wherever we're needed." Samantha said that her late grandmother in Jamesville, with whom she and her family lived, "was my life." At that time, Samantha realized that she had more of a sister role with her mother and a daughter role with her grandmother. When she and her husband married, she had two small children, and they had a son. In her construction of life experience, she commented, "The doctors were amazed that I bore three children natural birth due to my scoliosis due to my having polio. It left me very deformed." During times in which they were separated, she became aware that

> I thought I could be both daddy and mama and I come to find out, I'm not a man. (e) I can't be a daddy. So I had to learn how to be the best mom I could be (e) because I couldn't be the daddy.

The children are grown and have children of their own. Because of physical limitations, Samantha has not always been able to keep her grandchildren. Her husband and children have been aware of her limitations and assist her. She has told her grandchildren about her experiences:

> I was in the kitchen and she came over and she said, "Granny? Why you got that big hump in your back?" And I said, "Granny had polio." (av) And I said, "And you don't know what that is." I said, "That's a illness, it's a virus." I said, "And you probably don't know what that is." (bl) And I just

> said, you know....She's five. And I tried to explain to 'em that it was, they know sick, so I said, "It was a sickness. And Granny got real, real sick. And she couldn't walk and then it kind of just messed her body up." And I said, "What you see is what it did." And she understood (e) that.

She cited the impact of these experiences on her life and how she sees herself:

> I think that's what life is all about anyway. If you actually sit and put everything together. It's experiences. That's what makes the person.... in my book.

Samantha's standpoint

Samantha's personal identity description also emerged through her standpoint (Collins, 1991) and includes her interpretations of the life-long experiences with disability, decision making, participation and power, and issues of discrimination and oppression within her contexts of interaction.

Disability:

Since she was a child, Samantha has been aware of the attention given to her physical appearance (Davis, 1961; Goffman, 1963; Murphy, 1990; Thomas, 1982; Wright, 1983). As an adult, Samantha has noticed and responded to people:

> You just know. I don't know (e) how you know, (e) but you just know. It's a look in their eyes, it's an expression on their face (lc) and they be lookin' and you know it. And I'll just go and say, "Well, you know in '52, I had polio" and make it into a conversation and everything. And people feel so, (sound in voice like relaxing) you can see the tension and everything just drop from their faces and they go, "You had polio?" (av) and then they open up the conversation. I open up (e) the door to the conversation so they can inquire, whatever it is that they want to know. And yes, you can tell, it's just a sixth sense that you have. You can tell. And you just want to tell 'em, you know, "Here, let me satisfy your curiosity." (av) (bl) And it doesn't bother me. It used to when I was a kid. It used to, I would hate to talk about it because I didn't like it. And I didn't like what it had done to me. (e) I guess, I was, I wasn't angry, and then maybe I was, I don't know, I just didn't like it. I didn't like myself, I guess is what it was. I was ashamed of

> myself. I was ashamed of the way that I thought I looked to people. (e) Not knowing that people looked beyond (e) your handicaps or your physical appearance.

However, Samantha also has resisted perceptions which do not fit her own:

> Well, (av) usually just as a regular person. And I think it's mainly because the way I come across. And they don't see me as being physically handicapped, maybe mentally. (bl) But not physically handicapped, you know, because I tell 'em, you know, "I'm handicapped." (av) They say, "You not handicapped." (av) "Well, I am too." (av, emp, bl)

Throughout her narratives, Samantha described herself in relation to her disability and her experiences.

Decision making:

Samantha's self-perceptions have changed over the years and having polio affected many aspects of and decisions in her life:

> And good things (e) came out of it....The summer I had polio, I had just learned how to ride a bicycle and roller skate, and I've never been able to ride a bicycle and roller skate since I had polio. And that was sort of depressing and the other depressing thing about it was that when everybody else was out playing, I was in the house. I couldn't play like the rest of 'em, because I couldn't walk, (sc) so that's why I couldn't play. But then too, I was blessed because they didn't think I was gonna live, because all due to their diagnosis, and everything, "She's not gonna live. No way she can live. She's gonna have to be in this iron lung." And I never got in the iron lung, never did anything they said that....And I have defied everything that they said. I just think that's the reason why I am so close to the Lord because He has been so good and that's the only thing I know to do. Ain't been perfect all my life, ain't, still ain't perfect....I've done my wrong doings and everything, but God has always been there for me. You know I've learned a lot. And people say, "Would you go back and change anything in your life?" And I tell 'em, "No," because everything happened for a reason and I think I would not be the person today had I not had polio. I think that (e) was the turning point in my life.

Samantha believes, without polio, that her life could have been very different:

> I know, I think I know, (e) the road that I would have chosen would have not been the same road that I did choose after having polio. I think I would have been more (p) worldly. I would have probably been a prostitute.

Although she did not become a nurse to "repay" what had been done for her, she has always been involved with helping and relating to people.

Participation and power:

Samantha participated in her contexts of interaction by relating to, learning about, and gaining insight into people. Over time, Samantha's view of her life changed:

> It's the way I looked at life then. And I just wanted to have a big ole pity party for myself and everybody. Everybody feel sorry for her 'cause she crippled and she can't do this and she can't do that. (av, crying tone of voice) And that's the way I did it....My grandmama wouldn't make it any better. 'Cause she would say, and I liked it, "Oh, poor Faye." She called me Faye when she wasn't mad at me. "Oh, poor Faye, she's just." Or "Sweetie. She's just had polio and she almost died and the Lord just brought her through." She was really witnessing but I didn't understand witnessing at that time, but she made it worse than what it really was. You know, how people can really pour on the syrup. And she said, "Oh, she just did this and she's so pitiful and she would." And I ate up every bit of it. (av) Enjoyed every bit of it. And that's the way I started feeling about myself, because that's the way she saw it....I wanted to hear it that way. You know I liked that part of it.

Until her children pointed out that she cried all the time as an adult, she had not given much thought to pitying herself. Samantha emphasized that having polio "opened up a lotta doors that ordinarily wouldn't have opened for me," such as her educational experiences. Samantha's ability to relate to people and share insights actually began in her early years because "It [polio] slowed me down, I learned, I had time to learn, I had time to see others, I had time to feel (e) for

others." She has not always been able to participate in ways that she would have liked, but she is involved in many relational activities:

> I sit and I observe people and I listen and I can tell and that's what I do. It's a gift that, you know, the Lord has given me. And I can do that, (e) and it's no problem.

Samantha's capacity for participation with and observation of people has been influenced both figuratively and literally by her experiences with polio.

Gender:

In her interviews, Samantha expressed the belief that women are more compassionate than men and "assess things with more feeling." Samantha expressed these views regarding men, women, and disability:

> Well, (sigh-type sound) how do they treat women naturally, anyway? (e) We're always low on the totem pole, (chuckle in voice) no matter what we are. (bc) I don't think, I really don't think it's a, if you're handicapped, you're handicapped, whether you're male or female. I don't think, I think the handicapped comes first. I don't think it's a gender thing on handicap. I just think they see a handicapped person, (e) whether it be male or female. I don't think there's a difference.

Further, Samantha has recognized how people label her according to gender, race, and disability categorizations.

Race:

Samantha talked specifically about the issues of race and how they have affected her life. Her personal identity descriptions are interwoven with her childhood and adulthood stories of being an African American. She described her feelings regarding several situations:

> I had hurt, (e) I didn't have anger. I had hurt. When I saw the movie Kunta Kinte, that stirred up emotions for me, stirred up hurt feelings for me because I remember (e) being treated like that when I was a kid. And even

> when I was a young adult, and even sometimes now, you know, I've had people to come to my window, and not want me to wait on 'em because I am Black. (e) And you go into a store and just browse through and see don't you get about two people following you. Just do that, you know. That's, you just observe sometimes when you go to a store, and watch 'em watch you. And sometimes I say, "You better be watching that shoplifter over 'ere and leave me alone 'cause I ain't gonna steal nothing." (low voice, like a whisper, lc) You know, and sometime I do that. Just to let them know I'm not crazy, you know. But, you know, it's a hurt, it's a hurtful feeling. It's not that I get angry anymore. I just look at it as being stupidity.

In a recent Christian community reconciliation group with Black and White individuals in which she participated, Samantha noted, "I was made more aware of the unawareness that everybody had about prejudices." From her experiences, some of which will be presented later, she has recognized prejudice:

> When I'm in a prejudiced situation. Like, you know, I was saying, like when, oh by being Black you just know. Trust me, you just know. You just have this weird feeling.

She has resisted negative perceptions of herself by identifying their source:

> And that's the best thing to do because if I find somebody has a prejudice problem or something like that, that's their problem. (av) You know. I'm not going to go out of my way (e, cleared throat) to make them feel any more (e) comfortable or any less comfortable (e) because they have the problem. You know. And in order to solve a problem, you have to recognize there is a problem and you don't treat the symptoms, you treat the cause (e) and once the cause is treated the symptoms'll go away.

More than 25 years ago, Samantha was involved in a coworker sensitivity group in which, "You could say anything (e) that you wanted to." She verbally resisted some of the comments people made about her personal life with, "You don't know me." About the group experience, she recalled, "But then when we came to that last day, we were all laughing and hugging and just loving (e) one

another, you know, because we had worked out our differences." At work, she recognizes the categorizations people use to label her:

> And I'm a Black female, (e) you know. I'm, that's what I am. And that's the way I see myself. Except for when I go to work and I tell 'em, I said, "Y'all hired me since I'm a quota. I'm Black, I'm female, and I'm handicapped." I said, "When you hired me, you hired three in one." (av, ll). Now I'm almost 55. When I get 55, I can say, "I'm a four in one." I'm Black, I'm female, I'm handicapped, and I'm a senior." (ll) And I just love to do that.

