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Voices From a Marginalized Population: Life Histories of Individuals With Physical Impairments

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Voices From a Marginalized Population:
Life Histories of Individuals With Physical Impairments

by

James Peter Marsh

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Special Education
College of Education
The University of South Florida

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Dedication

This study and dissertation are the essence of four people who were willing to share their lives, their successes and failures, and what it is like to be an individual with a physical impairment.

To Mike whose wit and humor are so similar to mine that it is almost scary;

To Theresa who I could not admire more;

To Ellen whose forthright objectivity is exceeded only by her dedication to family;

To Bill whose acerbic eye allowed me to see closest what it is like to be an individual with a physical impairment.

I am forever in their debt as friends and confidantes. My life is richer for knowing each of them. I hope the impact they have on other people is as powerful as the impact they had on me.

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Voices from a Marginalized Population:
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James Peter Marsh

ABSTRACT

Individuals with physical impairments have been marginalized and discriminated against since the social identification of these individuals occurred as a sub-group within society. While much has been done to resolve prejudice against individuals with physical impairments, more needs to be done to decrease, or at least deter, discrimination and prejudice against individuals who have been marginalized. The purpose of this study is to give four individuals with physical impairments the opportunity to tell their stories. Through the telling of these stories, I believe others can identify with these individuals, and thereby, help decrease discrimination against individuals with physical impairments.

Life history has been shown to be an effective method to study individuals with impairments. In order to facilitate understanding of what it is like to be an individual with a physical impairment, four individuals with physical impairments shared their life histories. Research questions include: “How do these individuals with physical impairments understand and give meaning to their lived experiences?” and “How do participants in this study who have congenital disabilities differ from those who have acquired disabilities in the ways they understand and give meaning to their lives?”

The research questions and parameters of interest are intended to develop and share what it is like to be an individual with a physical impairment. The researcher has known each of the participants for at least ten years. The participants include a 33 year old male with a congenital disability who is white, a 32 year old female who acquired a disability 12 years ago and who is African American, and a married couple who are 62 and 63 years old, one with a congenital disability, the other acquired a disability when she was 14 years old. The researcher shares his responses and reflections, thereby becoming the fifth participant in the study.

Because this type of research depends upon verisimilitude, the responses to the research questions are presented for each individual. Each participant defines areas of his or her life that best defines how that person constructs his or her identity and what part the physical impairment plays in that definition.

The participants feel that there are some differences between individuals with congenital physical impairments and those with acquired physical impairments. The participants relate that individuals with acquired physical impairments have greater access to funds and equipment based on their perception of how funding agencies provide services and equipment to individuals with physical impairments. The participants also feel that there is a greater stigma associated with having a congenital physical impairment compared to having an acquired physical impairment. Recommendations for future research are offered.

Chapter One

INTRODUCTION

Individuals with disabilities have been described in various ways in the professional and research literature. Different voices have described the lives of individuals with physical impairments. In the early years, scholars spoke on behalf of individuals with physical impairments, with impairments that ranged from spastic quadriplegic cerebral palsy to varying forms of paralysis. All of these impairments were readily apparent to the casual observer. In 1978, Weinberg and Williams wrote about “How the Physically Disabled Perceive Their Disabilities.” Beatrice Wright (1983), an early scholar of individuals with physical impairments, wrote one of the first books on physical disabilities from a psychological perspective—what it is like to be an individual with a physical impairment. Erving Goffman (1963) described the stigma associated with individuals with physical impairments. Mitchell and Snyder (1997) provided an excellent historical perspective of physically impairing conditions and the individuals affected by these conditions.

It is difficult to determine exactly when individuals with physical impairments demanded a voice or when the disability rights movement started. It may have been in 1984 when the National Council on Disability became an independent federal agency, or in 1986 when Irving Zola founded the Society for Disability Studies (Fleischer & Zames,

2001). Regardless, the mid eighties sounded the rallying cry for individuals with physical impairments to speak for themselves.

A Justification

Advocates within the disability movement maintain that individuals with physical impairments have been marginalized and discriminated against since the social identification of these individuals occurred as a sub-group within society. Murphy, R., Scheer, Murphy, Y., and Mack (1988) describe how individuals with physical impairments have been forced to the periphery of society resulting in a *non-entity* status. These individuals are talked about, rather than talked to (Cahill & Eggleston, 1994). In his seminal work on stigma, Goffman (1963) depicted these “physical deformities” as “abominations of the body” (p. 4) and referred to these “attributes” as “deeply discrediting” (p. 3). Much has been done to resolve prejudice against individuals with physical impairments (see, for example, Barton, 1996 and Marks, 1999). However, more needs to be done to decrease, or at least deter, discrimination and prejudice against individuals with physical impairments.

The disability rights movement, empowering the voices of individuals with disabilities, is the historical landscape within which the present study was conducted. Central to the disability rights movement has been enabling individuals with disabilities to speak for themselves and be heard on all matters affecting their lives. In this study, individuals are provided an opportunity to speak directly about matters that have led them

to understand their lives in particular ways and to develop strategies for coping with life's demands.

In this study I look at culture as perceived by individuals who have been marginalized. Observing the world as they experience it helped provide a better picture of some of the centrifugal social forces such as labeling and stigma that hold individuals with physical impairments at the margins of society. This study provides a view of the social dynamics of their world and a basis for deconstructing the power arrangements of the world in which they live their lives.

Among the issues explored, two hold particular interest to me because of my background as a physical therapist and as an assistive technology provider for individuals with physical impairments. The first are the differences between an individual with an acquired physical impairment compared to an individual with a congenital impairment. The second is the role that assistive technology played in the lives of these four individuals with physical impairments (Bryant & Bryant, 2003; Church & Glennen, 1992; King, 1999).

Research Questions

We have a lot of research on the social construction of self in individuals who develop typically and have no severe physical disability (Erikson, 1963). We know less about the development of self in individuals with physical impairments, the ways they interpret their lives, and the kinds of attributions that give meaning to their social world (Dupont, 1989). Several ecological variables such as the limitations on exploring the

physical world, attitudes of others toward their disability, and their interactions with assistive technology may influence their development of self. This study asks two questions:

How do these individuals with physical impairments understand and give meaning to their lived experiences?

How do participants in this study who have congenital disabilities differ from those who have acquired disabilities in the ways they understand and give meaning to their lives?

Method

I am a physical therapist and have worked with individuals with physical impairments for many years. At one point in my career I became aware that students with physical impairments who had more sophisticated and extensive assistive technology equipment seemed to enjoy a higher social status among their peers, teachers, family and friends. I became interested in examining specifically how identity might be impacted or shaped by circumstances of family life, culture/race/ethnicity, gender, age, and access to assistive technology for individuals with physical impairments. I also wanted to learn whether individuals born with the physical impairments defined themselves differently than those who acquired physical impairments later on in life.

A life history pilot study was conducted from January, 2004 through April, 2004. Based on the protocol for the pilot study outlined and described in Chapter 3, three

additional life histories were conducted for the study in order to further explore areas of interest. The results of the pilot study were then included as part of the study.

Life histories have re-emerged as a viable research method within qualitative inquiry to give voice to individuals and groups in society who have been marginalized (Angrosino, 2002; Angrosino & Mays de Perez, 2000; Denzin & Lincoln, 2000; Lincoln & Guba, 2000; Lindlof & Taylor, 2002). Angrosino (1998) effectively incorporated life history as a research method in his studies of individuals with mental retardation who were also mentally ill. This study utilizes life history as a means and opportunity for individuals with physical impairments to speak for themselves.

Because I have known each of the participants for many years, we co-construct a narrative that is unique based on our previous and present relationships (Fransella, 2003; Kelly, 1991). I bring my own constructs to the interviews and to the life history process. The participants also bring their respective constructs to the interviews. The combination of each participant and the researcher, as well as the coordination of all five participants in the study (the researcher is included as a participant), culminates in a co-construction unique to the time, place, and participants. The major advantage of including friends as participants in this life history study is the unique in-depth narrative that otherwise would not be possible.

Although our long-standing relationship significantly adds to the study, that same prior relationship and prior knowledge carries certain risks. These risks include omissions of events or facts due to assumptions on the part of the researcher or participant that the topic or occurrence is common knowledge between the participants in the discussion.

Similarly, events may be reported as having occurred based on the researcher and the participant having been at the same event coincidentally, but not having interacted. An example might be both attending an event advocating for the rights of individuals with physical impairments, but each remembering the event differently; followed by the researcher reporting the event as he remembers it without receiving verification from the participant because the event is assumed knowledge.

While friendship is an integral contributor to this research, that same friendship between the researcher and the participant has the potential to act as a barrier of information (Seidman, 1998). There may be certain feelings or interpretations that the participant may be unwilling to share for fear of jeopardizing the researcher's opinion of the participant. Likewise, the researcher may phrase questions, guide the discussion, or even interpret events and conversations that reinforce a preconceived perception of the participant or of the relationship.

Participants

I have known each of the four individuals at least ten years in my work as a physical therapist, durable medical equipment provider, and/or colleague through advocacy agencies for individuals with impairments. The four individuals vary in age, gender, race/culture, family life, and the type and etiology of physical impairment—whether the impairment is congenital or acquired.

Analysis

These interviews produced a rather dense script of the participants' experiences of life and meaning. The data were analyzed in two stages. I approached the first stage of data analysis through coding and re-coding into categories (Charmaz, 2000; Glaser & Glaser & Strauss, 1967; Strauss & Corbin, 1990). Themes in each participant's script were compared for similarity and consistency and overarching themes were constructed (Charmaz, 2000; Glaser & Strauss, 1967; Strauss & Corbin, 1990; Weitzman, 2000). Based on the coding and categorization of the data obtained, I emphasized what I determined to be the salient points of each individual's life history as they were described to me. Verification of this coding has been obtained by comparative coding of the data by a colleague, a doctoral candidate trained in qualitative methods of inquiry. In the final interpretive analysis, I draw conclusions about how well the study answered the research questions.

The second stage of analysis involved the researcher's reflections on each life history. As the fifth participant in this study, I include my reactions, responses, and reflections to each of the interviews (Denzin & Lincoln, 2000; Ellis & Bochner, 2000; Gergen & Gergen, 2000).

Credibility

Using the pilot study as a trial base for the study, issues regarding credibility of the study are discussed. Various forms of triangulation as well as peer review and an

audit trail for the entire study are described. Referential evidence and researcher veracity are described as forms of authenticity.

Transferability

Transferability in life history research relies primarily on the principle of verisimilitude. What each reader brings to the reading of this study will influence what each takes away from the study. What appears to be true and real may differ depending upon the reader's background and how each reader defines his or her own sense of self.

Discussion of Ensuing Chapters

In Chapter II, a historical background of individuals with physical impairments is presented including definitions pertinent to the study. These terms include congenital physical impairment, acquired physical impairment, handicap, assistive technology, race, culture, and family. Cognitive ability of the individuals in this study is discussed. In addition, defining individuals with physical impairments from a medical model perspective is contrasted with the social model construct. Finally, individuals with physical impairments are discussed in relation to the educational system—from center-based schools, to self-contained classrooms, to fully included educational environments in regular schools, to post high school graduate experiences.

Chapter III provides further depth and description of life history interview as the preferred method of qualitative inquiry for this study. The site, sample selection, and interview process is discussed. Trustworthiness (Lincoln & Guba, 1985) and various forms of triangulation in relation to reliability related to this study are also described.

The life histories of the four participants are shared in chapters IV, V, VI, and VII. Based on the coded life history conducted with Mike in the pilot study and relayed in chapter IV, the life histories of Theresa, Ellen, and Bill are shared and described in chapters V, VI and VII in a revealing style that allows each participant to speak in his or her own voice. At the conclusion of each of the participant's chapters, I provide a response and reaction to each life history.

In Chapter VIII, I present summary responses and my summative reactions to narratives from the field. My reactions to interviews and to the participants, as well as the personal meaning of the experience, are presented for review and criticism. A discussion of how well the study addressed the research questions leads to recommendations for future research for individuals with physical impairments.

IRB and Informed Consent

In addition to complying with the Institutional Review Board's criteria for human subject investigation, each participant was asked to complete an informed consent form. Participants were also given periodic opportunities to review their interviews to authenticate veracity. All identifying nomenclature included in the study, such as personal names, site locations, and locales were changed to prevent disclosure of participants' identities.

Chapter Two

INDIVIDUALS WITH PHYSICAL IMPAIRMENTS:

A MARGINALIZED POPULATION

Students with Physical Impairments in the Educational System

Today, the educational placement for individuals with physical impairments runs the full gamut from self-contained classrooms at center-based schools to full inclusion at regular schools where the only visible difference between individuals with physical impairments and regular students may be the method of mobility—one walks to classes, the other rolls. In the public school system, placement for a student with a physical impairment is determined by an evaluation process that usually includes an educational assessment, a psychological evaluation, a medical assessment, and a social history (Education, 2003; Kranzler, 1997). Predicated on guidelines set forth in IDEA (P.L. 105-17), students with physical impairments have their educational needs met in the least restrictive environment (Crockett & Kauffman, 1999).

The educational setting for individuals with physical impairments covers a wide range, contingent upon the evaluations and the staffing team's recommendations. For students who require the greatest amount of educational, medical, social and/or emotional assistance, a self-contained classroom at a center-based school may be the least restrictive educational environment. Students with physical impairments who require less

assistance, but still need a center-based school environment, may be mainstreamed throughout the school curriculum for recreational, diversional, or vocational needs.

Some school districts physically locate self-contained classrooms for students with physical impairments on regular education campuses, encouraging interaction with peers who do not have disabilities (Jenkinson, 1997). Some private schools maintain separate school facilities for individuals with physical impairments at the request of parents and advocates (School, 2003). These parents and advocates feel that a separate facility is safer and that a child with a physical impairment has more social and extra curricular opportunities—going to the prom, running for student government, etc. than if the student with a physical impairment attended a regular school.

As the mainstreaming model of the 1980's gave way to the inclusive model of the 1990's (Barton, 1996; Swann, 1985), more students with physical impairments were seen in regular education, either within special classes for students with varying exceptionalities or in the regular classroom (Stafford, Williams, & Heller 2001). As we proceed in the 21st Century, perhaps the equal status for individuals with physical impairments will become more of a reality through education.

An individual with a physical impairment may be limited in post graduation opportunities. In a study done in 1990, Liebert, Litsky, and Gottlieb found that postgraduate vocational opportunities for students with severe physical impairments were determined more by social contacts of parents than by ability or disability of the individual. While many educational programs for individuals with physical impairments are geared toward vocational rather than academic futures, job opportunities and

placements appear to be somewhat limited for individuals with physical impairments. Higher education and continuing education may prove to be the viable alternative for individuals with physical impairments due to the liberal nature of these institutions and their ability to accept differences more readily. Individuals with physical impairments appear to be headed towards acceptance and integration. Headway has been made in education. Through education, progress can be made within society. Assistive technology appears to be facilitating change and increasing opportunities for individuals with physical impairments. Little has been done to explore varying perspectives of individuals with congenital physical impairments compared to individuals with acquired physical impairments. While society appears to be more willing to accept responsibility for the differences created between people who are different and those who are the same, these differences need to be explored and defined in order to provide an understanding of our differences. This study is intended to assist in bridging that gap in understanding.

Historical Context: The Disability Rights Movement

Much of the progress made toward full social/economic participation by individuals with physical impairments can be credited to the Disability Rights Movement. The main body of literature related to physical impairments is contained within the Disability Rights Movement. There have been few studies done concerning the demographics and distribution of individuals with physical impairments. The primary emphasis has been on the psychological aspect of having a physical impairment (Weinberg and Williams, 1978; Wright, 1983). Goffman's seminal work on stigma in

1963 served as the base for the social construct of disability. Works that followed often discussed the social aspects of having a physical impairment.