By acknowledging categorizations, she has resisted them, "I love it. I love to tell everybody. But see, I don't look at myself that way."

Class and personal financial situations:

Samantha described herself as "not a class person" in terms of how she has related to people, but made no other mention of class itself. She attended college but did not complete her degree after she became pregnant. After having her child, she returned to Jamesville to work:

> I was a domestic. uh, hum. 'Cause that's what I, oh, I loved (e) to clean house, and I did housework because back then wasn't anything for a young Black woman to do other than housework if you didn't have, if you weren't teaching. If you weren't a teacher, if you weren't a nurse, or if you weren't a beautician, there wasn't anything for you to do. (e) Because Blacks weren't being hired in downtown and as, or in, you know, a salesclerk. You didn't work in banks, you didn't, you didn't have no office job or anything, so it wasn't anything to do. So I did what I had to do because I wasn't a teacher, you know, or a nurse, or you know, any professional stuff like that.

She pursued vocational training and has worked with local mental health organizations, many of those years as a data entry technician. She believed, in at least one instance, a promotion, based on her experience and education, should have been offered to her but was not. Looking back and assessing her financial situation, she concluded:

> I've learned how to rob Peter to pay Paul. Like "Peter, you get paid this month." "Paul, you get paid next month." (bl) So, you know, that's the way you do that thing....Had I completed my college and gotten a degree, I would have had a better job. I know that. But since I didn't, I can't cry over spilled milk. You got to make do with whatcha got.

She has been concerned with paying bills and believes that she has what she needs:

> I mean, you know, I enjoy life and I love people. And I don't need nothing, you know, I got the Lord, I don't need nothing else. What else do I need? Riches I don't need because I'm rich in God. So what else do I need? As long as I can pay my bills, my earthly bills, I'm okay. You know I'm fine with it. So, I don't need nothing else. And I'm glad things happened the way it happened. (av, bl)

Awareness and issues of discrimination and oppression:

In a children's hospital, Samantha interacted with people from different backgrounds who had polio. Regarding her experiences with segregation, she said, "I've never been totally apart" and was able "to mingle with all kinda races and you know, different people." She recalled, "I could fit in with the mainstream," when she returned to public school, but it was not without difficulties. She seemed to feel different because of her disability and was sensitive to how she believed other people looked at her (Cooley, 1922/1956a). An encounter with students and a teacher affected how she looked at herself:

> I was ashamed of myself. I was ashamed of the way that I thought I looked to people. (e) Not knowing that people looked beyond (e) your handicaps or your physical appearance, and I had a teacher to tell me when I was in the 8th grade. I was going to a little country school. My mama and them thought it would be best for me to go, and that was like a one-room schoolhouse where you had grade 1 through 6, 1 through 8, I think. And I was in the 7th grade, and Miss Shirley Taylor was her name. She was the teacher and the principal. And a boy put a wasp down my back. I had on a back brace and everything and I had to go into the bathroom and undress, take off my brace and make sure that I wasn't stung or anything and that just killed me. (e) And it made me, you know, just felt like I was different and it made me look at myself differently. And Miss Taylor told me that, she

> took me to the side, in the cloakroam and she talked to me. She said that the guy was cruel and he should not have done that. And that I was no more less of a person now than I was before and that it's not (e) the outside appearance that makes the person anyway. It's the personality, it's the inside and it's what you are from within.
>
> And she told me, she said, "You are a nice lookin' young lady." She said, "You have a great personality." She said, "Develop (e) your personality." She said, "Become the best personality that you can ever have." (e) She said, "This is what you do and people will look beyond your physical appearance and see you." (e) And from that day on, and not that it was easy, (e) but the older I got, the more I understood what she talked about. And that's what happened. My personality supersedes (e) my physical appearance so people see me as Samantha. I mean you know, they don't see me as being a distorted (e) figure. You know they view me as being just, you know, a personality.

Many years after Miss Taylor's death, Samantha recognized the significance of that conversation. Thus, Samantha has encountered and experienced the effects of multiple, hegemonic perspectives throughout her life. Her narrative revealed a personal standpoint which resists "outside" perceptions of her (Dembo, 1974, 1977, 1984).

Conclusion: Samantha's personal identity description

The data suggest that Samantha sees herself emerge through her individual profile, personal pictures, and standpoints. In the first interview, Samantha readily identified relating to people as a focus and told stories about relationships and life-long experiences. Samantha concluded her third interview by reiterating how she sees herself, "I just love people. I'm just a people person."

Theme 2: Samantha's personal identity construction

Samantha's early foundations

The personal identity construction theme emerged in Samantha's narrative to reveal how she defines herself as a "people person" and a "peacemaker." In the first interview, Samantha demonstrated how she constructed her voice in a personal identity description that focused on relating to people within her contexts of interaction (Gilligan, 1982, 1993).

Samantha's personal identity construction appeared to be influenced by her early foundations as a child in Jamesville (Adler, 1927/1992). Her earliest recollection was at age 3 when her sister was born at home, and she tried to see what was happening. Two strong values from her family, "children came first" and "you pay your bills," continue to guide her life.

Several experiences connected with her physical appearance and prejudice from her early years stood out for Samantha. From the time she was a young girl, she interacted with children from different racial groups, but there were boundaries around certain activities. When she lived with her grandparents, she and the White children saw themselves as different from the Mexican children:

> I just remember going to school and playin' with two kids, I can't remember their names. I can see their faces, but I can't remember their names. Just the kids. I remember when we were in Rollins, I remember more of that because that was like 6 and 7 years old, I think. I can remember going to school. I can remember really crazy things, talking about the race reconciliation. My mother, my grandmother was a domestic worker and she worked in private homes. Well, there was no babysitters so she would take me with her when she was workin' when I wasn't in school. And the White kids and I played together, but we couldn't eat in the same kitchen when their parents was there because we had to be separated. But when we was just on our own we could be together so, we were, I was brought

up like, our state at that point was like a melting pot. We had Chinese, we had Mexicans, you had Blacks and you had Whites.

Well, (e, av) the White kids and I were friends and we didn't like the Mexican kids because the conditions that they lived in, you know, it was just like, different, I mean totally different. And it would be like a three-room house and they had maybe 20 or 30 people living in a three-room house. They had a outside toilet, so they wouldn't use the toilet, they would use just the yard and stuff and you couldn't go through their little neighborhood without, you know. And so, it was just funny, when I grew up and found out that, I think, prejudice is a taught thing, and it's a learned thing, you have to learn it because you're not born that way.

I was shocked to come to go any place and find out that I couldn't go where (e) everybody else went. I didn't understand it because the kids and I played together, ate together, talked about the Mexicans together. Chinese people didn't bother us so we didn't we talk about them, but we knew that they were different. And we didn't think that we were different. (e) We just thought we were, the way we was supposed to be and they were different, (e) so you know, I was really shocked to find out that I was also on the other end. Being different. And that's what I remember. That's the reason why I can understand mainly this racial thing because I know how I was. Because they were different. Because they did things totally strange from what I was used to and didn't speak the same language and, you know, and they was just like strange people and we didn't get to know them. So we didn't know if they were good or bad. We didn't know them. So that's what I mainly remember.

Later, she experienced segregation and integration when she was hospitalized:

Everything, yeah, everything was segregated. Hospitals, everything was segregated. Unless you went to therapy and then you went to therapy with everybody, you went to school, we all went to school together in the hospital setting. But we couldn't stay in the same wards.

In high school Samantha believed that girls were prejudiced toward her:

There's prejudice against you from people who are not handicapped. They're prejudiced against you for, you know just 'cause we're different, and there's some females who are prejudiced against you because you're not like they are, I mean. I had girls in school who didn't like me because I was friendly....I didn't have a boyfriend but all the guys hung around me because most of my friends were guys. Well, those girls didn't like me.

She remembered, "I wanted to be like the rest of the girls. I didn't want to be treated like that, but that's the way they treated me." Since Samantha's childhood, how she interacted and related to people have been important to her.

Samantha's changing orientations

How the disability experience changed Samantha's orientations occured as a result of her childhood "turning point" experience with polio, which impacted her interactions, relationships, and perspective (Ferguson et al., 1992a, 1992b; Thomas, 1982; Wendell, 1989; Wright, 1983). As a result of having polio, Samantha has experienced scoliosis all of her life. She wore braces as a child, but has not used any other orthopedic assistive devices. For years, she walked to the bus stop and rode the bus, but now drives her own car to work. In her early 40's, she began losing physical strength and exertion capacity. Before she was accurately diagnosed, Samantha went through 8 years of searching:

> And you go to the doctor and you ask him something. He go, "Well, yeah, that's, you about that age." You know that's what they was telling me the whole time I was in my 40's. I was explaining all this other stuff.

Her mother began to pursue alternative diagnoses after seeing some advertisements and information in the paper regarding postpolio symptoms. Samantha suspected the eventual diagnosis:

> So I went, "'Bout that age, yeah, uh-huh. Fooled you, postpolio syndrome." (sc) And that's probably all the symptoms working together, probably they were right. And the other doctors was right. One was probably playing on the other one. Postpolio was probably playing on menopause. Menopause was probably playing on postpolio. So, you know, it was about the same.

> And they did, gosh how many tests did I have? I had over $4,000 worth of tests done last year. (sl) Nerve damage tests and breathing tests and everything to tell me, "You had a bad case of polio." Like I told him that before I started, but anyway.