Cahill and Eggleston (1994) described the emotional response of being in a wheelchair in public. Berube' (1996) and McDermott (2000) described a parent's perspective of what it is like to have a child with a disability. While Murphy (1990), an academician, described the social response to an individual with an impairment from the standpoint of one who lives the life of an individual with an impairment; Sacks (1998), also an academician and advocate for individuals with disabilities, described the personal response to society's treatment of individuals with physical impairments as he became an individual with a physical impairment for an extended temporary period of time. Thomson (1997) included the feminist perspective of disability within American culture and literature. Marks' (1999) discussion about the disabling environment and the limitations that society imposes on individuals with disabilities reinforced the social construct of disability described by Barton (1996), Oliver (1996a), and Barnes (1996). Priestley (2003) attempted to take the emphasis away from the disability and draw similarities between the mainstream culture and individuals with physical impairments by emphasizing life's stages that are common to both groups. Priestley's life course approach acknowledged the individual model of disability that describes each person moving through their respective stages, but maintained that collective gains are greater when commonalties are compared and shared.

Although many events and individuals were instrumental in the historical underpinning of the disability rights movement, the formation of the Centers for

Independent Living (CIL's) in 1972 appears to represent the time when individuals with physical disabilities received public acknowledgement of their needs and of the quest for independence and equal status (Fleischer & Zames, 2001; Marks, 1999). The impact of activities preparatory to the disability rights movement prior to the formation of CIL's did not receive comparable public support. Even though Franklin Delano Roosevelt contracted polio in 1921, established Georgia Warm Springs Foundation for Rehabilitation in 1927 and became President in 1932, individuals with disabilities received minimal public awareness of their concerns (Houck, 2003; Krauthammer, 1997; Thomas, 1997).

As testimony to the lack of groundswell for the disability rights movement, the League of the Physically Handicapped was organized in 1935, but was disbanded in 1938 (Fleischer & Zames, 2001). However, individual and group efforts on behalf of individuals with disabilities continued. In 1948, Tim Nugent effectively established wheelchair accessible facilities and sports for people in wheelchairs at the University of Illinois (Fleischer & Zames, 2001). In 1949, the United Cerebral Palsy Association, under the leadership of Leonard Goldenson, president of the board of ABC Broadcasting and father of a child with cerebral palsy, united all the local cerebral palsy organizations into a national effort (Goldenson, 1991).

The Civil Rights Act was passed in 1964 and had a major impact on the disability rights movement. Parallels between the civil rights movement and the disability rights movement have been drawn on more than one occasion (Charlton, 1994; Fleischer & Zames, 1998). Following the passage of the Social Security Act establishing Medicare

and Medicaid in 1965, amendments were made in 1972 that would allow recipients of disability benefits under the age of 65 to qualify for Medicare (Fleischer & Zames, 2001). It was during this period of the 1970's that P.L. 94-142, The Education for All Handicapped Children Act, later known and amended as IDEA, the Individuals with Disabilities Education Act, became law in 1975 (Orsi, 2001). Through education, individuals with physical impairments could receive an *equal* education. Meanwhile, on the employment front, individuals with physical impairments were bolstered by the regulations of Section 504 of the Rehabilitation Act of 1973.

Five years after the United Nations declared 1981 as the International Year of Disabled Persons, Irving Zola founded the Society for Disability Studies (Fleischer & Zames, 2001). The American with Disabilities Act (ADA) became law in 1990 mandating equal accessibility, employment, and legal status for individuals with physical impairments (Congress, 1990). As ADA was implemented, voices spoke for individuals with physical impairments.

Medical Model vs. Social Model of Disability

The medical model is the traditional model of defining and describing an individual with a disability (Marks, 1999). While Billson et al. (1996) provide an organically oriented definition of the medical model of disability, I prefer to put this descriptive model of disability in a reparable malfunction perspective. That is—something is wrong (with the individual) and if worked at long enough, can be fixed. At the very base of this model is that someone external to the individual with a physical

impairment considers himself or herself a benefactor and is determined to do something *to* the individual with the physical impairment to *fix* the disabling condition. The onus and responsibility for the condition rests on the individual with the physical impairment. In this case, *the victim* is to blame for his or her difficulty (Marks, 1999). Ever since the inception of the disability, whether it is acquired or congenital, the medical community has diagnosed the problem. The sole purpose and thrust of all interventions is to help the individual with a physical impairment return to a state of normal—that is, without disfigurement and appearing to function as an individual who is able-bodied.

There are two notable examples of the medical model in action. The first is the evolution of politically correct designations of individuals with physical impairments. The derogatory terms of today (e.g., cripple, spastic) were previously acceptable clinical terms. For example, The Crippled Children's Society and The Spastics Society in Great Britain were not only acceptable terms in their day, but were also used to garner sympathy and generate funds for those less fortunate. It is exactly that perspective of the individual with a physical impairment being medically dependent that gave rise to charity support (and degradation) (Drake, 1996). Individuals with physical impairments were described by their condition. An individual who was paralyzed from the waist down as a result of an automobile accident was referred to as a *para* to connote that the individual's legs were paralyzed. Compare that designation to a *quad* who was someone whose arms and legs were paralyzed. A *spastic quad* was an individual who had spastic quadriplegic cerebral palsy, and in all probability, could not walk without significant assistance, experienced difficulty with expressive language due to spastic throat musculature, and

required a good deal of assistance for activities of daily living. A *spina bif* was an individual who had spina bifida, was essentially paralyzed from the waist down as the result of a birth defect (notice the term *defect* is short for defective). The individual with spina bifida was most likely incontinent of bladder and or bowel and was limited to a wheelchair for mobility.

Nowhere is the medical model more evident than in the educational system. This second example of the medical model in action is somewhat disconcerting because the perpetuation of the medical model is learned and passed along to the next generation. While individuals with physical impairments have progressed from being handicapped to being physically handicapped to being physically impaired and are finally, individuals with physical impairments, there is still a grouping and a delivery of services based on the handicapping condition (Riddell, 1996). Even as the educational system has progressed from having separate schools and classes for *spastic children*, to providing service delivery systems based on the severity of the disability (i.e., mild, moderate, or severe), it appears that the emphasis of the educational intervention is still based primarily on the handicapping condition and not on the individual.

The social model of disability is a contrast to the medical model. The emphasis in the social model of disability is “society’s failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization,” according to Oliver (1996b, p. 32). In the social model, fault of the physical impairment is not at issue. The physical impairment is not considered an aberrant condition that requires fixing. Rather, the onus is on society to make

accommodations that will facilitate acceptance of individuals with physical impairments as equals.

There is a long history of the social construct of disability (Barnes, 1996). Based in part on the industrial revolution and on the inability of individuals with physical impairments to compete equally in production assembly, a less-than-equal status was created for individuals with physical impairments (Finkelstein, 1980). Because the differences of the handicapping condition were readily apparent to the casual observer, individuals with the physical impairments were castigated for their differences, rather than accommodated and accepted. That is the summary of the social model of disability—arrangements for equal status for individuals with physical impairments are created and maintained and the commonalities among and between individuals with and without disabilities are emphasized and encouraged. The disability rights movement based on the social model of disability is quite similar to the platform of the civil rights movement.

Definitions

There has been considerable inconsistency in and confusion over, the use and definitions of terms related to the concept of disability. The terms “handicapped,” “disabled,” and “impaired” have often been used interchangeably. The terms *physically-handicapped*, *physically-disabled*, *physically-challenged*, and *physically-impaired* have been variously applied to individuals, more in an attempt to maintain politically acceptable terminology than as a way to accurately describe individuals with physical

impairments. (See Sutcliffe, 1972 in *Physiotherapy* as an example of referring to individuals with physical impairments as *physically handicapped*, and see Schoenman, 1995 as an example of referring to individuals with physical impairments as *physically disabled persons*).

In the 1980's, however, the World Health Organization (WHO) differentiated among these terms in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). An impairment is defined by the World Health Organization as any temporary or permanent loss or abnormality of a body structure or function, whether physiological or psychological. An impairment is a disturbance affecting functions that are essentially mental (memory, consciousness) or sensory, internal organs (heart, kidney), the head, the trunk or the limbs. A disability is a restriction or inability to perform an activity in the manner or within the range considered normal for a human being, mostly resulting from impairment. And a handicap is the result of an impairment or disability that limits or prevents the fulfillment of one or several roles regarded as normal, depending on age, sex and social and cultural factors (W.H.O., 1980; W.H.O., 2001). The preferred designation is to refer to the individual first and the condition second, i.e., *an individual with a physical impairment* (Fernald, 1995; Lehrer, 2004).

When clarifying the distinctions among these terms, this tripartite conception has been criticized by the proponents of the Social Model of Disability and the Union of Physically Impaired Against Segregation (UPIAS). UPIAS was specifically concerned with the limitations that society placed on individuals with physical impairments which prohibited participation in mainstream social activities (ENABLEnet, 2004).

In response to these concerns, a new set of definitions (ICIDH-2) has been introduced by WHO. According to the ICIDH-2, the disability experience is composed of three dimensions: impairment, activity, and participation. These dimensions were defined at the Fifty-Fourth World Health Assembly of the World Health Organization:

Systematically groups domains of health and health related domains for a person in a given condition (i.e. what individuals can do or do...when they have a disease or disorder). The body component defines functional structures of the body system. The activity and participation component covers a range of life domains in which individuals may engage (e.g. learning, moving around, self-care, work, etc). Capacity and performance of each individual can be coded in a defined domain. ICIDH-2 also lists environmental factors that interact with all these domains (W.H.O., 2005).

By using this classification system, impairments are viewed as health-related outcomes and not disabling or handicapping conditions. These health-related outcomes are norm-referenced on the mainstream population, thereby indirectly including individuals with physical impairments. By including the environmental factor associated with all three domains, the emphasis shifts away from the medical model and strongly accentuates the social model of disability (Turmusami, 2003).

However, until the service delivery system catches up with the definitions in ICIDH-2, individuals with physical impairments remain at a disadvantage. Almost all service delivery systems such as Vocational Rehabilitation and Developmental Services (part of Health and Rehabilitative Services) continue to provide services to individuals with physical impairments based on their medical diagnoses (Florida Developmental Disabilities Council, 2004).

The purpose of this study is to give four individuals with physical impairments the opportunity to tell their stories. Specifically, I explore the impact of assistive

technology and contextual variables (age, sex, race, culture, ethnicity, and family structure) on activity and participation in the lives of the four study participants and the way in which impairment, activity, and participation have contributed to each participant's sense of self.

Physical Impairment Defined

Physical impairments have been traditionally defined based on the medical model of disability, primarily by defining the part(s) of the body that do not perform in what is considered a normal coordinated movement (Bobath, 1967; Council, 2001; Myers & Shapiro, 1999). These impairments may range from mild, where fine motor activities are impaired (Abbruzzese & Berardelli, 2003; AOTA, 1997; Ayres, 1979; Case-Smith, 2002; Schwellnus & Lockhart, 2002), to severe, where total assistance is required (Bidabe, Barnes, & Whinnery 2001; Cook & Hussey, 2002). In addition, the individual may have problems with communication (Lloyd, in press) and self-help skills (Bundy, Fisher, & Murray 2002; Finnie, 2000; Kellegrew, 1998). Varying levels of assistive technology may be required dependent upon what portion(s) of the body are affected by the physical impairment (Iannaccone, 1992).

The causes for the physical impairment can be genetic. or may be acquired (Best, Heller, & Bigge, 2005; Bowman, McLone, Grant, Tomita & Ito, 2001; Chapman, 2002; Finnie, 2000; Kaye & Longmore, 1997; LaPlante, Carlson, Kaye & Bradley, 1996; Msall & Tremont, 1999; Myers & Shapiro, 1999; Obringer & Coffey 2003; Uyanik, Bumin, & Kayihan 2003; Willard-Holt, 1998). The *Oxford English Dictionary* on-line (OED)

defines congenital as “existing or dating from one's birth, belonging to one from birth, born with one (a congenital disease or defect).” Likewise, OED offers the third definition of acquired as “a development in an individual... occurring during its lifetime through the influence of its environment.” By combining these terms with an individual with a physical impairment, the terms used to describe an individual with a physical impairment has been categorized in one of two ways. Either the person is born with the impairment, in which case the person is said to have a congenital physical impairment, or the person incurs a physical impairment as the result of a life-altering event, and is said to have an acquired physical impairment.

The federal definition of a physical impairment is described as an orthopedic impairment, “impairments caused by congenital anomaly, impairments caused by disease, and impairments from other causes” (U.S.D.O.L., 1987). In the context of this study, I define an individual with a physical impairment as a person whose disability is readily apparent to the casual observer and whose impairment interferes with social integration.

While there may be similarities in disease or medical condition presentation, no two individuals with physical impairments can be considered identical due to the inherent individual nature of each person (Keefe & Jenkins, 2002), and because the medical condition affects each individual differently (Council, 2001). Consequently, it is the evolved social model of disability reflected in the definition of impairment by the World Health Organization that takes precedence and priority over the medical model of disability in this research. This perspective is reinforced by each of the participants as well as by the researcher.

Cognitive ability varies in individuals with physical impairments, just as cognitive ability ranges for any other group in society. In this study, cognitive refers to the action or process of knowing. The individuals in this study demonstrate the process of knowing by effectively describing his or her relationship to the environment, thereby demonstrating cognitive abilities that allow each individual to function within the mainstream of society.

Contextual Factors

According to the Florida Developmental Disabilities Council, most agencies that collect statistics on individuals with disabilities approximate that ten per cent of the total population in any given area within the United States has a disability. By combining this generalization with the lack of agreement of what constitutes a disability, much less a physical impairment, and it becomes evident that descriptive statistics may assist in providing a general description of individuals with physical impairments, but generalizations to target populations proves prohibitive.

For example, LaPlante (1992) reported that 17.4%, or 5,873,000, of the 36.1 million individuals with disabilities in the United States, had an orthopedic (or physical) impairment. Previous to that, Laplander (1988) described 13.9% of individuals less than 69 years of age with physical impairments had disabilities related to the back and spine; while 18.1% of those with physical impairments under the age of 69 had disabilities relating to physical impairments other than those relating to the back and spine. LaPlante (1996) limited the number of individuals who were disabled as the result of paralysis to 1.8% of the total number of people who were disabled in the United States at that time. In

the same study, LaPlante described 14.1% or 8,806,000 individuals as having orthopedic impairments. These two categories could roughly be equated with individuals with acquired physical impairments being equal to those with paralysis, and those with orthopedic impairments equaling individuals with congenital physical impairments.

Interpreting the data from the U. S. Census Bureau (2005) provides more definitive demographics pertinent to this study. The population for the United States in 2003 was reported at 262,582,164. Five percent of the population, or 12,766,882 individuals, were between 16 and 64 years old and reported having a physical impairment. Of these individuals with physical impairments, 9,693,540 were male; 4,038,381 reported that they were employed, and 5,655,159 were not employed. The females with physical impairments between the ages of 16 and 64 years of age numbered 519,327; 151,188 were employed, and 368,139 were not employed. Of this same age group of individuals with physical impairments, 9,510,262 listed their ethnicity as white and 2,036,574 described themselves as either African American or Black. These figures are provided for background only and are not intended to facilitate conclusions of any kind.

Factors that may contribute to feelings of marginalization for individuals with physical impairments include age, gender, race, culture, diversity, and family life. Researchers have contributed to each of these areas throughout the disability rights movement. Noonan, et al. (2004) and Neath (1997) provide interesting studies of gender perspective relative to physical impairments. Neath (1997) described the social causes of impairment and disability from the feminist perspective and explained how these

causes contributed to the abuse of individuals with impairments. Noonan et al. (2004) theorized a system of influences around a core of the *dynamic self* for 17 highly achieving women with physical disabilities. These influences on self include identity constructs (disability, gender, race/ethnicity/culture, personality), personality characteristics, and a belief in self.

Indications are that a large part of identity is socially constructed. Using Erikson's theory of psycho-social development as a base, the fifth stage of development, identity versus role confusion, implies a relationship with the environment. The environment is only one component that contributes to the creation of self. In addition to social competence as an indicator of self, physical competence, conceptual intelligence, and emotional competence all play a part in the personal competence of an individual. Borrowing from a model of personal competence outlined in Raymond (2004) and based on AAMR (1992), Greenspan and Granfield (1992), Gumpel (1994), Mathias (1990), McGrew and Bruininks (1990), and McGrew, Bruininks, and Johnson (1996), the formation, creation and maintenance of self is reflected in the individual's feelings of self which, in turn, are controlled by feelings of physical competence, social competence, and emotional competence. For the purposes of this study, self will be defined as what one is at a particular time or in a particular aspect or relation; one's nature, character, or (sometimes) physical constitution or appearance, considered as different at different times.

Oftentimes it is the personal construct of self that helps define an individual (Fransella, 2003; Kelly, 1991; Kelly, 2003). An understanding of an individual's place in

the world can be gained by looking at the constructs that an individual uses (Kelly, 1991). By looking at self-descriptors, an indication of the perception of self can be obtained (Markus and Nurius, 1986). Without making a value judgment regarding these self-descriptors, clues that help define the self of an individual can be obtained (Morse, 2005). In this construct, questions relative to the self are: How do individuals describe themselves; Are there indicators that inform how an individual deals with life? By searching for answers to these questions and assessing each participant's relative level of development using Erikson's stages of psychosocial development (Erikson, 1963), a definition and assessment of self can be constructed for each participant.

Race, culture, and ethnicity can have an impact on the marginalization of individuals with physical impairments (Block, Balcazar & Keys, 2002; Obiakor & Wilder, 2003). Individuals from a culturally diverse background have been exposed to the same marginalization that individuals with physical impairments presently undergo. In fact, comparisons have been drawn between the civil rights movement of the 1960's and the disability movement of the 1980's. (For an overview, see Zola's review (1994) of three books [*A Review of The Disability Business: Rehabilitation in America*, by Gary L. Albrecht; *No Pity--People With Disabilities Forging a New Civil Rights Movement*, by Joseph P. Shapiro; and *We Overcame: The Story of Civil Rights For Disabled People*, by Richard Bryant Treanor]). Of the four individuals in this study, only individuals from African-American descent and European descent have been included. However, individuals and groups who are part of other culturally diverse populations may identify with perspectives and opinions expressed by the individuals in this study.

Formative family life and present family structure can also have an impact on the perception that individuals with physical impairments have of themselves (Banks, 2003). The family unit will be discussed as the individual with the physical impairment matures, matriculates through school, and establishes his or her own family. A perspective of what family life means to an individual with a physical impairment will be addressed from each individual's viewpoint.

Assistive Technology Defined

Assistive technology has been defined as “the applications of science, engineering, and other disciplines that result in processes, methods, or inventions that support people with disabilities” (Bryant & Bryant, 2003, p. 2). Applied to an individual with a physical impairment, assistive technology is designed to carry out an activity with or without another person, or to facilitate the individual's involvement in regular activities (Council, 2001). The access to the activity may be the key use for assistive technology and may be oriented towards mobility for the individual who is non-ambulatory (Bergen. Presperin & Tallman, 1990; Church & Glennen, 1992). Assistive technology may be designed for positioning to allow the individual with a physical impairment a comfortable, therapeutic position that facilitates access to the environment (Cook & Hussey, 2002). Or, the assistive technology for individuals with physical impairments may be adaptations to access a computer or other electrically powered devices (Bryant & Bryant, 2003; Esposito & Campbell, 1987). Finally, assistive technology may modify the environment for the individual with a physical impairment,

such as electric door openers or voice actuated electronic devices (Angelo & Trefler, 1998; ScanSoft, 2003; Schmeisser & Seamone, 1979). Although augmentative and alternative communication devices (AAC) are an extensive part of assistive technology for individuals with physical impairments, communication devices and that segment of assistive technology will not fall within the realm of this study. Those interested in AAC are referred to Lloyd and Arvidson's Augmentative and Alternative Communication Perspective Series and the associated bibliographies (Lloyd, in press).

Use of Assistive Technology for Individuals with Physical Impairments

The scope of assistive technology becomes quite narrow when applied to individuals with physical impairments. Assistive technology can be used for positioning to prevent expensive and painful skin breakdown or to facilitate body alignment for erect posture that encourages midline head and body alignment for educational activities. This type of assistive technology includes sidelyers, adaptive chairs, adaptive strollers, cut-out tables and standing devices. Assistive technology can also be used for mobility for individuals with physical impairments that would include manual and power wheelchairs, strollers, and ambulatory aides such as canes, walkers, crutches, helmets, and gait belts.

Educational accessibility for individuals with physical impairments can be enhanced using assistive technology. Low-tech devices in this category include built up pencil grips, adaptive handles for utensils, and slant boards for reading and writing. Higher-tech assistive technology devices in this category range from switches to interface

with computers to environmental control units such as electric door openers, manual and electric lifts, and voice actuated computer programs.

In addition to the laws underlying and directing assistive technology in school settings, Levine (2000) discusses *reasonable accommodation* for including students with physical impairments into regular education. Weiss and Dykes (1995) relay the legal issues related to assistive technology ("Brown v Board of Education Topeka," 1954; "Individuals with Disabilities Education Act Amendments of 1997 Pub. L No. 105-17. 64 Fed Reg. 12406," 1999; Medicaid, 2003 "Technology-Related Assistance for Individuals with Disabilities Act of 1988," Congress 1990; Government, 2003).

Research in the area of assistive technology falls into one of four categories: mobility, positioning, environmental control devices, and augmentative and alternative communication devices. Mobility for students with physical impairments is one of the more common areas to which authors have directed their attention. (See Bergen, Presperin & Tallman, 1990; Butler, 198; Jones, McEwen, & Hansen, 2003; Korpela, Sirtola & Koivikko, 1992; and Primaro & Colatarci, 2003 for a sampling of this area of assistive technology for students with physical impairments).

A few authors have offered predictions of the future of assistive technology (see Hasselbring, 1997; Malcom, 1998; and Nickerson & Zodiates, 1988). However, the majority of research written about students with physical impairments and assistive technology addresses the concept and practical implementation of inclusion into regular education for students with physical impairments. (See, for example, Bleck, 1979; Blenk & Fine, 1995; Bodine, 2002; Lahm, 2003; and Zabala, Blunt & Clark 2000).

As Todis (1996) has pointed out, there are many reasons why assistive technology may not be effectively used for a student with a physical impairment. The primary reason appears to be that the student was not included in the equipment selection process. In addition, lack of training of the student, teacher, and family on the benefits and use of the equipment contributes to the lack of utilization of assistive technology by students with physical impairments. Although lack of funding can be an issue, the recommendation of expensive high technology when medium, or even low technology is preferable, contributes more to the poor utilization of assistive technology. Assistive technology works best for individuals with physical impairments when a team approach is used (Zabala, Blunt & Clark 2000).

In the text and in the interviews, the terms disability, impairment and handicap are used interchangeably according to the respondent's own vernacular. That is, each respondent will refer to himself or herself as a person who is handicapped, disabled, or impaired. How each respondent chooses to use the term will be considered to be correct.

Through the advent of the Disability Rights Movement and as a result of the transition away from the medical model of disability towards a social model of disability as reflected in the definition of an individual with a physical impairment by the World Health Organization, progress has been made towards decreasing discrimination against individuals with physical impairments. Regardless of whether education proves to be a medium of equality for individuals with physical impairments, caution must be exercised if the parallel continues between the disability rights movement and the civil rights movement, lest valuable ground be lost to *separate, but equal*.

Chapter Three

METHOD

Why Life History

Life histories have been used to study individuals with mental illness and mental retardation. Angrosino (1998, 2002) used life histories effectively in ethnographic research speaking for and with individuals with disabilities. By encouraging the individuals to speak on their own behalf, Angrosino created an environment that allowed the reader to identify with the participants of the study. In this study, life histories are used to allow individuals with physical impairments the opportunity to speak for themselves. Nuances of identity formation within social attributions of age, gender, race/culture/ethnicity, and family life can be explored, developed and shared from the first-person perspective of the individual with the physical impairment. Issues of the effect of time of acquisition of the physical impairment and whether assistive technology plays a role in an individual's life can be more poignantly shared. Life histories make personal contact with the audience (Angrosino, 2002) since individuals can identify with a life story told from the person who lived it. Therefore, a wider audience can be reached and more lives can be impacted.

In this chapter the role of a pilot study is described. Following that description, a discussion about sampling and participants in the study takes place. Next, methods of

triangulation are detailed. Immediately after that, an examination of the peer review process incorporated into the study is relayed. An audit trail for the entire study is then detailed. Next, referential evidence is described, followed by a discussion of transferability as verisimilitude. The final section of the chapter describes the researcher's veracity.

Pilot Study As Guide

Background

A pilot study as described by Maykut and Morehouse (1994) was completed as a precursor to this study. The participant in the pilot study, Mike, agreed to be interviewed and be part of the study for many reasons. First, and foremost, Mike had something he wanted to say about being disabled. He felt he had a story to tell and he wanted people to hear what he had to say. Because part of my agenda as a researcher was to relay the lived experiences of individuals with a physical impairments from their perspectives, our goals were mutually aligned. Life history was an appropriate method to accomplish our mutual goals.

Mike also agreed to be a participant in the study because of our long standing friendship. We have known each other for over 25 years in our roles as he being a patient and my being his physical therapist, co-inventor and supplier of durable medical equipment; but most importantly, as friends with very similar personalities and perspectives on life.

The benefits to Mike for participating in the study were a chance to tell his story (Ellis & Bochner, 2000), and to help deter discrimination against individuals with physical impairments by contributing to the research on the similarities of individuals, rather than the differences. A possible risk for Mike was the emotional stress resulting from talking about sensitive issues. Since we were such close friends and have known each other on a medical level as physical therapist and patient, on a business level as seller and buyer of services and products, and on a very personal level having discussed matters of intimacy and relationships about girlfriends and wives, I felt the emotional risk was minimal and I felt that I could provide the emotional support as needed. Being that our friendship would continue long after the study was done, I felt even stronger that if Mike needed counseling beyond what I could provide, that I could secure and ensure that it was provided.

We were, and are, close friends. That is relevant to the study because what Mike and the other three participants share with me is a more in-depth, more candid, more honest response and is closer to each person's core beliefs due to the nature of our relationship. There is a unique relationship of trust and interdependency established between an individual and his or her physical therapist. There is an emotional bonding that transcends intellect because of the private and personal touch between the (physical) therapist and patient. Because of this bond, a long-lasting deep, abiding, trusting friendship is possible between the physical therapist and the patient long after therapy stops. And when personalities and outside interests coincide between the therapist and the

patient, a meaningful, trusting friendship ensues. Such was the case with Mike and with the remaining three participants in the study.

In addition to being a therapist and a friend, I add a third perspective to the study. As a researcher, I offer a scientific perspective of what it is like to be an individual with a physical impairment. An outside researcher could offer different biases and perspectives, but could not offer the depth of the experience due to the absence of the intimate friendship. In this study a friend, therapist, and researcher interacts, records, and responds to individuals with physical impairments in an organized, scientific, coherent manner.

Pilot Study Protocol

The following protocol was used in the pilot study:

- Initial phone contact—I had seen Mike two days prior to my initial phone contact about the study, so the call came as no surprise to him. After exchanging pleasantries, I explained that I was doing a study on individuals with physical impairments and that I was interested in individuals speaking for themselves rather than someone speaking for them. I told him that in addition to the anticipated two or three extended interviews that would occur at a place and time that was convenient for him, that I would be including my perspectives of what he said as well as including what I knew and could find out about his life's history. He was typically sarcastically enthused about the prospect of talking about something that was important to him.

- First interview—at the first interview, I shared the informed consent form and emphasized the areas of interest included on the form—age, gender, race/culture/ethnicity, family life, time of onset of the disability, and assistive technology as they relate to forming the identity of an individual with a physical impairment. We reviewed the possible benefits to him of telling his story and helping to deter discrimination against individuals with physical impairments and the potential risk of emotional disclosure. Mike’s scoff at the potential risk reinforced my perception that emotional risk would not be a problem. To help organize the telling of Mike’s life history, a backdrop concerning some of life’s major milestones was offered. For example, I prompted with comments such as “When I think about how I would go about telling someone about my life, I think of the major stages or events in my life, such as where I was born, where I first went to school, the best (and worst) things that happened to me in elementary school, when my siblings were born, where I went to high school, what happened when I graduated, the major incidents in my life. For a start, where were you born...?”
- Providing feedback and clarification—I showed support and encouragement as Mike started to talk about his life. My focus was on providing a safe context for Mike to talk. In the beginning I specifically tried not to direct what he was saying.
- Beginning to direct the interview—one of my interests in the study is how a participant understands the self and how he makes meaning of his life as a person

with a disability. I began to explore this issue after Mike told me about his girlfriend. I then thought it reasonable to begin to encourage him to talk about his personal life and experiences. For example, “You said that you didn’t think that she broke up with you just because you were in a wheelchair. What did you mean by that?”

- Points of interest—when there were lulls in the conversation, points of interest that had not yet been covered were suggested. For example. “In thinking about your experiences in a wheelchair, are there experiences you have had that might be different to someone who is not a white male?” These additional probes continued throughout the interview process until all items of interest had been covered.
- Sensitive issues—Because of the quality and nature of our relationship and my having been Mike’s physical therapist, I thought it more likely that Mike would be willing to discuss sensitive issues such as sexuality and hygiene (incontinence secondary to spasticity). My perceptions proved true. At no point in our interviews did Mike display any verbal or non-verbal reservations about discussing even the most intimate of topics.
- Gender issues—Mike’s gender bias was subtle throughout the life history interview process. All attempts will be made to appreciate gender perspective and bias throughout the study.
- History with participants—having a history with Mike, I entered the life history process with a mindset based on 20 years of friendship. Therefore, I had special

knowledge of his life. Since my questions came out of that knowledge, I had to remain aware that we were co-constructing our story. Such would be the case with each participant. The culmination of the entire study was the joint product of all five of us.

- Second interview—Primarily due to our long-standing friendship and familiarity with each other, we were able to pick up where we left off fairly quickly in the second interview. Having transcribed the previous interview, I simply read back the last transcribed page and Mike continued his story as if there had been no interruption. The second interview also lasted almost three hours.
- Third interview—the duration of the third and final interview was also approximately three hours and was mutually concluded (Charmaz, 2000). That is, Mike felt that there was nothing additional he wished to contribute about his life history and, having transcribed and reviewed the interviews to date, I felt that no additional information would add to the pool of knowledge about the items of interest including age, gender, race/culture/ethnicity, time of onset of impairment, family life, and assistive technology relating to individuals with physical impairments. At the conclusion of the interviews, my commitment was given to Mike that I would provide him with successive copies of the transcribed interviews as well as the final proposal and dissertation to allow him the opportunity to review the data for veracity. I relayed, and he understood and accepted, that his review of the data was for accuracy, but did not include editorial authority. He affirmed that he was comfortable with those guidelines.

- Evaluating the interview—The interview process was critiqued by a colleague after audio tape recording and transcribing the pilot study. Following a careful review and analysis, questions, prompts, and cues were adjusted to obtain a smoother flow of information from each remaining participant.

Protocol for Main Study

The protocol that was used in the pilot study was the same one used for the succeeding interviews. Based on my experiences using life history method and on the protocol used in the pilot study, the following procedures were implemented in the final study:

- Establishing relationships—each participant is known to me as a friend, as a physical therapy patient, as a consumer of adaptive equipment that I supply, and as a co-researcher. It is the in-depth friendship that I enjoy as a result of the therapist/patient relationship that makes this study unique.
- Transitions—establishing trust and rapport are crucial to transition to topics of interest to the researcher. Unless the participant can be made to feel comfortable, guiding the conversation meets with resistance and ends in mutual frustration. My interpersonal skills and our established friendships have helped pave the way for smooth transitions.
- Sensitive issues—If the participants appear reluctant to share sensitive issues or concerns because they feel that might lower my opinion of them, I address the issue forthright, reassuring them that I value our friendship and trust and that my

opinion of them will not be negatively affected by anything they may choose to share. Likewise, I refrain from avoiding sensitive questions or guiding the discussion away from sensitive issues or interpreting the results based on a preconceived perception of the participant.