Since then, Samantha has taken various medications for polio-related problems and, currently, she takes an antidepressant, which has reduced the pain. At one point, doctors recommended that she have an 18-hour surgery to alleviate pain, which she decided against. Because of the curvature of her spine, physical pain has been a continual part of her experience, which has affected her work capacity. Samantha's days vary according to her physical limitations, and she has had to adjust her expectations:

> It's changing. It's slow, (e) but it's changing. I have to come to grips with it and that's the hardest part. It's because I can look at my mother who's like 20 years older than me and she can do things that I can't do. And I'm saying, "I'm supposed (e) to be able to do that. I'm supposed to be able to keep my grandchildren"....and don't tire me out real good. I can't (e)....So you have to adjust (e) yourself (e) to, you know, your situation. And you know explain a lot.

Samantha's family assists her and reminds her about pacing and modifying activities; and in public places, she has often been "the stroller pusher." With the suggestions of service providers, she has learned to modify and intersperse physical activities with rest and expects to be getting a walker with rollers soon.

Samantha stated that she had never thought about a philosophy of life or a motto, but then said this:

> Philosophy of life, (av) I never thought about. Be what you are, love yourself, accept yourself for what you are, and don't worry about it. (bl)

She reiterated:

> And don't worry about it. That's it. Don't worry about it. And just, the main thing is to put God in your life and you won't have to worry about it. That's, you know, that's the main thing.

Throughout her interviews, she emphasized learning to love herself:

> I just think you have to get to the place where you have to learn to (p) love yourself. And if you don't (e) love yourself, can't nobody else love you. So I had to learn to love myself, to love the way I was, and to accept (e) the way I am because I can't change it.

How she relates to God, herself, and people within her contexts of interaction is integral to her voice construction.

Samantha's evolving voice development within relationship

Samantha appears to have constructed and developed her voice within relationship, a component central in Gilligan's (1982, 1993) work on voice. Her identity and purpose as a peacemaker appear to have developed throughout her life. During the first interview, Samantha quickly defined herself as a "people person." Her narrative included relationships with family members, coworkers, clients at her workplace, friends, church members, and others with whom she had interacted and shared lived experiences (hooks, 1994):

> I relate to my experiences because that's all I have to relate to...and how God wants us to handle it and I go from that point of view. And most of the time, you know, they listen. It works out real well. You know. (clears throat) It came to me. I was here one day and I was meditating, I was praying, I was crying. I was just in one of those moods. And it came to me that I was trying to find out what I was in life, what, what God had for me to do in life and it came to me like, "You're a peacemaker. You make peace."
> I'm a peacemaker.

Throughout her narrative, she recounted several stories in which she had been a peacemaker. Relationships with God and people have been important to her:

> God. He's my resource. People, my resource. Because without God and without people, I never could have, I couldn't have made it. Because, I mean, people are part of my life, and God is, God is my life.

There have been difficult periods in her life, particularly the death of her grandmother and a separation from her husband when she considered suicide. Her relationship with God influenced her responses to depression:

> I'd go through the motions of living and then I prayed and asked God to really (e) come into my life and to really (e) set me free from all that depression that I had. I was on Valium. The doctor told me to take 10 miligrams 4 times a day, and I went, "I ain't taking that. I'm not taking that like that." (av) But I would take like one in the morning and one at night, and I weaned myself off the Valium on the 23rd Psalm. And the 23rd Psalms was my Valium. That's my Valium.

She talked about her love for husband and her children and how she came to see and take care of herself:

> And so now, I say, "It's time for self too, you know." So I'm beginning to get to be an all-round person, you know, because I was just all for everybody else. I did everything for the kids, I did everything for my husband...I could do for anybody else, and I was last on the totem pole. If I got around to me then that was good, and if I didn't, that was good for me, I didn't think about me. And then when the kids started to getting older, well, started getting grown, I realized I had taken care of everybody but me, and it was time to take care of me. I do little things for me now. And I don't feel guilty about it.

After many years, Samantha has seen the importance of taking care of herself in relationships with other people and has developed insights through her interactions. Some people, including family members and coworkers, have called her "weird" and "psychic," but she believes that God has given her insight and an ability to analyze situations:

> I can look at a situation and sum it up and know what's going on and know how it affects me....He's given me that. I can and usually when that happens, I grow from it. And even things on my job or anything, you know, I can see (e) things that should be that are not. I can see the way things should be. And tell somebody about it....But if they don't do it, then it just falls apart. And I think that's a gift that God has given me because (chuckle in voice) one of the therapists told me the other day, told one of my friends that, "She's psychic. She just reads you like a book." (sc) But that's a gift that I have.

Samantha has used her voice to connect with individuals and their situations and is able to identify with them easily through her experiences. She has perceived and played her role as a peacemaker in many situations, including one involving her father and an uncle. This peacemaker role is demonstrated in her interactions with teenagers:

> I'm a people person, and I love people....(clears throat) I enjoy teenagers because I can identify with a teenager. Teenagers and people my age are misfits. They're too old to be kids and they too young to be adults. I'm too old to be a young person, but I'm not old enough to be a senior citizen.

As a peacemaker, she has also been able to see problems from the perspectives of both the parents and the teenagers and has encouraged them to talk with each other. Samantha has not always been aware of her influence on people when she has related stories. Thus, when these same people have returned to thank her, she has "no earthly idea" to what they are referring.

Conclusion: Samantha's personal identity construction

How Samantha defines herself, as evidenced by her narrative, has been affected by her early foundations, changing orientations, and evolving developments of her voice. Samantha has developed and utilized her voice as a "people person." Her personal identity construction is rooted in relationships and her experiences (Clandinin & Connelly, 1994; Collins, 1991; Randall, 1995) and was demonstrated from the beginning to the conclusion of her interviews. How Samantha defines herself is grounded in the locations in which she positions herself.

Theme 3: Samantha's personal identity location

Samantha's ongoing involvements

The personal identity location emerged through Samantha's narrative and revealed how she positions herself as a "people person" and a "peacemaker." On an ongoing basis, Samantha is involved in many personal and public spaces. When asked if she has felt invisible, she responded that she had been in situations where she "couldn't do anything," but then stated:

> I don't feel (e) invisible in any situation because of that reason, of the main reason I have prayer. And prayer works. Prayer goes where nothing (e) can go. So I don't consider myself really invisible anymore.

She added, "I'm visible everywhere (e) through prayer," (av, lc) and because of prayer she has "no boundaries." Samantha believed that her personal and public space is influenced by prayer and has often reminded people, "See how the Lord works."

As noted in her childhood and adulthood stories, Samantha felt left out and different. In certain public spaces, interaction also has sometimes felt awkward:

> The only time I feel uneasy....when I'm not able to communicate. That's the only time I feel uneasy. If I can't find a means of communication, a level of communication, to where I'm just there and everybody is there and they're doing their thing and I'm just like left out. And I don't know the persons or the people well enough to (clears throat) open my mouth. And I have to sit there for awhile. It don't take long....If I can sit and listen for an opening and see where they're coming from, then I'm okay. I don't like to go anyplace by myself where I won't know anybody. (e) Because I feel like it'll take me at least a minute or two, (av) to learn what's going on, but I'll speak. (e) And usually once I speak, I can make a conversation. But then you have some people to whereas you can speak (e) and that's all, they'll just let you speak and they won't let you do anything else. Well, now that's when I get withdrawn, but I don't think it's because of my physical thing, that's just one of my psych, (sc, lc) one of my psycho points. (bc)

Samantha described herself as someone with a strong personality that some people might not like, but she also perceived that to be "their problem." When awkward situations have arisen, she said, "I don't dwell on it. Gosh, I guess if I dwelt on it, I'd be like always in a corner somewhere." (bl) Many of her activities have benefited people (e.g., sewing and serving as a deaconess in her church) and reflected the influence of childhood experiences with her grandparents:

> I'm a deaconess. And I've been a deaconess now for about 4 years and that was the dream of my lifetime when I was a little girl. Came up in the AME Zion Church, which is Methodist and it's African Methodist Episcopal Zion Church....I would see the ladies on the first Sunday, all in white....Almost like nurses, but these were the deaconesses in the church and they served communion. And I was about 4 and I always wanted to be a deaconess. And when I was chosen to become a deaconess, you know that was just like God has answered my prayer, (av) from a little girl. Here I am, that's one of my dreams.

These experiences and relationships are the primary examples for her continuing involvement with people.

Samantha's significant dialogues

Samantha's emphasis on relationships and conversation with people reflects a significant dialogue in which she engages. Samantha has shared her experiences with many individuals and demonstrated her understanding of the effects of polio. For example, in a conversation with her cousin who also has postpolio syndrome:

> She said, "Uh, we just thought we had it licked." I said, "Yeah, we did." I said, "But, that's all right." I said, "God saw us through that and He'll see us through this."

In her interactions with other people with disabilities, she noted, "I can relate." In one example, Samantha told about talking with a young man in her workplace:

> And he gets aggravated sometimes and he says, "I'm in this wheelchair and I." I said, "Listen," and I tell him my experiences. "I've been in a

> wheelchair, okay?" I said, "You're not solely the sole person that's in a wheelchair." I said, "So, you know, I know the capabilities and what you can do and what you can't do, and how you feel when you're in a wheelchair. I've been there," I said, "But you don't take it out on nobody else." (qv) And I talk to him and now I have won a friend. He comes in there everyday, and when we agree, I went, "We're agreeing and that's not good." And he gets so tickled. (av, e) I said, "'Cause we supposed to disagree." I said, "Now something's wrong when you and I agree. (e) Okay." And he loves (e) me to do that.

These narratives indicate how her shared understanding of others' experiences has created communication opportunities in locations where she positions herself.