- Because of our trust, sensitive issues are discussed and handled. Friendship encourages the open exchange of ideas and feelings that would not otherwise be possible. This study is dependent on the trust and friendship already established between the researcher and the participants. We were, in fact, all participants together in a mutual effort and product.
- However, because we are friends, I caution against assumptions being made by both the interviewer and the participant. Because our friendship bespeaks a common knowledge, the potential to assume that the other knows what one is saying can lead to the sin of omission of potentially critical information. Similarly, I run the risk of including events solely from my perspective without receiving verification from the participant due to an assumption on my part that the recall of the event is common knowledge. Because I am aware of these potential pitfalls of interviewing friends (Seidman, 1998), I monitor our discussions in progress, and after the fact, during transcription. I make adjustments accordingly, thereby keeping this potential problem to a minimum.
- Interviews—more than three interviews were required. Approximately three hours per interview were indicated. Each interview session was contingent upon the dynamics of each individual.

- Recording interviews—each interview was tape recorded and transcribed by the researcher. Dragon Dictates, a voice-to-print software program, was used for the first interview with Mike and was found to be technically pleasing to the researcher, but more time-consuming and laborious than productive. Its use was
- discontinued. Likewise, Atlas ti, a qualitative data analysis software program was used for data collection and storage, but due to its complexity and design as a grounded theory analytic program, was discontinued (Strauss & Corbin, 1990; Weitzmann, 2000).

Self-Descriptors

In order to obtain self-descriptors of the participants, a self data survey (Morse, 1978) was administered. Results of the survey for each participant are included as well as a response by the researcher. The self data survey instrument and each participant's response to the survey are included in Appendix A.

Analysis

The interpretive framework for each life history was chronologically oriented and followed the life span of the individual. Each participant's life history is shared in separate chapters with a sub-chapter following that provides the researcher's reactions and responses to the life history. A summative chapter of overall responses and reactions of the researcher follows the final participant's chapter.

Critical markers that relay significant or important self-defining issues in each individual's life were shared as they arose. Areas of interest such as age, gender, race/culture/ethnicity, family life, time of onset of disability and assistive technology serve as points of discussion within the overall framework of the narrative. Each life history interview was informed by verbatim material from the participants to achieve authenticity and to provide low inference descriptors (Ary, Jacobs, & Razavieh, 2002; Johnson & Christensen, 2000).

Issues for analysis included:

- Conflating the roles of researcher, therapist and friend and relaying how that affected the interaction between the researcher and the participants.
- My feelings of relating to each participant and the effect that had on us individually and mutually.
- Knowing the participants beforehand provided insights into areas that perhaps would not have been considered by another outside researcher. This also may have led to information that was assumed and readily apparent to the researcher and the participants, but would not be common knowledge to an outside researcher.
- The ethical issue of abandonment does not appear to be germane to this research. I was each participant's friend before the research began and will remain so following the culmination of this study.

Sampling

By selecting a diverse range of gender, age, race/culture, family and congenital or acquired physical disabilities, this purposeful sampling provided a variety of individual perspectives (Guba & Lincoln, 1981). Opinions by each respondent provided one perspective of what it was like to be that person. Incorporating five perspectives—mine, plus the four participants interviewed in this study, increased the potential for transferability of the results.

Participants

There are a total of four participants in the study. Mike is a 32-year-old single male of European descent with cerebral palsy. Mike has no children and lives alone in an apartment. Theresa is a 36-year-old single female widow of African American descent with a 15 year-old daughter and a 12 year-old son. Theresa and her children live in a house and she commutes back and forth to work and college in her power wheelchair. Theresa was paralyzed as a result of an auto accident 12 years ago. Ellen and Bill have been married to each other for 39 years. They are both of European descent; Ellen is 62 and Bill is 63. Ellen was paralyzed from the waist down due to a fall when she was a teenager, and Bill was born with cerebral palsy. They met in a special residential school for people with disabilities when they were young.

Triangulation

In addition to the recorded life histories of the four participants, I provide reactions and responses to each of the life histories, thereby including self as a participant. Maintaining a journal of reflexive field notes throughout the intensive, extended interviewing process assisted in defining my responses. Participant observation as an active participant in the disability movement over the last 25 years, as well as the ethnographic experience of interacting with each of the respondents throughout the last ten years is included as part of the life history process.

Peer Review

Peer review as a method of consensus is incorporated into the study (Denzin & Lincoln, 2000; Eisner, 1998). Based on the pilot study, data were organized through the technique of coding and re-coding (Dey, 1999; Strauss & Corbin, 1998) and provided a form of pattern matching. In the pilot study, each line was coded to reflect the contents. Obvious codes denoting gender, race, congenital and acquired were used as well as less obvious codes of personality, environment and circumstances. Codes were initially as elaborate as needed to describe each line of data, such as “psychological factors of individuals with physical impairments” and “sibling effect on household operation.” Each category was then evaluated for its pertinence to the study and was either incorporated into the study or was collapsed into a larger family of similar concepts, e.g., “sibling effect on household operation” eventually became part of “family life.”

After the pilot life history was coded, the list of codes and the uncoded data were shared with a colleague who was trained in qualitative data analysis. The colleague is a doctoral candidate in special education with extensive coursework in qualitative inquiry. She is also the parent of a child with a disability and has eight years experience teaching students with impairments. She independently coded the data using the code list provided. Similarity between code assessments was conducted and was found to match fairly consistently.

Audit trail

The colleague also conducted an audit trail three times in the study—initially following the pilot study, midway through data collection, and at the completion of the study. The audit trail consisted of reviewing the logistics of the interview environment, reviewing the characteristics of each respondent, reviewing the interview and transcription process, verifying the code/re-code procedures, comparing the narrative to the transcribed interviews and field notes and finally reading the narrative and the researcher's response for accuracy compared to recorded data.

Referential Evidence

Referential evidence as described by Johnson and Christensen (2000) is included using participant feedback as member checks. In addition to complete audio recordings and transcriptions from each respondent, each participant was given periodic

opportunities to review their interviews for authenticity. Reviews continued throughout, including the final draft.

Transferability as Verisimilitude

Each participant's story and narrative may have different meaning for each reader of this study. What one takes from this study will depend, in large part, on what one brings to the study. That is how meaning is created from this study—you, the reader, the four participants, and I co-construct the meaning. Together, we create a truth that has meaning for each of us. Transferability in life history research relies primarily on the principle of verisimilitude.

Researcher Veracity

Journal entries were kept to assist in reflexivity for the researcher. A sample journal entry from the pilot study:

March 12th—1:00 p.m. Initial interview with Mike.

Description of living environment—3 story subsidized apartment complex. Individuals must have physical impairment to live there, but must be independent of all ADL's (Activities of Daily Living). They must be able to exit building independently in case of emergency.

(Are there limitations on level of cognitive ability for residents?)

(How does Mike feel about the requirements for living here
and what are his opinions of his neighbors?)

The reflexive component becomes most poignantly applicable in the analytic section of this study when self as informant reacts to and responds to the interviews.

Having known each of the respondents for at least ten years in varying capacities as a physical therapist, medical equipment provider, colleague on advocacy boards and councils, and as a friend, I approached each of them with certain pre-conceived ideas of who they were and what each represented to me. Based on the pilot study, I found that at each stage of interaction with the data, I learned more about the individual. From the initial recorded interview, through transcription to proof reading the transcription, during coding and re-coding the data, while creating the first narrative from the field and in the proofreading stage, I developed a closer understanding of what it may be like to be an individual with a physical impairment. My preconceptions told me that there was no real difference between being an individual with a congenital physical impairment and being an individual with an acquired physical impairment. Mike, as the initial respondent in the pilot study, proved me wrong by relaying vocational opportunities and financial benefits that individuals with acquired physical impairments receive that are not available to individuals with congenital physical impairments. By including self as respondent as part of the analysis of the life histories, I added another interpretation of what it may be like to be an individual with a physical impairment.

The reporting of the data in each participant's life history differed. After reading, reviewing, analyzing, and assimilating each life history, I developed an intuition how best

to present each person's story to access the strengths of each life history. Underlying that intuition was an intent that I not speak *for* individuals with physical impairments; rather, that each person speak for herself or himself as much as possible. As interviews progressed, I was more able to finesse the discussions towards my areas of interest without disrupting the personal flow by the participant.

Would others studying the same topic and using the same methods reach the same conclusions? By incorporating various methods of triangulation, including an audit trail, incorporating peer review, utilizing reflexivity in journal entries and field notes, a truth about this subject can be shared allowing others to identify with that truth.

Chapter 4

MIKE: WHAT IT IS LIKE TO BE DIFFERENT

Mike is about 38 years old. He has never been married, but would like to be. He has loved and lost, much to his chagrin, due to his disability. Just like *King Gimp*, an individual with severe spastic quadriplegic cerebral palsy portrayed in a documentary on television, Mike was forsaken by a friend, a girl, because of his disability. Mike identifies with *King Gimp's* feelings of liminality as described by Murphy, (1988)—individuals with physical impairments are forced to the periphery of society; they are forced to assume a non-entity status. Mike also shares the *King's* sense of humor—looking at life from inside a body that does not do what he wants it to. Mike named his consulting company P. M. I. G.—which is *gimp* backwards.

Mike is the second born son of a typical Florida family. A sister and another brother followed his somewhat traumatic birth. In August 1965, Mike came screaming into this world, never to be silenced again. While his legs did not work within normal physical parameters due to congenital spastic diplegic cerebral palsy, there is nothing wrong with his entire language mechanism, and he continues to use it to his advantage every day.

We first met when I came to his school district as a physical therapist. Mike was mainstreamed as an *exceptional student* in a *special class* in a regular junior high school.

I was a relatively young (33 year old), idealistic windmill-chasing, out-to-save-the-world, pediatric physical therapist. What Mike and I immediately had in common was a dry, sardonic, somewhat jaded, somewhat cynical, sense of humor. We were both champions of the same cause—fighting for the underdog—but we knew that we would never win; hence the cynicism. The sense of humor kept us going. Mike was using a manual wheelchair when I first met him. He had long leg braces made of metal and plastic. We worked on locking the leg braces so he could get up from the wheelchair and walk for 20 feet or so using a reverse rolling walker. What we mainly did in those early sessions was solve all the world problems according to Mike and me.

Our friendship continued over the years as Mike progressed through high school and then to Bowler University as the first student with a significant physical disability ever to attend that university. We resumed our friendship when Mike had to return home from college after three years due to a combination of medical conditions, none of which was related to having cerebral palsy. Due to a combination of the annual influenza strain going around that year, a parasite in the water, and stress, Mike developed bleeding stomach ulcers. The condition was severe enough to require Mike to drop out of college and return home to recuperate. The recuperative process took over a year and a half.

Our paths crossed again when his wheelchair, (now power), needed repairs and I was in the business of making and repairing wheelchairs. He was older, but he was still Mike. I was older, but did not have the *know everything* attitude that I had before. I attributed my change to experience; Mike just attributed it to age. According to Mike, you always know more as you get older, regardless of your disability. This increased

awareness only continues up to a point, according to Mike, after that, the synapses start falling off.

For the first eight years of his life, Mike lived in Hollywood, Florida where he attended a “completely handicapped school:”

School there was a lot better than here even though they were both “completely handicapped schools.” Because here, they just put you “in that school” because they didn’t know what to do with you. In Hollywood, it’s like they had a plan and direction. I was with that brain-drain, Ms. Houston, until they took a whole bunch of us that weren’t mentally deficient or brain suckers in one form or another, and stuck us over at Becker (a regular’ elementary school). Ms. Houston, in her infinite wisdom, said, “Oh, let’s put them all in the third grade.” Well, you know me, that’s just like two years of my life just wasted. Pissed me off! On top of that, I hated Becker, because I hated Ms. Houston. She was one of them coddle ‘em, baby ‘em, and all that kind of crap. So I put up with that until I went to junior high school. And we got Ms. Hedges! I got a lot of breathing room. God was that fun! That was better. Much better.

Looking back, Mike thinks it may have been an age awareness thing. When he was younger, he really didn’t see himself as different from other kids. All he knew was that it was raining and he couldn’t go outside and play. As far as he was concerned, the extent of it went as far as “I just busted another wheel on the wheelchair, now I gotta go get another chair from Salvation Army before I can go play in the mud again.” As Mike

got older, he was made to feel the differences that having a physical impairment brought.

Mike relays:

At Streamside Junior High School people were starting to figure it out.

Okay—there are handicapped people here and they could deal with it. And I'd have the occasional person say to whoever was pushing my wheelchair, "What's his name?" And I'd look right at them and say, "Oh God, I don't know. You wanna know my name? Ask me, for God's sake!" In high school, we had less and less of that. And by the time I got to college, it was just fun because all my friends, no matter who they were or where they came from, just, "Oops, it's Mike." Not, oh, there's the guy in the wheelchair, none of that crap. It's just Mike. And Mike happens to be in the wheelchair; if you can't deal with it then, too bad, because that's the way it is.

Mike has a solution to the problem. It all boils down to integration. When he wins his copyright lawsuit, Mike plans on building a large apartment complex that is totally integrated with individuals from *regular* walks of life, individuals who are in wheelchairs, individuals from varying socioeconomic backgrounds, and individuals from varying cultures. It will be a totally integrated living environment.

Mike presently lives in a HUD Section 8 subsidized apartment complex for individuals who are disabled and who are receiving Supplemental Social Security (SSI). Living in the dorms during college eliminated a lot of the discrimination. Everybody saw him and was around him every day and it was no big deal. Now he feels segregated and discriminated against.

Mike relays a story that poignantly demonstrates his point:

So we were over at the airport picking him up and I'm in the elevator. And there's a very pleasant lady there with a little girl, 5 1/2 years old. And she looked up at her and said, "Mommy, why is that guy in a wheelchair?"

And her mother gave one of the best answers I've ever heard in my life. You know, most people are like, oooh, don't stare, don't say anything, and all that stuff.

Well that's a stupid thing to tell a child. Don't ever deny me a child's curiosity. You know, just don't.

"Umm, well, you remember that talk we had one time about God's special people, they're just a little bit different sometimes?" And she said, "yes." And she said, "he's one of those special people."

And I thought, well there's a good way to explain it to a kid. Cause it's something that makes sense when you are that young and they'll figure out the rest as they grow. And I thought; now if all the parents would do that, life would be a hell of a lot easier. And I still see it.

After recuperating from bleeding stomach ulcers for a year and a half, Mike moved into his present two bedroom subsidized apartment. After three months, he asked Sam Pebble, a friend from high school who was also in a wheelchair, to move in with him because everyone else in the building "gave him gas," except for Lana. I suggested that Lana was an exception because she had no expressive language. Mike was totally non-responsive to my observation.

Mike then proceeded to get a real estate license because Vocational Rehabilitation (Voc/Rehab, V/R) told him that the only job he was suitable for, and for which they would help train him and help him secure employment, was at a hospital. According to Mike, Voc/Rehab's rationale was that he "wouldn't be as noticeable in a hospital; everybody there is used to seeing people in wheelchairs." This was reason enough for Mike to do anything else.

So Mike went to the local community college to pick up credits that he needed towards his major of business administration. His best experience at the community college occurred in his favorite professor's class:

I loved the guy, he was a hoot. Thought I was brilliant. Half the time I was brilliant, half the time I wasn't. We got along fine. And I think I took him for two or three classes, we got along fine. One was business law, one was economic something, I don't remember what the other one was. But, yeah, I loved the guy; he was fun. I remember I was sitting there one day in class and he walks up to me and says, "you know something? One of the girls chewed me out Tuesday after class." I said, "for what?" "She said for me telling you to get your damn wheelchair out of my way." I said, "are you kidding me?" He said "no, she was offended by that." I said, "well don't that beat all? I didn't care." "Get that damn chair out of my way." Yes, sir. You know, he was a colonel in the Army. I loved it. That's the way it is. I loved it.

It was apparent to me that Mike just wanted to be treated like everyone else. I saw that attitude reflected at his home at an early age. His parents treated him no differently

than any of their other three children who happened not to be handicapped. Mike was just beside himself with joy the first time he came home from college to find a ramp:

I didn't get a ramp until I damn well moved out of the house. I came home from college, and look at this shit, look at this, I gotta ramp, I can get in and out of the freakin' frickin' front door. Look at this; I can even get the key in there when I get up to the door. I damn sure shoulda' had this when I was a kid.

After taking all the classes that he could tolerate at the community college, Mike enrolled in an accelerated business administration program at the university extension in town. He'd catch a ride with a friend or relative to the bus stop, and then take the wheelchair lift-bus to classes. Mike had tried driving and found it to be an exhilarating experience, but just too difficult to manage so many variables:

I did drive, but I found it to be, although highly, highly enjoyable, and a great deal of freedom, I found it to be a very complex set of variables to coordinate at one time. Because, having spastic cerebral palsy, if you move this, something else is going to move, no matter what. So I always had two things moving at once when I only wanted one. So I found it a very complex set of variables to coordinate, but fun as hell. Yeah, if I ever get around to doing it again, I'll try to learn it again. It's a lot of freedom.

Mike had been working as a real estate agent for over a year by the time he earned his bachelor's degree in business administration. Mike knew he had selected the right person to work for when he went for his interview:

I go all the way out there, and I go in there for the interview, and he's looking at me and stuff. "Took a lot of guts to come in here in a wheelchair for a job like this." And I said, "yeah, well, I guess so." We're talking, back and forth, and he says, "where do you live?" And this was before I moved in here, so I said "well, that way [pointing toward the east], way out there, that way, way out by Miquilla State Park. Oh I don't know, 40-50 miles that way." And he goes, "Huh? You mean to tell me that you came all the way over here, up my back steps (Mike was in a manual wheelchair and there was no ramp) and in here for a job?" And I said, "yeah, do I have the right place?" And he said, "yes! You're hired."

John has since sold the real estate agency, but Mike continues to work for him on a part-time commission rate as needed. What Mike really wanted to do was "play Monopoly with real houses." According to Mike, his expertise and area of interest in college was leveraged-buy-outs (LBO's). He wanted to test theory to practice and set up a real estate deal buying a building and land on Fiesta Key worth 1.5 million dollars. Although his financial plan was solid and was endorsed by his college professor and admired by a bank president, he was unable to secure the total capital necessary to "do the deal." He got \$800,000 committed, but because he "was in a wheelchair," he couldn't get the remaining \$400,000 needed. Even though one bank vice president had described his preparation and presentation as "not having seen anything this clean and beautiful since the eighties, a textbook case;" he would still not loan him the money. Mike thinks "they didn't want the little guy in the wheelchair makin' all that money. And they didn't

want to loan the little guy in the wheelchair all that money.” “I actually had four private guys tell me they were not going to loan it to me because I was in a wheelchair.”

After the deal fell through and Mike lost the escrow money, he ventured into private consulting. Having a background in finance and in computer programming, he secured a sub-contract from a major accounting firm to write a program that would allow differing accounting software programs to talk to each other. Mike included a covenant in the contract with the accounting firm that guaranteed Mike copyright of the program he wrote if he was not paid for his work. If payment was received, the copyright would revert to the accounting firm. Mike wrote the program; it worked, and he was not paid. Mike has been suing the accounting firm for at least two years and hopes that it’s resolved before he dies of old age. “Copyright suits are some of the trickiest, but I think I’ll prevail. It’s just a matter of before I’m 40, or before I’m 60. Hopefully it’s before I’m 40, because it’s holding me up. Well, I can’t go back and get my master’s degree before I settle.”

Mike’s plans include a Master’s in Business Administration (MBA) and even a Doctor of Jurisprudence (JD) if he can ever finish the lawsuit. But he can’t leave now; he’d “be a nervous wreck; I can’t trust somebody here to handle it all if I’m not here.”

Mike’s perception of other factors that may impact what an individual with physical impairments can and can’t do, such as gender, race or ethnicity was the same. “I don’t know what impact gender or race has on an individual with a physical impairment; I’ve never looked.” Not so with the apparent inequity between an individual with an acquired physical impairment and a person with a congenital physical impairment. Mike

has discussed this issue at length with his friends Sam and Nate. Both Mike and Sam were born with a disability. Mike has cerebral palsy and Sam has spina bifida. Nate was paralyzed when he was 27 as a result of an auto accident. All three use manual wheelchairs for mobility. Mike also has a power wheelchair that he uses when the distances are too far to propel.

The commonalities in perspective of all three had to do with anger at their disability. According to Mike:

I actually had somebody ask me that once, he said, “are you angry about this?” And I said, “angry about what? Clinton bein’ in office? What?” And he said, “no, about being in a wheelchair.” I said, “why? It's natural. How can you be angry about something that's natural? I have my bad days, just like everybody else. Well, no matter what you do, your legs aren't going to work right, and some muscle is not going to do what you want, and you just have a bad day. But other than that, there's no reason to be mad about being in a wheelchair.” And he thought I was nuts because I wasn't mad.

Mike and Sam asked Nate his perspective of having acquired a disability:

Cause we talked about it a lot, cause we were curious. How do you look at it, Nate? It's nothing for us because it's just normal. But we were curious; how do you look at it? And he said, basically, that he looked at it the way that we looked at it with the exception of there were days that he was angry cause he couldn't do what he was doing before. It doesn't mean that he was angry about being disabled,

he was just angry because he couldn't do what he was able to do before. And that was a little bit different way of looking at it.

According to Mike, the difference between individuals with acquired disabilities and individuals with congenital disabilities is the way people treat them:

One, people feel sorry for people in an accident in a different way than they feel sorry for guys like me. I, as the victim (of a handicapping condition), become the accused; I am somehow responsible for my handicapping condition. But he's not; he's a victim of circumstances. And he's taught things that we didn't know. The first thing they taught him in a rehab hospital was how to deal with his limitations—how to manage, how to handle the wheelchair, up-and-down. They never taught us that shit, ever. You want to know how I ended up learnin' that stuff? Trial and error; smashin' my head on the sidewalk. To this day, I've never had a lesson. What's one of the first things they teach them? This is a wheelchair; this is how to use it. They never taught us that stuff. Ever. And it's easier for him to get financial aid than it is for guys like us. Because they will spend as much money as needed, even supplanting his income, to rehabilitate him to get him back in the work force. At the same time, they won't spend 1/20th of that amount to habilitate us to get us into the work force, unless it's for a job that they've pre-determined that's all we can do because we're gimps.

Mike doesn't see much difference in the perception or the use of assistive technology between individuals with congenital physical impairments and those with acquired disabilities:

It's all according to what you need and if you're smart enough to use it. It's not so much a matter of who uses it more, or who knows more about it; it's a matter of who can afford it. So from that standpoint, I guess guys with acquired handicaps use it more because they have better access to funding.

[According to Mike], society is divided into the *haves* and the *have-nots*. If an individual with a physical impairment is not part of the *have-nots* when starting out, that person certainly will be by the time *the system* finishes with them. See, I understand there's a disparity between the *haves* and the *have-nots*. The *haves* do not want the *have-nots* to have. Then they would be *haves*, and the *haves* do not want the *have-nots* to have it; they want the *haves* to have more and the *have-nots* to have nothing.

Even though Mike comes from a cohesive middle-income family, and is a college graduate with advanced skills in finance, computer technology and real estate, he falls into the lower socioeconomic status, according to his tax returns. One reason for that may be that Mike created a 99-year irrevocable trust for all his personal assets and business interests. Mike continues to place all income and assets in the trust to maintain minimal tax exposure because the trust isn't required to file a tax return (Mike secured a ruling from the IRS and keeps the chapter and verse listing of the IRS regulation at the ready); Mike's reportable income is well below the poverty level.

I asked Mike, "and now, looking back, if you had a way to do it over again, what would you change?" Mike replied:

Wouldn't have changed a thing when I was a kid, I had a hell of a good time. I did. I had a good time when I was a kid. I had a lot of fun. I had a lot of fun in college too. I wanna' go back and do that all over again. The practical jokes—oh God, were they fun! I probably wouldn't have tried to buy that one piece of property; I would have saved my money and done it different.

Going back farther than that, I probably would have figured out some way to avoid the whole event in Miami when I was there for that weekend, I'm sure, (Mike is referring to breaking up with his girlfriend). I'm not quite sure what I would have done, but I would have thought of something. I'm not sure what it is, but I would have figured it out if my life really depended on it. I probably would have backed out of Bowling University earlier than I did, and skirted it a different way so I could have made it all the way through to graduation.

But now Mike has visions for the future. "I don't know exactly cause you just go with the flow as it comes along. I've got a lot in my head."

Pete: yeah, married, two kids...

Mike: unless it kills me first, yeah (laughter).

Pete: graduate school in Lorland?

Mike: probably Dadeland. But don't quote me on that; that could change. They have a program there, and I want it. If I find it somewhere else, and the opportunity is there, I'll go somewhere else.

Pete: do you see teaching in your future after you finish school?

Mike: I don't know. And that's a good question cause it's come up a couple of times cause I used to teach. And most of my friends are teachers. You know, that's just what a whole bunch of us ended up doing when we got out of college. So it's possible. But if I taught, I'd only teach college and up. Because anything below that is not worth it. Too much attitude. Too much discipline. Too much trouble. College and up, that's for sure. And if it was, it would probably be something like finance, business law; you know that stuff that's just right up my alley, that's all in my head, anyway.

Mike's vision for the future includes advocacy:

I wanna do something specifically. The worst thing in this county is two things. Handicapped facilities, in general, period, across the board; they suck. Two, handicapped assistance, no matter what they say, anywhere, stinks. If any kind of handicapped individual, anybody, that's anybody that wants any kind of assistance in the United States, they're up the wazoo. And the reason is, there's no money in it. When there's no money in it, you're not going to get any help; it doesn't make any difference if your head's falling off, if there's no money in it, they're not going to stop and pick it up for you.

The best place for a handicapped person to be is in Canada. Well, I don't want to go to Canada; Canada sucks. So, you have to get somebody's attention here. So there has to be a way to do it in a way that's not really abrasive, but I've got to get somebody's attention. And the way that I figured that I can do that, is to

get enough money behind me so I can go out there and do whatever needs to be done in the world so they will notice.

Even though “things have gotten better for handicapped people; who gets stuck holding the bag?—The people in wheelchairs again.” Mike wants to change that.

Self-Description

Mike describes himself as a cynic with a warped sense of humor. This perspective is reflected early on in our discussions as we “solved all the world problems, according to Mike and me.” Mike’s assessment of being smart is probably accurate if his irrevocable trust is reviewed and his comparative success in college is taken into consideration.

Mike’s self-assessment of being loyal is reflected in his long-term friendship with Sam. Sam also has a physical impairment, and he and Mike went to school together since the sixth grade. Mike encouraged Sam to move into his apartment with him, and, although they are no longer roommates, Mike continually takes responsibility for Sam’s social life. The friendship has lasted over 24 years.

When asked how the person who knows him best would describe him, Mike deflected the question by responding that she would probably use the same descriptors that he had used to describe himself. However, he did say that his girlfriend in college, whom he described as the person who knew him best, used to say that “she wished I could see myself the way that she does.”

Mike’s responses to who he is most like is probably the best reflection of how Mike sees himself. He is like his mom because he has “what you can call, ‘kid stuff.’ I

like super heroes, magic, and fun.” Mike is like his dad in that he “has the ability to stand his ground and his temper.” He is like his paternal grandfather because he “has control of his temper; has a healthy dose of street smarts (common sense); and has a sense of humor.” Mike is like his paternal grandmother because he “has a sense of order (anal), sternness, and a lot of ‘backbone.’” And he is like his maternal grandmother because he “has moxy, an eclectic nature, and is intelligent.”

Reflections and Response to Mike

Mike, as an individual with a congenital physical impairment, cites three ways that individuals with acquired physical impairments are different from individuals with congenital physical impairments. For Mike, as an individual with a congenital physical impairment, there is no anger associated with his disability. For him, being in a wheelchair is as natural as not being in a wheelchair is for an individual who is not physically impaired. However, Nate, an individual with an acquired physical impairment is occasionally angry at the things that he cannot do—the things that he was able to do before the accident.

“People feel sorry for people in an accident in a different way than they feel sorry for guys like me.” In this statement, Mike reveals how society reacts and treats individuals who are physically impaired. He acknowledges that there is a differentiation between individuals with congenital physical impairments and individuals with acquired physical impairments. According to Mike, individuals with acquired physical

impairments have a distinct advantage over individuals with congenital physical impairments.

This preferential treatment for individuals with acquired physical impairments extends to financial assistance. Individuals with acquired physical impairments are substantively assisted to re-join the work force. Individuals with congenital physical impairments are never given that opportunity at the same level as individuals with acquired physical impairments. The inequity is obvious to Mike.

As an individual with a physical impairment, Mike does not know if age or gender plays a part in how individuals with physical impairments perceive or define themselves. He has “never really looked at it that way;” nor has he discussed it with anyone else.

It appears that socioeconomic status plays a part in defining an individual with a physical impairment. According to Mike, he came from a middle-income “typical Florida family.” And yet, as an adult, Mike is classified in the lower socioeconomic area. Although Mike may have chosen that status by creating a 99-year irrevocable trust, he may well be representative of individuals with physical impairments, regardless of how that status is attained.

Mike says that he “picked a good family” to be born into. As a result, he had “a great time as a kid.” Not all children with physical impairments may be that fortunate. When I was a program specialist for students with physical impairments for the local school district in 1994, I took an informal survey of the 123 students identified with physical impairments in the school district. Eighty-three percent of these students came

from single parent families, and 56% of these families were identified as having incomes below the national poverty level (at that time poverty was considered to be an annual income of \$14,400 or less for a family of four).

Mike did not have an opinion about culture and ethnicity as it relates to individuals with physical impairments. That is entirely understandable. As a member of the non-marginalized majority, I am acutely aware of the fine line that I cannot cross by society's standards. "What's it like to be black? I don't know; what's it like to be white?" Take out the words "black" and "white" and insert "disabled" and "temporarily able-bodied" (a term Mike, and others in the community of disabled individuals, use to refer to individuals who are not in wheelchairs yet), and a comparison and conclusion can be made explaining why Mike does not have a perspective on culture and being disabled.

A good part of how Mike defines himself is tied into his disability. "Well, no matter what you do, your legs aren't going to work right, and some muscle is not going to do what you want, and you just have a bad day."

Combine Mike's perception of how society "feels sorry for" individuals with physical impairments and a picture begins to emerge that individuals with physical impairments define themselves in terms of their disability and how society perceives that disability.

According to Mike, the use of assistive technology by individuals with physical impairments is more directly related to funding than to need, or to knowledge that particular technology exists, or to the intellect or ability of the individual to use assistive

technology. Mike describes the use of assistive technology as relating more to economics—the *haves* and the *have-nots*, than to viable decisions by individuals with physical impairments.

Chapter 5

THERESA: HALO WITH A TILT

Background

Theresa projects the distinct impression that she would be equally competent whether she is standing erect on legs that function or dependent on a power wheelchair for mobility. Theresa is a 32 years old, black female (her preference of designation), with two teenage children and is essentially paralyzed from the neck down. She is not married and has never had any difficulty disciplining her children since the car accident 12 years ago. Her children were three and one at the time of the accident.

Theresa is working towards a Master's in Social Work (MSW) degree while working full time. When Theresa first went to college:

I wanted to work with girls who were teenage parents. And then once I got hurt it was, "I should do this" [work with patients with spinal cord injuries]. So I think for myself, the different things that I've experienced in life, and all the trials and tribulations that I've been through. Personally, I think I can lend a different ear, or position for somebody else, because I have been through so much. I just think I would be helpful, valuable.