Although the right of people to equal access has been legally established, individuals with disabilities still face many types of barriers in their own contexts of interaction, including the workplace (Shapiro, 1993; Treanor, 1993). At one point, Samantha was asked to drive to some other work sites and told her supervisor that she could not because of her physical capacity. She does not believe that she has been treated any differently at work because she has a disability and has been "verbally reprimanded" and "written up" along with other people. However, marginalization processes influenced by power structures and notions regarding rights, roles, and responsibilities have affected her experiences (Ferguson, 1990; Hahn, 1983, 1984, 1990; Hannaford, 1985; Wendell, 1989). At times, Samantha has felt overlooked and/or ignored in her job. In 25 years, she has never been promoted and stated that in "key places" there are no Black individuals. Because of this and other situations, she said, "I do get angry (e) sometimes because I see things that should be (e) and they're not." (e) Samantha stated that her work and other contributions have not always been acknowledged, "I didn't care about the pat on the back. I just wanna be recognized for what I do. You know, like I have some sense." As evidenced in

the data, sites of repression, resistance, and transformation can occur within and through the margins of Samantha's personal identity locations (Ferguson, 1990; Hall et al., 1994; hooks, 1990; Wendell, 1989). Samantha's voice has become a voice of resistance and transformation within and through the margins of her personal identity locations (Greene, 1990; hooks 1984, 1989, 1990). For example, she spoke against one decision that she believed to be inequitable:

> I was hurt, everybody got a salary adjustment and I didn't get one. It wasn't a salary adjustment. It was like a reward (e) for doing great work. We had made so much money and the different programs were compensated for the amount of money that they had brought into the center and I did work for countywide. Although I'm a James County employee, I did work for the people who got the raises (e) and I didn't get one....On top of that, I had finally got this nice little office with a window (e) and was right near everything and here comes a new employee who was going to be whatever Bill was, and they took my office. On top 'o all this other stuff, and that was just a little bit too much for me. And I got really, really, really angry and I started crying, and I just told 'em, "I will not be here tomorrow. Tomorrow, I'm taking a mental health day. And I stayed here and I cried and I prayed and I cried and I prayed, that was on a Thursday. And Friday I said, "Well, I done had my pity day so I'll go on back to work." (av, lc) So I went back to work. They started packing in the little office, and everybody was coming in and they had all long faces and everything and they said, (cleared throat sound uhhm) "How you doing?" (av) I went, "Oh, I'm fine." (av) "How can you be fine with all this going on?" (av) I said, "Well, I had my pity day, my pity party yesterday, and I prayed and the Lord said, 'You've had your pity party. Now put it behind ya. And go ahead and get on with your life.'" I said, "So here I am, bright-eyed, bushy-tailed, ready to go." (av) And they looked at me and went, "You're amazing." (av) And I went, "No, you just pray, you get your answer and you do what you have to do, you know, and go on about it."

Eventually, she expressed her opinion to the administrators:

> But I wrote a letter and I wanted a interview. I wanted a interview with the heads to let them know how I felt and I told 'em. And they said, "Well, we not gonna be able to give you the money." I said, "I don't want the money. I just wanta make my point." And I thanked 'em all for listening and told 'em how dumb I thought they were, in a nice way, and that how they don't do things the way it should be done, that they do things backwards and

> quote "and they got the degree." And I don't have mine, but I can see things that they should do that they aren't doing. And they don't want to listen to the people who can tell them what to do, you know, and how it should be. "So I voiced my opinion, so thank you for listening and I'll go ahead on and get to work." (av)

In this location, Samantha resisted the people with power in her workplace and let them know how she believed things should have been (Medgyesi, 1992). She did not get the "reward" that others received, but she voiced her opinion, which was "the main thing" she wanted to do.

Samantha's personal impacts

Particular situations in Samantha's personal identity locations demonstrate where she believes her participation is influential. Samantha was able to identify her impact on various relationships and contexts, including her family. For example, Samantha's daughter was asked to be a deaconess in her church, continuing the legacy of her mother:

> I thank God because it's a blessing that you can look around and see that, "Hey, all your work wasn't in vain." I'm just so prouda her I don't know what to do, but I thank God that we both worked and served together. That's a blessing.

She pointed out that she had not always been aware if she were making an impact, but then understood later that she was:

> I didn't think that they were listening and that they observed it or heard anything I said. And then years later, I hear them repeating something that they learned or I had said. That's the main thing that stands out, when I see one of my children who were then children that are grown now, repeat something or do something that I know that I had a contribution.

Recognizing the impact of her presence as peacemaker, she has learned about times to speak and not to speak and to "see the other side." Over the years, she has learned to silence herself in certain situations:

> When I know something is gonna cause some trouble or something, I won't say it. I just won't say it...just go on and let it happen and just keep my mouth shut...don't cause a lotta problems that way. And that's a learning experience. I had to learn that 'cause Mama used to say, "You gonna have the last word or die." (e) 'Cause if I was right, I wanted everybody to know I was right. (e) But, that was when I was younger and the older I got, the more wisdom I gained. Well, I prayed for wisdom, it had nothing to do with being older. The Lord answered my prayer because I prayed for wisdom and understanding.

In her personal identity locations, people have often thanked her for how she has related to them and shared her insights and experiences. At the end of the third interview, she emphasized, "My mission is a peacemaker. (e) That's what God has me down here for" and:

> If I have God's peace, I can always instill God's peace and it spreads so that's it. That's my goal. That's my mission. And I'm good at it. (e) Thank you, Lord. (av) I'm good at it.

Samantha's mission correlates with her personal identity description, construction, and locations.

Conclusion: Samantha's personal identity location

As illustrated above, how Samantha positions herself emerges through her ongoing involvements, significant dialogues, and the personal impact of her voice. In her personal identity locations at home, work, and church, she has experienced sites of repression and resistance. Thus, her voice has become transformative through her relationships with people in her contexts of interaction.

Analysis summary

The study investigated how three women constructed their voices or identities, and if and how the women experienced the margins within their contexts of interaction. The research questions were developed to explore the standpoints and experiences of women with disabilities, which have been reported through anecdotes in the literature but rarely examined within a conceptual framework employing anthropological, critical, feminist, sociological, standpoint, and disability theories.

In the review of the literature, I found no single definition of voice, but rather multitheoretical definitions of voice: in knowledge (Belenky et al., 1986), by expression (Reinharz, 1994), within relationship (Gilligan, 1982, 1993) and as resistance and transformation (Delpit, 1988; Freire, 1970/1993; Greene, 1990). While I expected to find these aspects of voice in the data analysis, I did not expect to find an emphasis on one aspect of voice in each of the women whom I studied. Further in my review of marginality conditions and marginalization processes (Ferguson, 1990; Ferguson et al., 1992a, 1992b; Hall et al., 1994), I became interested in the sites of repression, resistance, dialogue, and transformation related to the margins in each woman's experience (Freire, 1970/1993; hooks, 1984, 1990). My data suggest that each woman's voice became resistant and transformative in and through the margins of her personal identity locations. For example, Hope's voice was heard in knowledge. Samantha's voice was heard in relationship. Victoria's voice was heard in expression. Therefore, coming to voice was unique for each woman; yet there were striking similarities in the women's experiences. Each woman's coming to voice was affected by what changed in her life, how individuals

responded, and where she focused in relation to her disability. As each woman faced what she could no longer do, she began to find what she could do. That focus was central to how each woman developed her voice. For example, Hope began coming to voice as she educated herself about the "unknowns" of M.S. and shared what she was learning with others. Victoria began coming to voice as she involved herself in various equity issues and expressed her opinions about them to others. Samantha began coming to voice as she engaged in relationships and shared her experiences with others. Each woman's motto and mission seemed to reflect how she validated her own experiences and revealed how she viewed her life through her narrative.

Although the women's identities are shifting and evolving entities whose fluidity makes static interpretations impossible, in this analysis, the themes of personal identity description, construction, and locations emerged distinctly in each woman's story. Therefore, the validity of these themes at these particular points in the three women's lives was supported. The personal identity descriptions provided glimpses of how the women saw themselves as individuals. The personal identity constructions provided glimpses of how they defined themselves through their voices. The personal identity locations provided glimpses of how they positioned themselves in their own contexts of interaction. Moreover, because of the involvement of two of the women, Hope and Victoria, in the disability community and the strong support for disability interests and issues of the third woman, Samantha, the focus on disability as a defining characteristic was also supported. However, it should be noted that such an identification might not be the case in a study of individuals who were less involved in such community activities. Further, for Samantha, race, rather than disability, was the central identifying characteristic. Additionally, none of

the women selected gender as a prominent identifier. The findings suggest important implications for those who wish to understand the experiences of women with disabilities from their own perspectives. These implications and recommendations for future research are presented in Chapter V.

CHAPTER V

CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

Introduction

The study focused on the phenomena of voice and marginality as lenses through which to examine the experiences of three women who have disabilities. It was framed by interpretive, symbolic interactionist theory and guided by what had been discovered through a review of literature focusing on women's construction of voice and processes and conditions of marginality as found in feminist and critical theory. The research centered on each woman's "insider" perspective (Dembo, 1977, 1984) as expressed through her own words rather the researcher's interpretation of them.