She owns her own home in a quaint neighborhood and drives her power wheelchair five miles back and forth to work every day. Rather than improving her

income by collecting disability, she prefers the independence and status that working brings:

For one, my whole purpose of going back to work is to let my kids see. I had two small children and I didn't want their life to be affected by my disability. Having a parent with a disability doesn't mean that their lives have to be different. So I looked at it—If I'm here on disability, my kids are never going to have a normal life. Would they ever have a yard of their own? I don't think I ever would have moved out from my grandmother's. Anywhere you move you have to have a job. You just can't be getting a "check" every month.

That was the first thing. The second thing was always living in somebody else's household. You have to live by their rules. How could I raise my children the way that I wanted to raise them living underneath somebody else's house? Then what type of example would I be to my daughter? As a woman, and that type thing. OK, then my son—same thing.

And then living with my grandmother, while I think she did a great job, I didn't agree with every tactic she used with raising kids. So I wanted to have the independence to raise my kids the way that I wanted to raise them, for them to have the values that I wanted to instill in them. So I had to make certain steps for myself to make sure after I took the steps that I could raise my kids the way I wanted to. Working was the first step of that.

Theresa describes her childhood as different:

I was born here in Brighton at Mango Memorial Hospital. I am a native Floridian. February 29, 1972. I'm a leap year baby. Every four years, so now I'm only actually seven. I was raised by my grandmother. When my parents were divorced, they couldn't agree on who was going to have custody of me...the only thing that they could agree on was that my father didn't like the man that my mother was dating. They did agree that my grandmother would get custody of me. Theresa was 15 when her daughter was born yet she still received a college athletic scholarship to play basketball. She describes what it was like playing high school sports and having a daughter:

Yes, I went back to playing basketball after I had her. When I was at basketball camps and games and like that, either my grandmother kept her or my aunt would keep her. And like during basketball games, we would go pick her up from day care, get her bag ready, and go take her to the game. She would go to almost all my games whether they were away or at home. She would usually ride with one of the parents. It was different, you know, to play basketball in high school and look up into the stands and see your daughter. To be a senior in high school and look up into the stands and see your daughter watching you play basketball. She could care less what you're doing at that time; she's looking at everything else. It was strange, looking up there, like most people would look up and say there's my brother or my sister watching me; and I would look up and say, there's my daughter. It was school in a way, but it was different. It was a different childhood, it was a different bringing up, it was just different.

Her son was born after her first year in college and the car accident was soon after that:

We were driving from Aldonia, me, my mom, my son, his dad and my mom's boyfriend. And there was an 18 wheeler on the wrong side of the road, and I swerved to keep from hitting it head on and I couldn't get back control of the car and the brakes locked up, instead of just letting the car coast (now that I know), I hit the brakes and the brakes locked and made the car flip. My mother was killed in the car accident, and I was hurt and that was it. My son and everybody else was okay. I'm a quadriplegic C-4-5-6...

Pete: incomplete?

Theresa: actually, it's severed, but I'm a weird case.

Pete: yeah, because you shouldn't be able to extend your wrist.

Theresa: and I have complete feeling.

Pete: you do have complete feeling? You told me that before; I don't know why I forgot...

Theresa: I have total feeling. In my lower extremities, I can't tell hot and cold. If you were to pinch me, it wouldn't hurt, but I could tell that you were pinching me. Like, I pulled my toenail off my toe the other day. I knew that should have hurt. My toe was spasming and I knew that it should have hurt, but it didn't hurt me. I can tell what happened and where it happened, but so far as pain, I don't really experience that.

Pete: how old were you when the accident happened?

Theresa: I was 20.

Peers with Disabilities

Up to that point, Theresa had very little exposure to individuals with disabilities. She remembers a teammate's brother who was handicapped and another student in school who was in a power wheelchair, who they called Speedy:

One of the girls on the basketball team, her brother, John, was a quadriplegic. He was doing flips on a mattress and he landed on his neck. He was in my classes when I was a senior. He came to all our basketball games. He was there in his wheelchair all the time during the summer when we went to her house; he was bothering us all the time. When I was in high school there was another boy in a wheelchair, he was white. I think he had muscular dystrophy...we used to call him Speedy because he had a motorized wheelchair. He would go so fast [hmmm...that sounds familiar] [Theresa likes speed in her wheelchair]. I think I'm the first black person I've ever saw in a wheelchair.

Age and Disability

Theresa feels that age of onset of the disability for the individual makes a difference:

If you are a teenager and get a disability, you're going to be pushed differently, you'll be motivated differently. If you're in your mid-twenties or

thirties, the motivation will be different. I remember when I was in the hospital there was this guy, he had a head injury. He got hurt in a motorcycle accident, his girlfriend was killed but he got a head injury. Because he was so nasty and uncooperative, they totally dealt with him differently. They put the time in that they were supposed to put in with him, and that was it. Whereas with me, my therapists came in on Saturdays and took me out to the mall, they took me out to taverns to have lunch. The nurses, on their days off would come in to sign me out and take me shopping. So it strictly depends on the person. Your motivation motivates the people around you that want to help you.

If it's a teenager, hopefully the therapist or the people working with them, no matter what their attitude is, no matter who the child is, they push them no matter what. Versus an adult who has an acquired disability, they can't be pushed away easily. Take me as an example—as a 32-year-old woman, if I had a very nasty attitude, always negative, I think a therapist would give up and say, well I'm going to teach you what I'm going to teach you, and then I'm going to go home. Versus, I'm that 32-year-old woman who comes in there with an attitude of 'I've gotta' do this.' They're more motivated to help you. They're going to help you; they're going to work harder for you because you are putting forth to be better. Versus that teenager who is going to be pushed from day one, cause he's got his whole life ahead of him and they're going to push him the hardest. Until they just totally shut down on themselves out of rebellion. And then when they don't want

to do anything, the therapist is going to say, okay, I'll leave them here for their parents. But I think initially they're going to push them both.

Race and Disability

Theresa has definite opinions on race and disability:

I think when it comes to the white community, there's a different embracing there. There's a different push there. Throughout the black community you have differences. Like, for instance, a kid that is born with a disability, you have a different motivation for getting that child to be as normal as possible, when they're born with it. They want them to be normal. They want them to be accepted. They want to let them know that they can do everything that everybody else can do, they just do it differently.

I think that's why black people aren't exposed to disabilities, because they think, why, what's wrong with her? I think black people have it in their mind that things like that don't happen to them, because they don't see it. And therefore, it's not true. So it's just like when our kids are born with cerebral palsy, and our kids are born with other handicapping conditions, we don't deal with it because something is wrong with her—Mama did that, something's wrong with her. Because what did she do to have her child born with that? Because we are not exposed to it. We don't think that can happen to our kids because it's not put out there for us. I think that goes whether it's black or white, as far as if it's a congenital disability.

In the white community you have that parent that financially or socially will stick by you to the end. In the black community, that support system may be absolutely, positively zero. So, it is totally different how it's done and the way it's done [in the black community as compared to the white community].

Gender

As far as race, gender and disability are concerned:

I think white men accept all aspects of disabilities, as far as urinating on themselves, as far as being incontinent of bowels, all that kind of stuff. Black men—Nah. To be with a woman that somebody else has to come in and help in the morning, get up to bathe, and so forth or even if the man had to get up a couple of hours early to help his wife and get her up in the morning—I just don't see a black man doing that. I think a black woman will take on the disability of the black man easier. She'll be more able to take care of that man, and clean his butt and do all the kinds of things that he can't do.

When asked if it would it be preferable to be a male or female with a disability in the white community, Theresa responded:

I think it depends on their status quo [financial, SES]. I think it depends on, if it's a man is in a very high-powered, high-paying position, and he has an image to uphold, I don't think he would have that woman with a disability that he would have to do all that work for. If he did, she would be the woman at home where he would have another woman on the side. I think that when they're both

not poverty level, but middle-class, I think he would find it more accepting to where he would be more willing to do those things for her, or could afford to do those things for her.

Acquired Versus Congenital

Theresa makes the transition from race and disability to acquired versus congenital disability. She relays:

I think that as far as the black community, you're cursed either way you go. I think if you acquire it, people tend to not know how to take it. But then again, if it's something that you are born with; people are more stand-offish. They're more stand-offish to the point where they don't ask, don't tell. If I don't know then I don't have to worry about it; so, they don't ask. But if it's acquired and they knew you before you got the disability, they hang around trying to figure things out, and then they ask questions. It's a 50-50 thing and it depends on the person with a disability. I guess when you're born with it, the system helps you more.

Disability and Assistive Technology

When asked if a person with an acquired disability or one born with a disability has an advantage getting assistive technology, using assistive technology, or learning assistive technology, Theresa replied:

I think if you are born with a disability, you're better off. But then again, no. Because if it's an acquired disability, if it's going to help you get out there better than...I take that back, I guess either way. When it comes to computers, it's as easy as getting a driver's license, anybody can get one, versus a rent-to-own, versus going to Wal-Mart and buying it, putting it on layaway and paying for it. So I guess it's the same for being acquired or if you're born with it.

Blending It All Together

According to Theresa, a lot of the issues associated with disability, such as race, gender, age and inception of the disability are intertwined. You can't look at one without including another:

I think that as far as John was concerned (he had an acquired disability), I think he was embraced by more people just because of the fact that people knew him. This actually happened while we were in middle school. John's sister was on the basketball team too. So people just embraced him differently. He hung around with a different crowd—the girl's basketball team, boys basketball team and football players. Athletes come together you know. He was embraced by that sort of people.

Where Kyle, (the one with the congenital physical impairment), was embraced more by his surroundings, the people in his classroom. He didn't really get into the athletic world or the "in crowd." And it was mostly girls that were surrounding him, mostly white girls.

So where John hung around more black kids (John had an acquired disability, but was white), it was more like they (individuals with acquired disabilities) were embraced more by the athletes. So John was more popular; he went to football games because he had a wheelchair van. Our senior year is when he learned to drive also. He did almost everything we did. He would go to (basketball) camp with us in the summer; watch us play games and all. His friends were really good to him. They would come and take him to go fishing; take him in a boat and all. His friends would come take him to do everything. They'd put him in the van and go everywhere. John even had a girlfriend. That surprised me at that point and time too. He dated a black girl, too. He was embraced more by blacks because that's just who he hung around.

Theresa doesn't necessarily think that the black community is more embracing, more supportive of a person with a disability:

It depends on how you look at it. I think if it's something new. When people see me riding down the road every day they're just at a disbelief—"You're always smiling, you're always happy, you're always this, you're always that," you know. You know it's more of a disbelief thing because they are not exposed to it. It's not something that they're exposed to. It's not something that you have to embrace in our community, I think in the black community it's more so something that happens to you. I'm not saying it doesn't happen to people, but you don't see it because they don't continue to live their lives in the community. They look at it as a curse rather than a blessing.

I think it's something totally as a black community that we're not exposed to. So you don't know how to embrace a person with a disability; you are totally caught off guard. You don't know what to expect. So you go to a lot of people in the black community and ask them what a paraplegic is and they have no idea. For me to explain what happened, and what I can and cannot do, they're just totally amazed. They're like, huh? They don't understand the physical challenges of getting out of bed. They don't understand the physical challenges of getting here, or taking a shower, or just eating, or just wanting to be me more than just a statistic and not sit home and just collect disability. "Why are you working," that type of thing. So it's just a whole different outlook for us, for the [black] community.

As far as the white community and disability and age and congenital versus acquired, Theresa thinks that:

When it comes to the white community, there's a different embracing there. There's a different push there. Throughout the black community you have differences. Like, for instance, a kid that is born with a disability, you have a different motivation for getting that child to be as normal as possible, when they're born with it. They want them to be normal, they want them to be accepted, they want to let them know that they can do everything that everybody else can do, they just do it differently. I think that goes whether it's black or white, as far as if it's a congenital disability.

But when it's an acquired disability, you're fighting a different battle, especially when it comes to age differences—at what age were they hurt? At what age did they get the disability? What are their support systems going to be like? Do they have a support system? It's a totally different fight. But it goes past the disability, it goes back to the person with the disability. I think, speaking for myself, when talking with the elderly people in the black community, when they finally get around to speaking to me—they ask me what happened and they always say I'm smiling. Whereas most white people that see me, they're not sure if I'm faking or if they come up to me, am I going to rob them or something, you get that...I don't know if that's just the way the world is today, not trusting people and all, but it's kinda' funny seein' that I'm in a wheelchair and all. It's more stand-offish for them in the white community; where in the black community, they're more apt to act different.

Disability and the Civil Rights Movement

Comparing the disability movement with the civil rights movement, Theresa relays:

When you look at the civil rights movement, you look at protests that black people were trying to be treated equal, saying that they have to have the right to work, they have to have the right to make a better life for their family, to not be judged by the color of their skin, but by the character of who they are. If you're going to judge a person, judge them by meeting them and what they

present to you. If they present a lazy bum, then judge them as that. But if they are productive and working hard, judge them by that.

And it's the same thing as being disabled. Don't judge me because you see this hardware attached to me. It's the type of thing where the wheelchair doesn't define who I am; I define the wheelchair. It's not the "oh, you see the wheelchair right there with the girl in it?" It's "the girl in the wheelchair." I'm not just the wheelchair. I'm the girl sitting in the wheelchair. The wheelchair is not who I am. I'm the person in it. It's the same as "look at that person in that car." You don't want me to judge you by the car you drive—don't judge me by the wheelchair. So it's really one and the same—you're just fighting to be treated equally, fighting for the chance to prove yourself, fighting for the chance to be treated equally.

Just as individuals with the same skin color should not be judged based solely on the color of their skin; neither should it be assumed that all people in wheelchairs are the same. Theresa explains:

I remember when I first got hired here; they hired somebody else in a wheelchair. Well they took that person to be like me. You can't expect every person that you hire in a wheelchair to have the same abilities as me, to have the same drives as me, to have the same attitude or personality as me. And they were totally shocked because that person didn't work out. And I had to tell them that, "You know, you can't judge every person the same. Everybody's not going to be the same just because they are in a wheelchair." My whole thing when I came to work was that I had a point to prove. Everybody else kept saying that I couldn't

do it. “Well, you might be able to do this; you might be able to do that.” So I was like “okay, I’ll show them.”

Disability and the System

As a person with an acquired disability, Theresa sometimes becomes frustrated with *the system*:

I get up and go to work every morning. I work, I pay my bills and so forth, but I'm dependent on someone coming to help me get out of bed and get dressed. If no one shows up to help me, I'm in bed all day. With my job, they are very patient with that. But as far as insurance companies—they say “we can't send someone out to help you do that because that's a teaching skill.” But if I was on Medicaid, you would send a nurse out every morning. But I can't get Medicaid; I can't get disability, because the state of Florida doesn't consider me disabled because I'm employed, which is fine. But if I was to, say for instance, lose my job, become unemployed, you would give disability, you would send a nurse out every morning to get me up, you would give me Medicaid, you would give my children money. You'd do all this because I can't work now. You'd do all this to help me get back to work, but instead of helping me keep employed by sending that nurse out, you won't do that. That angers me most of anything. So you have a person who doesn't want to become a statistic, who wants to make their own money, but you won't help now. It just doesn't make any sense. It's almost like a rule of fate. There are times that I thought it would be easier for me to go on

disability, have my kids raised by their dad, put myself in a nursing home and forget about it.

I couldn't do that; but it's almost like that's what they want you to do. It's like, why try? Why try to better yourself? Why try to become independent? Why try to do all this stuff right here? They don't want you to do that. The state doesn't want you to do that—that's the message the state is giving to the disabled.

Individual before Disability

It depends on the person with a disability is a recurrent theme throughout Theresa's recount of her life history and that position is reflected very strongly as she relays her opinions on disability and race, age, gender, family life, assistive technology and acquired versus congenital impairments:

It boils down to being yourself, being who you are. Respect me first because I'm Theresa, then respect me because I'm a mother, then respect me because I'm disabled. Those things are more important than respecting me as a black woman. And that goes back to being a person, being who you are. I am a person with a disability; I am a person first. I have just acquired something that you haven't acquired yet.