Thus, a critical aspect of the study was what each woman said about herself rather than what has been said about her, in both individual and global contexts. Historically, research about disability (Hahn, 1983, 1984, 1990) has been presented more from the perspective of those who know about rather than experience disability. The "expert" researcher has been the "colonizer" and the person with the disability has been the "other." hooks (1990) describes this process of "othering":

> I am waiting for them to stop talking about the "other," to stop even describing how important it is to be able to speak about difference. It is not just important what we speak about but how and why we speak. Often this speech about the "other" is also a mask, an oppressive talk hiding gaps, absences, that space where our words would be if we were speaking, if there was silence, if we were there. This "we" is that "us" in the margins, that "we" who inhabit marginal space that is not a site of domination but a place of resistance. Enter that space. Often this speech about the "other" annihilates, erases. *No need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice.*

> *Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I write myself anew. I am still author, authority. I am still colonizer, the speaking subject and you are now at the center of my talk.* (p. 343)

In research that insists on "othering," the voices of people in the margins remain silenced. In "Toward a Feminist Theory of Disability," Wendell (1989) makes some critical observations about "othering":

> When we make people "other," we group them together as the objects of *our* experience instead of regarding them as fellow *subjects* of experience with whom we might identify. If you are "other" to me, I see you primarily as symbolic of something else–usually, but not always, something I reject and fear and that I project onto you. We can all do this to each other, but very often the process is not symmetrical, because one group of people may have more power to call itself the paradigm of humanity and to make the world suit its own needs and validate its own experiences. Disabled people are "other" to able-bodied people, and (as I have tried to show) the consequences are socially, economically and psychologically oppressive to the disabled and psychologically oppressive to the able-bodied. (p. 116)

By contrast, in collaborative research, the voices must be identified and heard for who they are and not for how they are perceived (Fine, 1994; hooks, 1990). Thus, how a woman experiences life cannot be explained by male-dominated or ability-dominated perspectives nor examined fully through anecdotal stories. As a subject rather than an object in this study, each woman used her own language to discuss her own perspective on disability and other aspects of her life. Wendell stresses the importance of such knowledge in our culture:

> As with women's "special knowledge," there is a danger of sentimentalizing disabled people's knowledge and abilities and keeping us "other" by doing so. We need to bring this knowledge into the culture and to transform the culture and society so that everyone can receive and make use of it, so that it can be fully integrated, along with disabled people, into a shared social life. (p. 121)

Conclusions regarding construction of identity

Three major themes emerged in each woman's story. These themes examine how each woman sees herself in a personal identity description, how she defines herself in a personal identity construction, and how she positions herself in a personal identity location within her own contexts of interaction. Each woman's "insider" descriptions, constructions, and locations resist hegemonic, "outsider" constructions of disability experience (Dembo, 1977; Foster, 1995; Ladson-Billings, 1994). As suggested by the data, the themes are interrelated in each woman's story.

Personal identity description

The personal identity description theme is grounded in each woman's experiences in relation to disability, decision making, participation and power, and issues of oppression and discrimination. In each woman's narrative, disability is not the single but, rather, a significant influence in her life. Decision making was also affected by each woman's experience with disability, and the people outside that experience have sometimes influenced and made decisions with which each woman did not agree and against which each woman sometimes resisted. Further, some of the decisions the women made in their lives would not have been made had there been no disability. Because of disability and physical changes, each woman has experienced interactional changes in her avenues for participation and power. As a result of those changes, each woman appears to have evaluated what she could not continue to be or do. Based on these evaluations, each woman has then found and

focused on new ways of being and doing. As a result of this process, each woman has developed new perspectives regarding the inner and outer capacity of her body. The data suggest that each woman revealed not only how she saw herself but how she would like to be recognized through her personal identity description.

Personal identity construction

The personal identity construction defined each woman within her contexts of interaction. The related theme was grounded in each woman's voice or identity development over time. Thus, the woman's interests and involvements appeared initially in her personal identity description and became more evident in her personal identity construction. The early years in each woman's life, in concert with continuously changing situations, influenced how her voice or identity evolved. Therefore, each woman has focused primarily on one aspect of voice. To illustrate: Hope has developed her voice as an educator through gaining and sharing knowledge within her contexts of interaction (Belenky et al., 1986); Victoria has developed her voice as an activist through expressing her opinions within her contexts of interaction (Reinharz, 1994). Samantha has developed her voice as a "people person" and a peacemaker by relating to others within her contexts of interaction (Gilligan, 1982, 1993). With her own voice, each woman has resisted hegemonic perceptions of what she can and cannot do. Further, the data suggest that each woman revealed not only how she defined herself but how she would like to be understood through her personal identity construction.

Personal identity location

A personal identity location emerged as each woman positioned herself within her contexts of interaction. This theme was grounded in the women's involvement in specific situations. The responses to each woman's use of voice in those situations illustrated varying types and degrees of repression, resistance, and transformation. The women handle these locations very differently, developing their own verbal and nonverbal responses and finding their own ways to negotiate margins. As these women's narratives suggest, individuals often try to impose their interpretations and explanations for these women's lives. Despite this, each woman has resisted and sometimes transformed the places where social and physical barriers have affected her. As the data suggest, each woman revealed not only how she positions herself but how she would like to be heard through her personal identity location. The personal identity description, construction, and location emerged as global themes; and the findings illustrate the differences in how three women handled their life experiences.

The data analysis further suggests that the three themes can be linked through each woman's answers to the questions "Who am I?" "How have I become who I am?" and "Where have I become who I am?" This linkage connects each woman's constructions of who she was, is, and will be, and of what she could, can, and will do in her contexts of interaction (Adler, 1927/1992; Clandinin & Connelly, 1994; Rubin, 1983). As previously stated, the data suggest that gender does not influence the women's experiences as much as disability (Asch & Fine, 1988; Deegan & Brooks, 1985; Fine & Asch, 1985; Gill et al., 1994; Hillyer, 1993; Morris, 1991, 1994a; Wendell, 1989), and the women's

narratives support the finding that people viewed them more in relation to their disabilities than their gender. How each of the women also described herself in relation to her disability varied. Victoria reiterated that she saw herself as a person with a disability and not as disabled or handicapped. Hope and Samantha both used the word handicap and handicapped to describe their experiences as well as how people viewed and referred to them.

Another finding of this study resists the generalization that marginalizing processes and marginality conditions (Ferguson, 1990; Hall et. al., 1994; hooks, 1984, 1989, 1990) create overwhelmingly negative results in both individual and group experiences. As hooks (1984, 1989, 1990) and others have pointed out, individuals can share language and dialogue through the margins that create positive connection, communication, community, and contribution. Each of the women discussed these elements in her narrative. All of them recognized connections and shared communication with people who have the same and different disabilities in varying degrees. Each of them has also been active in and contributed to her own community, suggesting that the margins can become positive sites.

Implications regarding voice, marginality, and experience

The phenomena of voice and marginality did have explanatory power in the individual experiences of these women. Further, the women's experiences, collectively and individually, also have explanatory power for theory, research, and practice related to the phenomena of voice and marginality.

Voice, as described in the literature, is a metaphorical term for an individual's identity construction. In new ways, these women's personal identity

constructions illustrate what was identified in the literature. Each woman's identity can be closely connected with one aspect of voice: Hope in knowledge, Victoria by expression, and Samantha within relationship, and each woman's voice became transformative in her contexts of interaction, as she focused on what she could do and what was significant to her.

Each of the women has experienced individualized processes in dealing with her disabilities. Moreover, voicing her thoughts and experiences in her own contexts is important to each woman since, in so doing, each woman makes contributions and differences based not on who she was but on who she is now. Rather, each continually constructs her identity based on the influences, interactions, involvements, interests, and issues in her own life. In turn, the interactions impact each woman's personal identity description, construction, and location. In some sites, their voices are repressed, resistant, and transformative, depending on the situations and the interactions. Generalizations cannot be made about all women with disabilities from the specific standpoints and experiences of the three women presented in this study. Further, disregarding distinctions can strengthen existing hegemonic construction of disability by emphasizing the sameness of the experience rather than exploring the diversity of the experience (Asch & Fine, 1988; Fine & Asch, 1985; Glick Schiller, 1992). Exploring the intersections of disability, gender, race, and class also is crucial to understanding how women with disabilities construct their identities. In this study, for example, Samantha was aware of the multiple forms of discrimination she had experienced related to her race, her gender, and her disability throughout her life. Yet, Hope's perspective suggests that race has affected her life very little. Finally, Victoria seems to identify with Black individuals who have experienced similar forms of oppression to her own.

A person's life can never be contained by a single or a static construction.

The homogenizing and mythologizing of disability are pervasive and have often permeated the interactions of people with and without disabilities (Davis, 1961; Goffman, 1963; Gramsci, 1971; Murphy, 1990; Thomas, 1982; Wright, 1983). Because of these perceptions regarding disability, an individual is often not seen and heard for who she or he is. Each of the women has been aware of this phenomena in her own experiences and has consciously constructed responses in explicit ways. Samantha, who has known that appearance affects how people view her, has resisted those perceptions and concentrated on her personality and being a peacemaker. Victoria has been conscious of how her voice sounds and how people hear her and has resisted stereotypes about disability by expressing her opinions as an activist. Hope recognizes that physical characteristics and use of assistive devices make people think of her as having a sickness or disease. She has resisted those definitions and educated people about M.S. Thus, in each of their interactions, these women have found that people focused on their disabilities and sometimes have been hesitant or resistant to speaking to them as individuals. All of them mentioned how people communicated with them verbally as well as nonverbally. In some of these situations, people have expressed or acted on assumptions about the women's needs, feelings, or rights based on "outside" perceptions that were unrealistic. For example, Hope described a man who said that he "hurt" when she was the one who fell. Victoria talked about individuals who tried to assist her in ways that actually hindered her. Samantha reported that people sometimes say that she is not handicapped, requiring her to respond that she is. In each woman's experiences, either individuals or groups behaved in ways that confirmed a belief that they understood disability issues. Moreover, in each

case, these individuals or groups felt vindicated and/or validated by their responses without considering the woman's standpoint. Hope's encounter with a man about handicapped parking is one example of the phenomenon.