Theresa's identity is intertwined with her disability. She reflects her individuality before her disability:

I was talking to a friend a while back and I was telling her that it was funny that I always said I wished that before I got hurt, my biggest regret was

having my kids so early. I could have been playing in the WNBA. I could have been doing this; I could have been doing that. If I hadn't had Brandi when I was in school, I would have gone to college, I would have played basketball, if I hadn't done all this other stuff. But if I hadn't had my kids early, would I have the same drive that I do? No, I honestly don't think that if I hadn't had my children before I had my accident I would be person that I am today. Just because a lot of my focus, a lot of my drive is my children, to make sure their life isn't disrupted, to make sure that their life is what I perceive it to be as normal. My past makes me who I am now. To change something may be changing a vital part of who I am.

Knowing who you are is a big part towards accepting what you did wrong or right. I haven't led that person's life; I don't lead that person's life...I made mistakes. I'm going to make mistakes. But at the same time, those mistakes made me the person I am. The good things are part of who I am and the bad things are part of who I am. I may have a halo, but it's tilted a little bit, one side may have a horn. I'm not going to be the perfect person; I'm not going to live up to everybody's standards. I'm not going to please everybody; I'm not going to make everybody happy, everybody's not going to like me. Okay, so what? That's life.

Issues in my life may suck, but my life doesn't suck. I have issues that suck, but those issues are not going to overwhelm me so that my life sucks. No, that's not going to happen.

Summary

Theresa has some final thoughts on what it is like to be an individual with a disability:

I don't know if I said this to you before but, I think that when people talk about being handicapped, and I always refer to myself as being disabled; I'm not handicapped, I'm disabled. Disabled is a compound word—dis is a prefix of able. I no longer am able to do what I used to do; I'm disabled. I think of a person who is handicapped as being born with it. They're handicapped; this is something they've always had, and they're trying to get past; they're handicapped. You got it from God. When you get a handicap, it's something you have; you try to get past that handicap, you have to deal with it and go on.

I just think if people stop looking at a disabled person as a handicapped person, if you stop defining people by the situation, and define the person first, all of us would be better off. As a disabled person, don't try to define us, let us evolve, let us become who we want to be, let us be ourselves first. When you define a person with a disability, you put a limitation on them.

Self Description

Theresa accurately describes herself as persevering and committed. The phrases that Theresa chose to best describe herself on the Self Data Survey (Morse, 1978), include “never say never,” “take nothing for granted,” “never put off tomorrow what can be done today,” and “don't try and categorize me.” The

healthy commitment to her family, her job, and her continuing self development are reflected in her life history. She sees herself as a role model for her children demonstrating what can be done. She is a valued employee; the company for which she works is willing to accommodate a flexible work schedule to allow her to attend classes. The fact that she drives her power wheelchair five miles back and forth to work and school every day is testimony to her dedication.

When asked how the person who knows her best would describe her, Theresa's responses included "treat her like everyone else," "never feel sorry for her," and "just as stubborn." Theresa prides herself on her healthy attitude of being "differently able." When she originally started back to college in pursuit of a degree in social work, she wanted to work with females who had become paralyzed. She has since expanded her interests to include wanting to work with juvenile offenders, perhaps in a half-way house. She is certainly secure enough in who she is to be able to give of herself to others to try to help them. Theresa explains, "a lot of my family members and friends call me for advice and sometimes just to have someone to listen to their problems. I never judge them. I'm just there for them. I may not always agree, but I try to be what they need at that time, whatever it may be." As far as her children are concerned, Theresa feels that, "I try to be mom and best friend. My children and I talk about all subjects. I am learning when to be mom and when to be friend." Theresa views herself as "a very strong, independent woman with enormous faith."

Reflections and Response to Theresa

There is a tendency for me to assign noble characteristics to certain individuals with disabilities, which they may not deserve. Green, Davis, Karshmer, Marsh, and Straight (in press) discuss the stigma associated with being disabled and the impact that having a disability has on the person with a disability and on society. I'm not sure if the tendency to assign noble characteristics to certain individuals somehow makes me feel better about myself by indirectly generating empathetic emotions towards the individual with the disability, or if assigning these noble characteristics raises my own self-esteem by recognizing another person's worth at a higher level than is warranted, thereby raising my own level by association. Either way, Theresa points out that I have failed to recognize the individual in the wheelchair as an individual:

Don't judge me because you see this hardware attached to me. It's the type of thing where the wheelchair doesn't define who I am; I define the wheelchair. It's not the "oh, you see the wheelchair right there with the girl in it?" It's "the girl in the wheelchair." I'm not just the wheelchair. I'm the girl sitting in the wheelchair. The wheelchair is not who I am. I'm just the person in it. It's the same as "look at that person in that car." You don't want me to judge you by the car you drive—don't judge me by the wheelchair. So it's really one and the same.

Respect me first because I'm Theresa, then respect me because I'm a mother, then respect me because I'm disabled. Those things are more important than respecting me as a black woman. And that goes back to being a person, being who you are. I am a person within a disability; I am a person first.

It appears so trite, “How do you treat a person with a disability?—Like a person,” but more than any other poignant quote or perspective that Theresa may have shared, this message was eloquently communicated through her verbal and non-verbal messages.

Of course Theresa was equally eloquent in her messages about the parameters associated with disability. She talked about race and disability, about gender and disability, about age and disability, about family life and disability, and even a little about assistive technology and disability. As a black woman [again, Theresa’s preference of designation], Theresa’s observations about disability and the black community appear to cross all other areas of interest. Whether a person is born with the disability or acquires the disability later in life impacts how the black community reacts to and responds to that individual. Theresa relays that there is a feeling of shame associated with having a child with a disability and the parent’s main concern is “helping them get over” and helping the child understand that they can do everything that everybody else can do, they just do it differently. Yet a person with an acquired disability is often seen as a person out of context in the black community. “People don’t know how to react to me,” Theresa relays; and “I am the first black woman with a disability that I have known.”

As a pediatric physical therapist working with children with congenital disabilities for 20 years, and as an assistive technology equipment provider for the last ten years, I have not appreciated the lack of exposure that individuals with physical impairments receive in the black community. I have been to many patients’ houses in the black community in varying roles as therapist, as equipment supplier, on behalf of the school system, and as an advocate, and as a friend. Yet I was never made to appreciate that I was

seeing these individuals in their home, behind closed doors. In that respect, my eyes have been opened to discrimination that occurs within cultures against individuals with physical impairments. Notwithstanding that Theresa is one person's opinion and perspective, but it is a truth for her, and therefore bears merit for thought for me.

What became apparent towards the end of our discussions is how Theresa had managed to incorporate philosophies of disabilities—the medical model versus the social model, parallels of issues of discrimination between whites and blacks compared to able-bodied and disabled, and had intertwined the areas of interest of race, gender, race/culture/ethnicity, family life, time of onset of disability and assistive technology in a way that each was inextricably linked to the other. I had thought that there was a marked distinction between the erudite philosophers writing for the disability movement and the working class people with physical impairments with whom I socialized and worked. Even though researchers such as Oliver, Priestley, and even Sacks when he was temporarily physically impaired were speaking for the disability movement as individuals with disabilities, I felt they were disenfranchised from the person on the street who was in a wheelchair. Not that these skillful researchers were out of touch with the day-to-day indignities associated with being a person with a disability, but that they were writing from a philosophical perspective that was not necessarily connected with the common person with a disability.

Although Theresa is well on her way towards an advanced degree, she recounted her life and the areas of interest in such a manner as to connote the common person perspective. By so doing, she demonstrated that the issues of concern of age, gender,

race/culture/ethnicity, time of onset of disability, family life and assistive technology not only played a significant role in her life and helped her define who she is, but that her views, observations and outlooks about disability coincided with authors and experts in the disability movement. Theresa used different words than the experts, but, in my opinion, spoke far more eloquently about what it is like to be a person with a disability.

In Theresa's case, I was not wrong in assigning noble characteristics to her. She would have those characteristics regardless of her physical condition or form of mobility. Theresa's observations were candidly unique and poignantly shared. I have a much better perspective of what it is like to be a black woman in a wheelchair from Theresa's perspective.

Chapter 6

ELLEN: FAMILY IS EVERYTHING

Ellen is now 62 years old. She is white and was born and raised in the Northeast corridor in Connecticut. The first time she met anyone from an ethnic background differing from hers was when she was eighteen and living in a residential hospital school. She fell through a glass skylight on a roof and became paralyzed from the waist down as a result of the fall. Ellen acquired a physical impairment when she was fifteen.

Family is everything to Ellen: “They were good when I had my accident when I was 15. My mother was 37; my father was the same age; they were born in 1910. My father was used to people with disabilities. He had a brother who had infantile paralysis and muscular dystrophy; they used to put him in a wagon and took him everywhere. He died by the age of 17.” Even after Ellen got married, her father was there for her: “Of course my father had to build the ramp. There was no question, he did whatever I wanted and needed to have done.” Ellen’s father died at 54 of a coronary thrombosis two weeks before he turned 55. Her mother died at 90 in the year 2000. Ellen has always been afraid of death.

I’ve always been afraid of death; they thought I had died when I fell through the roof. I thought, “Oh well, I’m dying, so what?” Because that's what I thought, because that's what it felt like, and I did die. They couldn't find any

breath in the mirror or anything like that, and they gave me adrenaline I guess, and brought me back. And I wasn't told for quite a while after that that I had died. They thought I was dead. But I don't remember seeing anything like people say they see. I don't remember seeing any of that.

The Accident

The Fall

Her accident occurred when she was 15:

I was bored, a lot of kids were bored; you had nothing to do, and no places to go. So we had this thing of climbing roofs—climbing on top of roofs in the downtown area. And on that roof there was coal, for some reason, I don't know why. There was coal over near the area where the door was when you got onto the roof, so we never went that way. We used to go around coal piles to go across to the other roof. And I was leaning over the roof and looking down and I had just lit a cigarette and I looked down and I saw my boyfriend was downstairs and he was yelling up to me—“You'd better get off the roof and come down or else we are through.” And my temper took over and I said, “who does he think he is?” I stormed off and I went where the coal was, instead of around where we used to go. And there was a black glass that I stepped on. And when I stepped on it, it turned out to be glass because it was painted black because we used to have blackout days back then. And you had to pull black curtains and stuff down whenever they had the air raids. And that was painted black, and they never

changed it. And I went down 40 feet in an air shaft. And there was a bench down there, and I landed on the bench and I passed out; I don't remember landing; I just remember putting my foot up and then starting to go down and that was it.

The Hospital

Ellen's life was changed forever:

I remember when I got to the hospital and they were trying to get my jeans off, I couldn't feel them doing that and I just started yelling at them, "don't amputate my legs, don't amputate my legs." I thought I had broken my legs. I didn't know. I had never broken a bone in my body before. I had no idea what sensation or what it is you get with a broken bone. But it was a broken back. They said that I broke my lumbar spine, the first and second vertebrae. Later on in years when I was at Lucerne and had Baclofen, Dr. Green looked at my x-rays. He didn't think it was the lumbar spine. He said that it was thoracic, T9, T10 around there. So I don't know, that's what he said. But I was told it was lumbar first and second vertebrae.

Ellen relays what it was like in the hospital:

My mother and father had Blue Cross/Blue Shield. But after eight weeks of being in the regular two-bed room, a semi-private room, insurance was running out, so they had to move me. And they moved me down to the woman's ward which they had nicknamed the snake-pit. When they put me down there, they left me on my back all day and all night. I had a cast that was put on when I had my

accident. I lost 20 pounds, bam, just like that. So then you could put your hand there and move the cast around. Well, it caused a pressure sore on the spine. The doctor came in and took the cast off and left me laying on the front of the cast on my stomach, he took the back off so I could lay on my stomach. And I was laying there and it was getting very, very painful laying on the cast. I started crying and my father came in and he was saying (I had a toothache) “you shouldn’t be crying about a toothache with all this going on.”

I was laying there crying and they had a group of people that were going to become nurses, they were going to go to work there. They had them come around and here I was... they had them coming around to look at me. My sister-in-law, who ended up being my sister-in-law after that, was one of the people in that group and she thought that was terrible that they did that. They brought everybody in to look at me laying there in the bed just like that, crying away because I was in such pain. And she always remembered that.

They had separated the cast; they put the cast on the floor, the back part, and the cleaning lady came in and took the cast and threw it away. And everybody was saying goodbye to her. I guess they thought that the doctor was going to have her fired. Half my cast gone—she threw it away. So I never had another cast put on after that. And I was there about eight weeks. And then Dana, my sister-in-law, was working in the snake-pit. It was her and her friends that had come in; it was that group when I was in there. That's where she was working.

So when I went down to the woman's ward and they put me on the sun parlor. They started using the sun parlor as another room. And they had two or three beds on each side of the doorway, lined up. And then I started getting a pressure sore where I just had surgery on. That was in 1953. I got that and they put me on the striker frame.

The striker frame is about as wide as your body is, and I was very skinny at the time. You get flipped over on your back, and you get put in like a sandwich, and you get flipped over on your back or over on your stomach and they put this thing here that your face goes through, when you're lying on your stomach so you can breathe. And that's it. You don't lie on your side. And I always wondered, if I had such a bad pressure sore on my back, why did they have me lie my back, unless there was a place there where there was an opening and I'm not sure that there was.

So they put you in this thing and they sandwiched you in and they're supposed to strap you in while they flip you over. Well they didn't. I held on, but I couldn't hold on with my legs. So they would take chances and they would flip me over, hoping that my legs wouldn't fall out. And my mother came in to visit one time, and they had my mother help them. And she could see that my legs were going to fall and she knew that I was worried about my legs falling out. So she tried to grab my legs to hold them, and she got her arm caught in the machine as it was turning.

So they flipped me over to my stomach and left me sandwiched, and grabbed my mother and took my mother to emergency as I, the brat that I was, was screaming and yelling, “get me out of this thing.” I didn't know what happened; they didn't tell me what happened. They just took off with her to emergency to get her wrist sewed up while I'm in this position. They should have had another nurse and put straps around my legs. When I went to Lakeville, they put straps around so that my legs wouldn't fall out.

Somehow or other I was able to get out and look behind me, and that was the first time that I had ever seen it (I had never been in the hospital other than to get my tonsils out), to see that sore, you could put your fist in it. They had to debride it and do all kinds of things to it, it was so bad, and it never healed that much because it was so close to the bone. And that's what's been breaking down on and off all these years, until the doctors just went in and did a muscle flap transplant.

I also had surgery that took some of my feeling away. It really surprised me that they did that kind of surgery because I was only 16 or 17 years old. They did what they wanted. They got permission from my parents. But they didn't know what was going on. They didn't know any of that stuff.

Retrospection

If there was anything that she could change in her life, it would be:

I wouldn't go on that roof. I absolutely, positively would not have gone on that roof that night. If I could go back, I've said many times, I wish I could go back and change those two seconds of my life. That screwed it up. Changed it certainly.

I guess in some ways I'm more fortunate because I can't feel certain areas because then it would cause more difficulties. I'd probably hurt more than I do now. My muscles, my shoulders, and my arms are killing me all the time, and my neck. So I could imagine what it would be like if I could feel everything.

So would I like to do stem cell and get everything back? I guess I would even though I know I would be in an awful lot of pain there for a while. My husband, Bill has been telling me for years—you don't want to get everything back; do you realize how much you're going to hurt when you do because of all this that's been going on over the years? Yeah, I still would.

Would I like to be able walk again, like normal? I'd love it. I can get out there dancing in a wheelchair, but it's nowhere near like being able to get out there and dance. I'd love to be able to roller skate. I used to be a great roller skater. All those things.

And do you know what the funny thing is? Not too long before my accident I stood in front of the mirror in my bedroom and was looking at myself and said, "thank God I've got my legs." And then I had my accident. I feel lucky

with my diabetes when I see my brother, but still...I need to exercise and lose weight, but I'm not doing it. I wish that I could get up and walk like I used to. I used to love to walk.