Perceptions about who holds knowledge, power, and the ability to provide assistance are fed by mythologies about individuals with disabilities and their experiences. Hope and Samantha both searched for answers about their symptoms and suspected their diagnoses before their doctors confirmed these conclusions. Victoria visited doctors for several years before a diagnosis was made, and when she sought guidance from vocational rehabilitation counselors at Easter Seals, she found, "They were the experts I thought and they didn't have a clue." As each woman began adjusting to changes associated with her disability, she began finding and focusing on what she could do, on her own, and with those whom she chose to be involved. Thus, each woman was an agent for her own growth, resistance, and transformation. Each woman became her own spokesperson and advocate within her contexts of interaction.

All of the women identified individuals and groups who have been important to and involved in their experiences. Hope participated in an M.S. support group that she called "A real comfort zone...real comfortable like "Been there, done that." Victoria stated, "My relationships with people with disabilities is a true understanding of what it's like to be a person with a disability." In her interactions with other people with disabilities, including her cousin who has postpolio syndrome, Samantha said, "I can relate." Through their narratives, Hope, Samantha, and Victoria revealed how they see, define, and position themselves and how they want to be recognized, understood, and heard. This suggests that to be effective practitioners with those who have disabilities, it is

critical to look, listen, and learn with individuals as well as to talk and work with rather than for them.

Further questions and recommendations for practice

The findings and implications of this study can have significant application for the experiences of women from varying backgrounds. The review of literature and the research findings suggest further study regarding the validity of the themes that emerged in these three women's experiences in the experiences of other women. How an individual sees, defines, and positions herself/himself can only be described by that individual.

Further, specific elements in the process of coming to voice must also be investigated to determine how a woman can or cannot define and develop her voice or identity construction in relation to knowledge, expression, and relationship. Additional attention should be given to aspects of the exercising, silencing, and empowering of individual and collective voices within specific contexts of interaction. From such research, informative and instructive models regarding the process of "coming to voice" could be developed for theoretical and practical application for women of varying backgrounds and experiences. One of the emphases of this research has been on women as subjects who act rather than as objects who are acted upon in their contexts of interaction. Therefore, it is important to examine why, what, when, where, and with whom a woman identifies and involves herself.

Greater attention also needs to be given to how a woman encounters and negotiates margins. The nature of repression, resistance, and transformation is often influenced by institutions and systems and is individually and collectively

experienced. How a person with a disability experiences repression in certain interactions can be illustrative. Further, the forms of resistance employed by an individual as well as how a person's voice transforms and becomes transformative within situations can also increase knowledge of individual and systemic impacts that exist in various contexts of interaction. These can be studied further by researching the experiences of more women with disabilities and examining how they define and describe being heard, silenced, and or/affecting change. Such research could be conducted with women by observing, discussing, and investigating their physical, attitudinal, and interactional experiences with them.

Elements of effective agency and advocacy among women with and without disabilities regarding a variety of issues need much more attention in research. The three women in this study came to understand what was happening in their own experiences through their own avenues of knowledge. Each woman was given initial, unsatisfactory answers before what she was saying was acknowledged and investigated. Further, when they sought but were given little effective advice or assistance, the women oriented themselves to changes in their lives. Finally, speaking out and communicating about these experiences is a vitally important dialogue for women from different backgrounds, situations, and contexts of interaction. More interview studies and participatory research groups could extend needed discussion and collaborative research. While recognizing that "All is never said," the question must continue to be asked, "Are we willing and able to listen and respond with respect and regard for each other?"

Further questions and recommendations for research

Relevant theory, research, and practice must be informed by lived experience to be of any lasting value. This study illustrates that metatheoretical frameworks and qualitative methods can be utilized to understand the experiences of women with disabilities. The focus on the three women's stories facilitated a dialogue in which they were presumed to be the experts rather than the novices. As an initial approach in research, this study is descriptive and explanatory. While an attempt was made to address the research questions as thoroughly as possibly through these three women's lived experiences, there are additional questions to be asked of many women.

Using the phenomena of voice and marginality as a lens revealed aspects of the women's experiences that have not been accessed in traditional disability-focused research. What has been gained from these women's perspectives can generate new avenues for exploring and defining conceptualizations of voice and marginality with more specificity and depth. Other significant constructions of identity beyond those presented here need to be investigated.

In this study, all of the women had physical disabilities. It is important to research the experiences of women with other kinds of disabilities, which involve different health and medical issues and affect their lives differently. Every woman's interactions and experiences vary according to her contexts and can be worthy of study. Personal identity construction is also an individualized process that needs further examination in relation to the aspects of disability, decision making, participation and power, and issues of discrimination and oppression discussed here. All of these could be examined in greater depth, but

there are many aspects that could be explored, such as the cultural contexts within which individuals interact. In the women's narratives, they described how they viewed themselves in relation to intersections of race, class, and gender. These intersections must be explored with other women from diverse backgrounds. Additional questions need to be developed that explore these and other intersections more thoroughly in connection with their impact on women's experiences of voice and marginality.

Through this study, three women with disabilities have had much to say about their lives. By speaking up individually and collectively, they have attempted to address misconceptions about who they are and what they can do in their contexts of interaction and, in so doing, have demonstrated that the voices of women with disabilities can be heard through the margins.

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APPENDICES

APPENDIX A

PILOT INTERVIEW GUIDE

1) Tell me about your experience as a woman with disability.

--onset
--background
--treatment
--health care
--activities
--work
--changes in your life with disability
--how do you see yourself?

2) Tell me how you have responded when you have been asked questions about your disability.

Tell me about factors that influence your response.

Think of situations that stand out in your mind.

--what was happening
--tell me what you were thinking
--how you felt later

3) Tell me about situations in which you have felt excluded.

--groups from which
--made to feel different by others
--felt different from others
  opinions
  appearance
  situation
  issue
  barrier

Tell me about situations in which you have felt included.

4) Tell me about experiences that you've had in which your voice has been heard.

--health care
--ed/school, other situations
--employment

Tell me about experiences that you've had in which your voice has been silenced.

Tell me about a time when you expressed an idea or opinion that was acknowledged and made an impact.

5) Tell me about significant relationships with people in which you interact.

--family
--friends
--doctors, other health care professionals
--activities
--your roles

6) Tell me about your personal goals at age:

--18
--25
--other significant times in your life

Tell me who has played influential roles (of any nature--positive, negative, etc.).

Tell me about factors that have been significant in your pursuit of goals.
--change, adjustment, failure, achievement.

7) Tell me about short- and long-term goals you now have.

APPENDIX B

INITIAL INTERVIEW GUIDE

In Research Interviewing: Context and Narrative, Mishler (1986) describes an interview "as a discourse between speakers and on the ways that the meanings of questions and responses are contextually grounded and jointly constructed by interviewer and respondent" (pp. 33-34). He also states: "In sum, interviewing practices that empower participants also produce narrative accounts. There is, however, an additional implication of empowerment. Through their narratives people may be moved beyond the text to the possibilities of action. That is, to be empowered is not only to speak in one's own voice and to tell one's own story, but to apply the understanding arrived at to action in accord with one's own interests" (p. 119).

The method for this project is grounded in the above propositions. The topics selected focus on how each woman constructs meaning about her experiences through narrative. These topics serve as guides during the interview process--ideally resulting in similar areas being discussed in each interview. Topics are as follow:

-- Disability Experiences
-- Health Care and Medical Issues
-- Relationships and Roles
-- Activities and Interactions
-- Education and Employment
-- Gender Issues
-- Ethnicity Issues
-- Class Issues
-- Descriptions and Interpretations of Marginality Experiences
-- Descriptions and Interpretations of Voice Experiences

Because each interview will be approximately two hours, discussion of the topics will be covered in more than one interview. A tentative schedule of interviews and related topics follow:

I. Experience with Disability and Related Health and Medical Issues

Questions:
Tell me about your experience, as a woman, with disability.
situation
diagnosis
perception of self

Tell me about your interactions with medical professionals and others related to your disability and related health and medical issues.
- issues
- needs
- resources, access

Tell me about your interactions as a woman with a disability in the community.
- family
- friends
- other people with and without disabilities

II. Chronologies of Experiences (Significant Roles, Relationships, Activities, Education, and Employment)

Discussion of significant life events

Questions:

Tell me about:
- significant events
- roles, relationships
- activities
- education
- employment

Tell me about your personal goals at age 18 and 25.
Tell me about short- and long-term goals you now have.
Tell me who has played influential roles in your pursuit of goals.
Tell me about factors that have been significant in your pursuit of goals.

III. Experiences of Voice and Marginality

Questions:

Tell me about how being a woman has affected your experiences.

Tell me about how your ethnic background has affected your experiences.

Tell me about how economic status and resources have affected your experiences.

Tell me about situations in which you have felt excluded.

Groups from which you felt excluded
Made to feel different by others
Felt different from others (e.g., opinion, appearance, situation, issue, barrier)

Tell me about situations in which you have felt included.

Tell me about experiences that you've had in which your voice has been heard.

Tell me about experiences that you've had in which your voice has been silenced.

Tell me about a time when you expressed an idea or an opinion that was acknowledged and made an impact.

APPENDIX C

STUDY INTERVIEW GUIDE

I. Experiences as a Person

1) If you were to tell yourself who you really are, how would you do that? (Belenky et al., 1986)

2) If you were to describe yourself to others, how would you do that?

3) Tell me about your experience, as a woman, with disability (specific disability?).

diagnosis, onset, background, knowledge and learning about disability, treatment

current situation, activities

perception of self...is it different than from in the past...changes

how do others see you?

how does society generally view people with disabilities?

--women

how does this fit with how you see yourself?

4) Think about how you have responded when you have been asked questions about your disability.

Think about factors that influence how you respond.

Think of situations that stand out in your mind.
What was happening?

What were you thinking?

How did you feel later?

When have you felt uneasy...speechless,

or felt that you could say anything?

Who are some people who have been easy for you to talk with (why?)

Who are some people who have been awkward/dif. for you to talk with?

Questions you like/dislike being asked?

6) Think about your experiences with doctors and others related to your disability.

issues

communication

needs

resources, access

7) Tell me about your relationships and experiences with people....

8) **Tell me about the family in which you grew up. What was life like?**

relationships with/influences of parents, brothers and sisters, other relatives

...Attitudes, beliefs in your family.

9) **Tell me about your earliest memory.**

Other specific memories of when you were younger.

Challenges you faced and how you dealt with them (compensation).

Ways in which you felt overlooked and/or neglected

...accepted and/or understood.

10) **How do you see yourself in your family now?** (family of origin/now)

...with friends

...with people with and without disabilities (co-workers, neighbors, others...)

II. **Constructions of Life Experiences** (discuss at end of first interview)

Each woman will be asked to make a construction of her life experiences utilizing **a structure of her choosing that reveals significant incidents, events, changes, turning points, years, relationships, interactions, places, thinking-learning...**

("This is Your Life," "Game of Life," Picture, Map, Journey, Timeline, Stories)

Demographic sheet (what should be on it?)

Possible ways for the women to think about construction:

What stands out for you in your life? (Belenky et al., 1986)

What has been most important, what stays with you? (Belenky et al., 1986)

Who's, what's, where's, when's, why's, how's of your life.....

What is your life like right now?

During second interview, begin to by asking them to

Tell me about this...things that are important to you....
Possible Areas of Exploration:

Significant events, "how old were you when that happened?"

People, family (beliefs, philosophy, experiences), friends, relationships

Activities, Ideas, Culture

Education

Employment, etc....

Personal experiences and times in your life (changes, goals, etc...)

Short and long-term goals you now have.

Who has played influential roles in your pursuit of goals?

Factors that have been significant in your pursuit of goals.

Construction of Life Experiences

Please make a construction of your life experiences utilizing a structure of your own choosing that reveals significant experiences, incidents, events, years, learning/thoughts/ideas, changes, turning points, people, relationships, interactions, places, activities, and other "things" (beliefs/philosophies, books, music, ideas, hobbies, etc.) in your life.

Your construction might be thought of as "This is My Life," "Game of Life," Picture(s), Map, Journey, Timeline, Genealogies, Memories, Stories, etc.)

Possible ways for you to reflect on your construction:

What stands out for you in your life?

What has been most important, what stays with you?

Who's, what's, where's, when's, why's, how's of your life.....

What is your life like right now?

(This is something I will need to keep.)

THANK YOU!

Life "Information"

1. Name:

   Place/Date of Birth:

   Places lived:

2. Significant People in Your Life (past and present):

3. Significant Events/Experiences in Your Life (past and present):

4. Significant Activities in Your Life (past and present):

III. Experiences in Society

Tell me how being a woman has affected your experiences.

Tell me about how your racial/ethnic background has affected your experiences.

Tell me about how economic situation and resources have affected your experiences.

Tell me about situations in which you have felt...invisible &

were there, (visibly invisible)...overlooked

...powerless...overlooked...

didn't have an impact, helpless, frustrated. (excluded)

Groups/situations in which you felt uncomfortable, awkward...

Made to feel different by others

Felt different from others (e.g., opinion, appearance, situation, issue, barriers)

Tell me about situations in which you have felt...a sense of belonging...being included...being accepted.

Groups/situations in which you felt comfortable

Felt "like" people

Situations in which you felt that you were making a contribution.

May not have felt included necessarily, but felt that you had a role or were making a contribution (Voice in the wilderness....)

Tell me about experiences that you've had in which your voice has been heard.

Tell me about experiences that you've had in which your voice has been silenced.

Is your inner voice, how you talk to yourself, different from the voice you use with others? (describe) (Abell & Sommers, 1991)

Tell me about a time when you expressed an idea or an opinion that was acknowledged and made an impact.

APPENDIX D

FORM B

IRB # _____
Date Received in
ORA_____

The University of Tennessee, Knoxville

Application for Review of Research Involving Human Subjects

I. IDENTIFICATION OF PROJECT:

Principal Investigator:	Laura M. Payne, 974-2321 Rehabilitation and Deafness Unit 102 Claxton Education Addition Knoxville, TN 37996-3400
Advisor for Project:	Dr. Olga M. Welch, 974-2321
Title of Project:	Voices from the Margins: A Qualitative Study Exploring Voice and Marginality in the Experiences of Women who have Physical Disabilities
Department:	Rehabilitation and Deafness Unit, College of Education
Supporting Agency:	NA
Grant Submission Deadline:	NA
Starting Date:	Upon IRB approval
Estimated Completion Date:	August, 1996

II. OBJECTIVES OF PROJECT:

The purpose of the study is to examine the phenomena of voice and marginality in the experiences of three women with physical disabilities. Using the work of Carol Gilligan (1982), Belenky, Clinchy, Goldberger, and Tarule (1986), hooks (1989), and Reinharz (1994), the study focuses on voice as a metaphor for women's personal identity

constructions in relation to disability, power in social contexts, decision-making, full participation as disabled members in society, and issues of oppression and discrimination (Blumer, 1969; Denzin, 1992; Ferguson, Ferguson, & Taylor, 1992; Fine & Asch, 1988, 1985; Hahn, 1983, 1988; Hannaford,1985; Higgins, 1992; Thomas, 1982). With respect to marginality, the study will explore how or if margins become sites of repression and resistance (hooks, 1990; Ferguson, 1990; Hall, Stevens, & Meleis, 1994, Wendell, 1989).

III. METHOD

In order to examine the phenomena of voice and marginality in the experiences of three women with physical disabilities, narrative case studies will be developed. Data from three sources: narrative interviews (Mishler, 1986; Reinharz, 1992; Weiss, 1994), medical and vocational documentation, and chronologies of life experiences (Clandinin & Connelly, 1994) provided by the women, will be collected, analyzed, and interpreted. Medical and vocational information will be provided voluntarily by each individual. No information will be requested from institutions or physicians by the researcher.

Each subject will be interviewed three times, with each interview lasting approximately two hours. An interview guide (attached) will be utilized. Interview sessions will be audiotaped to facilitate transcription of the information. Each interview will be transcribed as soon as possible in preparation for subsequent interviews and data analysis. To further ensure accuracy, each woman will be asked to review the transcripts of her interviews. As soon as accurate transcriptions are completed, audiotapes will be erased.

Data analysis will be conducted by the principal investigator throughout the interviewing and writing processes. A qualitative interview case study method will be utilized in order to facilitate pattern matching (Yin, 1994). To arrive at emerging definitions of voice and marginality among the women, data analysis will be conducted using analytic induction, systematic comparison, and typological analysis for grouping data and developing categories and themes (Weiss, 1994; Yin, 1994; LeCompte & Preissle, 1993). As part of the analysis, each woman will be provided with the initial data interpretations and asked for feedback.

IV. DESCRIPTION OF SUBJECTS:

Selection of subjects developed through the principal investigator's standpoint as a woman with cerebral palsy and through the community nomination process described in this section.

Standpoint Epistemology:
Within the framework of standpoint epistemology, attention will be given in this study to the experiences shared by women with physical disabilities, which "provide a unique angle of vision on self, community, and society--and theories that interpret these experiences" (Hill Collins, 1990, p. 22). Factors such as age, ethnicity, type of disability with accompanying limitations, class, and interactions with others result in diversity of experiences. Women with physical disabilities as a group may have shared experiences and perspectives, but self-defined standpoints as constructed by these individuals must be explored. A review of the sociological, anthropological, rehabilitation, and feminist literature regarding women with physical disabilities convinced the principal investigator that the voices and accounts of women themselves have been largely absent from that literature (Atkins, 1982; Browne, Connors, & Stern, 1985; Danek, 1992; Deegan, 1985; Fine & Asch, 1985, 1988; Hanna & Rogovsky, 1992; Hillyer, 1993; Lonsdale, 1990; Morris, 1991; Saxton & Howe, 1987; Spencer, 1993; Wendell,1989; Willmuth & Holcomb, 1993).

Selection of Subjects:
This study uses the community nomination process suggested in the work of Foster (1995) and Ladson-Billings (1994) in which the researcher seeks to gain an "emic" or insider's perspective on a particular issue or issues. For the study, the process was facilitated by the principal investigator's personal involvement in the disability professional community and in religious organizations focusing on cross-cultural exchanges.

This involvement resulted in introductions to prominent disabled people and community leaders in the Knoxville area. In turn, these individuals provided access to other disabled people whom the principal investigator did not know. The three female subjects for the study were identified through these networks, providing the "insider" perspective sought by the principal investigator (Note: Additional information on the selection process available upon request).

V. SPECIFIC RISKS AND PROTECTION MEASURES:

Those participating in the study will be subjected to minimal risk. Procedures are non-invasive. Participation in the interview sessions will be strictly voluntary, and participants will be advised both verbally and via Informed Consent (attached) that they may terminate the interviews at any time. The participants will be interviewed at times convenient to them, and in a quiet, unobtrusive place agreed upon by the participant and the principal investigator. Participants will be advised that their interviews will be audiotaped and will be given the opportunity to refuse to participate in the interviews if they are not in agreement. They will be identified on the audiotapes by pseudonym only. Anonymity is not possible because the subjects' identities are known and recorded by the principal investigator. Verbatim transcripts of the interviews are mandatory for content analysis. The only written identification of the subjects will be their signatures on the Informed Consent Statements, and these will be kept in a separate file in a locked file cabinet in the office of the project advisor, 102 Claxton Education Addition. Access to all data, with pseudonyms, will be limited to the principal investigator and the project advisor. The transcriptionist will be privy only to the audiotapes using pseudonyms. Once accuracy is checked and modifications made to ensure confidentiality, audiotapes will be erased. These precautions assure a minimal risk to confidentiality. Audiotape recordings will be utilized for accuracy only and will be modified to ensure confidentiality. The tapes will then be erased. Interview transcripts will be utilized for compilation and analysis of data. Access to the data will be limited to the principal investigator and the project advisor. Data analysis will be used solely for the principal investigator's doctoral dissertation. Transcripts, medical and vocational documentation, and the chronologies, identified by the women's pseudonyms, will be destroyed after the study is completed. Consent forms will be maintained and stored for three years after completion of the study in the office of the project advisor, 102 Claxton Education Addition.

VI. BENEFITS vs. RISKS:

The anticipated risks to the subjects of this study are minimal in that they are no greater than than those ordinarily encountered in daily life. The potential benefits are great, albeit indirect; with increased understanding of voice and marginality experiences among women with physical disabilities. The "telling of one's story" often has positive effects, which can be anticipated for those who choose to participate in the research project.

VII. METHOD OF OBTAINING "INFORMED CONSENT" FROM SUBJECTS:

The investigation will be explained to all persons involved and permission will be received. Reading and signing of an Informed Consent Statement (attached) will occur prior to interviewing. A copy of the statement, complete with name and address of the principal investigator and project advisor will be given to the participants. The consent statements will be kept in a locked cabinet in the office of the project advisor.

VIII. QUALIFICATIONS OF THE INVESTIGATOR:

The principal investigator is a doctoral student in the Rehabilitation and Deafness Unit, College of Education, the University of Tennessee, Knoxville, and is a Certified Rehabilitation Counselor. She has a master's degree in rehabilitation counseling and worked from January 1990 to November 1992 as a rehabilitation counselor with the South Carolina Department of Vocational Rehabilitation. The principal investigator has been involved in qualitative research courses, (CI 560) Introduction to Qualitative Research in Education and (CSE 660) Ethnographic Research Methods in Education with Dr. Kathleen deMarrais. She is a research associate in a qualitative research study (Project Excel) co-directed by Drs. Olga M. Welch and Carolyn Hodges.

IX. ADEQUACY OF FACILITIES TO SUPPORT RESEARCH:

Not applicable.

X. RESPONSIBILITY OF PRINCIPAL INVESTIGATOR:

By the Compliance with the policies established by the University of Tennessee, Knoxville, Institutional Review Board, the principal investigator subscribes to the principles stated in "The Belmont Report" and standards of professional ethics in all research, development, and related activities involving human subjects under the auspices of the University of Tennessee, Knoxville.

a. Approval will be obtained from the University Committee prior to initiating any change in the research project

b. Development of any unexpected risks will be reported to the University Committee.

c. Signed consent statements will be kept for the duration of the project and for at least three years following completion of the project.

d. A status report (Form D) will be submitted at 12-month intervals or as requested attesting to the current status of the project.

PRINCIPAL INVESTIGATOR: Laura M. Payne

_____**DATE:**_____
Signature

ADVISOR FOR PROJECT: Olga M. Welch, Ed.D.

_____**DATE:**_____
Signature

XI. DEPARTMENTAL REVIEW:

Departmental Head: S. Wayne Mulkey, Ph.D.

_____**DATE:**_____
Signature

The application described above has been reviewed by the Departmental Committee and has been approved.

Departmental Review Committee:
James H. Miller, Ed.D.

_____**DATE:**_____
Signature

Approved:
Steven Pulik
Coordinator of Compliances
Research Administration

_____**DATE:**_____
Signature

Statement of Informed Consent

This research project focuses on the experiences of voice and marginality of women like yourself who have physical disabilities. There is a great deal of information available about women and disabilities, but little which includes actual accounts by the individuals themselves. It is those accounts which this project seeks to examine. With your permission, the information needed to learn about your experience will be gathered from three sources: interviews, medical and vocational documentation, and chronologies of life experiences.

If you choose to participate, you will be interviewed three times, with each interview lasting approximately two hours. These interviews will be audiotaped so that there will be an accurate account of your story. The audiotapes will be stored in a locked filing cabinet in the office of the project advisor, Dr. Olga M. Welch, at the University of Tennessee, Knoxville. Only the project advisor and I will have access to the tapes. As soon as the audiotapes are transcribed, they will be erased and any identifying information will be modified in the transcripts. After the study is completed, your transcripts, medical and vocational information, and chronologies of life experiences, identified by pseudonym, will be destroyed. This consent form will be maintained and stored for three years after completion of the study in the office of the project advisor, 102 Claxton Education Addition. These measures are to ensure that your information will remain confidential.

There are no anticipated risks to you beyond those experienced in the course of everyday life. Although there are no direct benefits, there is a clear benefit in the possibility for an increased understanding of the experiences of voice and marginality among women with physical disabilities. Your participation in this study is completely voluntary. You may withdraw from this project at anytime. There will be no compensation or incentives for participation and no penalty for withdrawal from the study.

You may direct any questions you may have about this project and your rights as a participant to me: Laura M. Payne, at 102 Claxton Education Addition, the University of Tennessee, Knoxville, TN, 37996-3400, or to my project advisor, Dr. Olga M. Welch, in the Rehabilitation and Deafness Unit, at (615) 974-2321.

****

I _____, have read and understand the above description of the research to be conducted by Laura M. Payne for her doctoral dissertation. I agree to participate in this study with the understanding that I can withdraw from the study at any time without penalty. I agree to participate in the interview process and for the interviews to be audiotaped.

_____ _____

Name Date

_____

Signature of Participant

INTERVIEW GUIDE

In Research Interviewing: Context and Narrative, Mishler (1986) describes an interview "as a discourse between speakers and on the ways that the meanings of questions and responses are contextually grounded and jointly constructed by interviewer and respondent" (pp. 33-34). He also states: "In sum, interviewing practices that empower respondents also produce narrative accounts. There is, however, an additional implication of empowerment. Through their narratives people may be moved beyond the text to the possibilities of action. That is, to be empowered is not only to speak in one's own voice and to tell one's own story, but to apply the understanding arrived at to action in accord with one's own interests" (p. 119).

The method for this project is grounded in the above propositions. The topics selected focus on how each woman constructs meaning about her experiences through narrative. These topics serve as guides during the interview process--ideally resulting in similar areas being discussed in each interview. Topics are as follow:

-- Disability Experiences
-- Health Care and Medical Issues
-- Relationships and Roles
-- Activities and Interactions
-- Education and Employment
-- Gender Issues
-- Ethnicity Issues
-- Class Issues
-- Descriptions and Interpretations of Marginality Experiences
-- Descriptions and Interpretations of Voice Experiences

Because each interview will be approximately two hours, discussion of the topics will be covered in more than one interview. A tentative schedule of interviews and related topics follow:

I. Experience with Disability and Related Health and Medical Issues

Questions:
Tell me about your experience, as a woman, with disability.
situation
diagnosis
perception of self

Tell me about your interactions with medical professionals and others related to your disability and related health and medical issues.
- issues
- needs
- resources, access

Tell me about your interactions as a woman with a disability in the community.
- family
- friends
- other people with and without disabilities

II. Chronologies of Experiences (Significant Roles, Relationships, Activities, Education and Employment)

Discussion of significant life events

Questions:

Tell me about:
- significant events
- roles, relationships
- activities
- education
- employment

Tell me about your personal goals at age 18 and 25.
Tell me about short and long-term goals you now have.
Tell me who has played influential roles in your pursuit of goals.
Tell me about factors that have been significant in your pursuit of goals.

III. Experiences of Voice and Marginality

Questions:

Tell me about how being a woman has affected your experiences.

Tell me about how your ethnic background has affected your experiences.

Tell me about how economic status and resources have affected your experiences.

Tell me about situations in which you have felt excluded.

Groups from which you felt excluded
Made to feel different by others
Felt different from others, e.g., opinion, appearance, situation, issue, barrier

Tell me about situations in which you have felt included.

Tell me about experiences that you've had in which your voice has been heard.

Tell me about experiences that you've had in which your voice has been silenced.

Tell me about a time when you expressed an idea or an opinion that was acknowledged and made an impact.

APPENDIX E

EXCERPT NOTES

(av) animated voice

(c) chuckle (bc) both chuckle

(chuckle in voice)

(e) or (emp) emphasized with voice

(ina. filler) inaudible filler word

(iw) inaudible word

(l) laugh (bl) both laugh

(laugh in voice)

(p) pause

(qv) quiet voice

(s) smile

(sigh)

VITA

Laura Mellen Payne was born in Knoxville, Tennessee, on November 10, 1960. She attended public schools in Knoxville and graduated from Bearden High School in 1979. She earned a Bachelor of Arts degree in English from Bryan College in 1982. After working for several years, she began attending graduate school at The University of Tennessee and received her Master of Science degree in rehabilitation counseling in 1989. She worked as a rehabilitation counselor with the South Carolina Vocational Rehabilitation Department from January 1990-November 1992. During 1993-1994 she served as a graduate assistant in the Special Education/Rehabilitation Department in the College of Education. She began and continued in a graduate research assistantship from 1995-1998 with Project Excel, a research study in a center city high school, which examines academic identity construction in African American adolescents.

Her major interests at The University of Tennessee have been focused on the experiences of individuals who have disabilities. She received the Doctor of Philosophy degree in August 1998.