Family Life

The Early Years

Ellen grew up as the “last of four kids. I’m the baby. I have a sister that is the oldest and I have two brothers in between.” When she had her accident she was the only one home at the time. “My sister had gone into the Air Force, my older brother, John was in the service, and my brother Bill had taken off; he had come to Florida. He was 16; he was a year older than me. So at the time it happened, I was the only one living at home. It was very devastating to my parents.” But it wasn’t the first time she had fallen from a building:

I got an upside down “v” scar on my lip from when I was three years old and I fell over a railing. A friend of my mother's was babysitting my brother and me and we were on the porch throwing pebbles over the railing and looking to see where they went. I got up on the railing to look over to see where mine went and I started to go and my brother grabbed my feet but he couldn't stop me; he started to go with me, so he had to let me go. So my brother ran in and got the babysitter and she took three flights of stairs like it was three stairs. There was a black kid that just happened to be standing down there and he caught me. I was headed for a picket fence before he caught me. That's the story that I've been told. I don't know

how come he was there, or...I don't know, I was only three years old. I don't want to fall three stories again. Third time...

Ellen's family didn't make much money when she was growing up:

My father was a local truck driver. He drove for a company called Stone Express. He delivered to Jordan Walsh and Pisces Basement in Boston. What he did before that was he drove, I'm not sure which company, but around in the city where we used to live he used to drive the truck and bring home cow skins from cows—the skins from the cows and stink up the whole area, the whole neighborhood. He had them in the truck and he would come home for lunch. And he would stink up the whole place; I remember that because I would be coming home from school for lunch, and here would be dad coming home for lunch. Then he went to work for Stone Express.

My parents didn't have very much money; my father used to make seven dollars a week back then, and we lived in a four room house with four kids and two parents. It was—we used to call them twin houses—it was two houses together where the middle of it was a cement yard. We used to play hopscotch in the cement yard. The houses had cellars. And we had two stories.

My mother stayed at home until I was in school. Then, she worked in a laundry. Back then you used to send yours sheets out to a laundry, and she did that. I can remember going to the laundry where she worked. They used to have these great big long mangles, that they would put sheets on, and they would have to come through the mangle. And then they would take them and they would have

that special way of folding. She did that for a while and then she went to work at Vernon's Plastics and she worked there pretty much for the rest of her working years. Until Vernon left Massachusetts and my mother left Massachusetts and then she went to work for another plastics factory. I think she used to pull plastic and I'm not real sure exactly how she did that. And I think she had carpal tunnel and I think she didn't realize it; no one ever realized what she had but her hands used to bother her all the time. And she was in her forties before she ever learned how to drive. Back then, the women didn't drive that much. My father used to drive us back and forth to Boston.

Adolescence

Ellen had just starting dating Danny when the accident happened. But they stayed together as a couple for four years following the accident. Danny used to come see her in the hospital every day until the insurance money ran out and she had to go to a sanatorium:

Danny and I went together for four years. We had just started going together not long before I got hurt. We were planning on running away to get married when I turned 16 in December (the accident was the previous September). I was supposed to be teaching him to dance and we were going to go to the radio station dance the next night. I was supposed to start teaching him to dance the day after I had my accident. I guess he does okay now [dancing] I don't know. [They are friends to this day].

Of course I got hurt, and that took care of that. And my father was allowing me for the first time to go to the midnight show of Frankenstein. So Danny went to the dance after my accident, and they announced things about me over the radio. And a popular singer was at the dance and she signed dollar bills and gave them to me. I don't know what happened to them.

And when I went to Lakeville Sanatorium, not sanitarium [Ellen's emphatic clarification] it was an old TB hospital, it was two hours away. And my parents would come one day on the weekend. After a while I talked them into letting me go out for rides.

Civil Rights

Ellen was born in Lyon, Massachusetts in 1938. For her, growing up in the 1940's and 1950's in urban Massachusetts near Boston did not provide much opportunity for racial interaction. When I asked her if there were any kids with differing backgrounds at the sanatorium where she lived, went to school, and underwent rehabilitation, she asked me what I meant, then replied, "I knew one guy, his name was Gerald. He was black. I remember he was tall, thin and he walked on crutches. We were friends. We never went out; we were just friends." Ellen relayed that there were only one or two individuals who were black at the hospital school. She implies that race has no particular bearing on disability, either on having a disability, or how people view an individual with a disability. While Ellen does not give any indication of racial prejudice, she still feels that:

...obviously I'd rather be white. They're still having a lot of problems with blacks and we were fortunate to be born white. And, sure, I'd like to be young. There are too many problems. You have enough problems being disabled and then it adds to it because of age. But ours are added to more because we're disabled. So more aches and pains in there because we're disabled.

The Medical Model

However, it does not appear that Ellen has allowed the fact that she is disabled create barriers in her life. She met her future husband, Bill at the hospital school for the handicapped (Ellen's term). Bill had been born with cerebral palsy and had undergone numerous surgeries to correct physical deformities. Ellen and Bill shared a medical background and a medical orientation toward disabilities. After Ellen and Bill were married and lived with her parents for two years, they bought their own home and worked for the original Goodwill Industries, Ellen as a cashier and Bill as an electronics technician. They didn't make a lot of money:

We both worked at Goodwill and we left and went to work at Ace Electronics, so we used to go to work together. The guy hired a lot of handicapped. I guess it was to his advantage, too. But we went from 55 cents an hour (at Goodwill) to \$1.10 an hour at Ace. And that's \$52.00 a week for the two of us. I'd get \$30.00 if I worked six days. I was a cashier there.

Travel, Vocation, and Employment

But Ellen had always wanted to go to California:

Bill's brother was over there [in California]. So we went to their house first. We were only in Long Beach, California for five months. We drove out there, Bill and me and the dog. On the way out to California we got the last motel room at Howard Johnson's in Pennsylvania during a snow storm and we got stuck in mud in Indiana. And he had German boots that his brother had gotten in Germany, and he had those boots on and he left them in the mud. He's walking on his crutches in the mud, trying to get help. And this guy says, "don't you people have any mud back East?" It took us about a week to get out to California. And we stopped in Las Vegas. That's the first time that we ever went to Las Vegas.

Bill had a job in Fullerton, California before we left Massachusetts. And when we got there, the job wasn't there. So we drove around for five weeks, looking for a job. He finally got a job with Air Research Corporation and Richard and Kara (brother and sister-in-law), wanted us out, so we got a small place. He worked there for 2 ½ months, and you had to work there three months to be considered full time and they laid him off. He was the last one hired, so he was the first to go when they cut back. They gave him severance pay, so we called up New England Instruments to see if they wanted him back. They did and they even sent us the money to get back home.

So we left in July, we bought a used U-Haul trailer and packed it full and we set out. We went back through Las Vegas. It was hot. We bought a swamp

cooler—it had water in it and you put it in your window and rolled up your window and the air blew water mist into your face. But when we got back East and it was cold, we couldn't get it out of the window and I nearly froze.

We almost got killed in Wyoming. We didn't have the right hitch and the trailer started swaying and all. And I had to get out and look at it. And we were on the edge of an embankment that went down nearly 30 feet. Why I didn't fall down that embankment in my wheelchair, I'll never know.

We drove a '61 Ford that could only go 10 mph up a mountain pulling that trailer. Truckers used to get so mad at us.

They went back to New Hampshire and lived there for a year or so. They then moved to Massachusetts:

We bought a ranch style house in Bellingham, Massachusetts in 1968 and lived there until Bill got laid off. Then in 1970, Bill's mother died; she was exactly the same age as my father when he died. Before, we were both wondering if we would make it past the age of 54 (their parents had died at 54). (They are 66 and 65 now). We didn't pay the mortgage for over a year because Bill had been laid off and we weren't getting that much from unemployment. I had already started getting disability at that time. I was getting \$ 98.00 a month. It wasn't very much. So we finally got in touch with Ted Kennedy and no one bothered us about the mortgage for quite a while. Then they started foreclosing on us, so we had to move. So we ended up getting a 14' by 60' mobile home. We had it built for the disabled. We had a great big long ramp on the trailer, and I used to shovel that

ramp. I'd just take the shovel and push it along in front of the wheelchair. I can't stand to be penned in and not be able to get out, so I kept the ramps clean.

The cold winters got the best of them, and they moved to Florida:

We moved to Florida because I wanted to get away from the cold. That's why we went to California. We wanted to get to the warm weather. My grandfather and grandmother and aunt and uncle lived down here in Florida. We got the house through Farmer's Home (a type of funding agency). We moved in here in 1978. At first they weren't going to give us the mortgage because we were both in wheelchairs. But then something came through that said that you couldn't discriminate. So they stepped all over themselves trying to lend us the money. John Hill, I remember his name, with Farmer's Home. He was a black guy and he didn't even want to keep the appointment.

And then they said that I had to have a job so I got a job at Belk-Lindsey making signs. But I got fired because I said something to the boss about how he was wrong about changing his mind after I started making the sign and would have to start over. Of course they also asked me not to come into the store when they were having the grand opening because they were going to be so busy and I was in a wheelchair and would take up too much room. So I put in for the program through VocRehab to go to cosmetology school and I got accepted.

Starting A Family

Ellen had always wanted children, but had come to the conclusion that adoption was the only way that was going to happen. The adoption process was not easy for them because both she and her husband, Bill, were disabled:

We had tried husband insemination. But we found out that since I had a catheter and because I had leaking around it, that was probably killing the sperm and that was the reason I couldn't get pregnant. We didn't know that until years later. We did different positions and everything else, and we went to the doctor and finally decided to try to adopt.

When we went to the adoption agency, they asked me all the questions, what kind do you want? Well, blond, blue-eyed, all those things. And then when they found out I was in a wheelchair, they asked me, "well, how are you going to do that in a wheelchair?" I never told them Bill was disabled. So when they asked, what are you going to do at night? I said my husband would take care of it. So we never could get any foster children.

We finally were able to adopt Morgan. Morgan was one of three kids of friends who said they wanted friends or relatives to take care of the kids while they traveled to Arizona. After two years, my sister-in-law asked the mother why she just didn't let us adopt Morgan. She was 21 months when she came to live with us and she was 4 when we moved to Florida. We applied for adoption and right after they officially abandoned her, we immediately went in and applied to adopt her and we got her.

I tried to get Morgan in touch with her biological mother a few years back and she saw her the last time we went to Massachusetts. I was able to get Champus insurance for Morgan because her biological father died in the military. I couldn't get her on my social security because she was adopted after Bill went on social security, so they wouldn't allow us to put her on social security disability. That's why we had to get her on Champus.

Advocacy

Because of everything that she has been through, Ellen has somewhat of a unique perspective on being disabled. She acquired a disability when she was 15. She has been married to Bill who has a congenital disability for 38 years. Married couples where both partners are disabled are not all that uncommon in Massachusetts, according to Ellen:

That's not all that uncommon up in Massachusetts. A lot of it has to do with we all went to one school—the Massachusetts Hospital School. So we knew each other, dated each other and married each other. Everybody was disabled. A lot of people met in those places and married from those places. And people that we knew that weren't in the hospital school we knew from MAP—Massachusetts Association for Paraplegics, or the Disabled Vets.

Another part is that we were so involved with wheelchair games. I used to bowl. I have a 205 game out there. Of course I was bowling with my father and his group.

Ellen and Bill consider themselves successful at accessing services and advocating on their own behalf as well as advocating for other people with disabilities:

So we got a lot of things changed for accessibility up there. We didn't have a lot of things then. A lot of things that young people have now they have because of what we did. And they still complain. I don't know if young people get more now because I haven't really stayed in that for a long time now.

We're not involved with the groups like we used to be. We used to picket. We picketed city hall in Boston. We used to have meetings with MAP and the alumni association from the hospital school.

Down here, we can't get people to get together. We found that out when we tried to get into groups down here. Everybody was separate. Nobody wanted to get into a group to access things and do things. Other people just went their own ways. All people wanted to do was socialize. I didn't want to go to advocacy groups to socialize. I don't need handicapped to socialize. I socialize with anybody.

On self-advocacy related to the time of onset of the disability, Ellen thinks:

A lot depends on the individual. It's knowledge and what you do. A lot of people don't know anything. People that are newly disabled don't know anything. People that are newly handicapped or older people that get handicapped don't know anything or you can't get them to do anything. You see some stupid things that they do and you say, "Why?" When it's out there and you go looking for it, and you ask for it; you don't just go and live with what it is without trying to get

some kind of help or asking someone about it. We have people call us all the time and ask us about the van, and different things. When they see that van, they want to know how we got it. They have to understand that it's quite a process to get something like this. It's not as simple as just getting a ramp.

Gender and Disability

So far as gender and disability, Ellen thinks:

I don't know. Because Bill and I go through different agencies for different things. And I have to say; except for a few times up in Massachusetts when I had problems with Vocational Rehabilitation, other than that, I've never had problems with the agencies I deal with. When I lived in Massachusetts, I used to get a manual wheelchair from them every two years. And I would sell the one I had or give it away.

Age and Disability

When it comes to age and disability, Ellen thinks in terms of availability of services:

I just got in touch with VocRehab again about getting another power chair. Up in Massachusetts VocRehab allows homemaking as a profession. Down here, they say they do; but they don't. They'll put a ramp on the house or something like that if you need it; but that's about it. I don't know if it's more difficult to get stuff when you're younger. Up until a couple of years ago I was able to get everything I wanted. I've just been lucky I think. I've had bad counselors and I've had really good counselors (VocRehab). If you have bad counselors, you just do

what you can, or try to get a different counselor. We've done a lot of stuff over the years. It's getting harder now

Self Description

Ellen and Bill, as wife and husband, appear to be well suited for each other. Both consider themselves independent. In addition, Ellen sees herself as "self sufficient," and "controlling." Ellen is committed to task and conscientious about most things that she undertakes. She "likes to see things that are started, finished." And when she thinks of something, she "wants to do it now."

Ellen chose her daughter and her granddaughter who both live with her as the people who know her best. Ellen's impression of how they would describe her is "grouchy," "mean," "that I expect more out of them than they are willing to do." However, Ellen counters this authoritarian impression with humor as she relays how Bill thinks of her, "he thinks I shop too much."

One of the indicators of how a person effectively deals with life's challenges is a sense of humor (Markus and Nurius, 1986). Like her predecessors in this study, Mike and Theresa, Ellen incorporates humor into her daily life. She will laugh at the irony of not being able to use the last wheelchair accessible parking space because the lift gate for their van is on the side and not the back of the van, and the handicapped parking space does not allow enough room on the side for a wheelchair lift to operate. The humor to her is that she has advocated long and hard for enforced handicapped parking in her community.

According to Ellen, she is “most like her mother. She liked to play bingo, and she was a terrific dancer, as was I, before I had my accident.” Ellen has led a productive, positive life. She has raised a family and contributed to her community. She demonstrates how she deals with life through her intensity and dedication to family and community.

Reflections and Response to Ellen

I have known Ellen and her husband, Bill, since 1980. We met at the United Cerebral Palsy Telethon. Ellen and Bill were being interviewed as consumers; Bill has cerebral palsy. I was being interviewed as a pediatric physical therapist working with kids who had cerebral palsy. Later, all three of us would join the board of directors for United Cerebral Palsy. Ellen and Bill provided the critical perspective of direct consumers to the board as we tried to build programs and services for individuals with developmental disabilities. Ellen kept the board of directors honest and on task because she was bluntly outspoken about what a person in a wheelchair needs. She never allowed non-consumers on the board of directors the false luxury of providing fluffy, unnecessary programs *to* individuals with disabilities; hers was the realistic, hands-on needs from the perspective of someone with a disability.

It was that perspective, combined with Ellen’s 40 plus years of experience of dealing with disability issues, which led me to want to include her life history in this study. I expected from Ellen outright demands and ultimatums on what individuals with disabilities need. What I got was concern and compassion for the family unit as the

pivotal influencing factor in an individual's life. If the individual also happened to be impaired, then the family unit was all that more critical.

I knew a lot about Ellen, the advocate, before we started the interview process. I knew that her self-determination had developed in Boston where services for the disabled were some of the best in the country. Such was not the case in Florida. When Ellen and Bill moved to Florida in 1978, Florida was second only to Mississippi in being the worst provider of services to individuals with developmental disabilities in the United States (Florida Developmental Disabilities Council, 2004). Because services for individuals with disabilities in Florida compared so poorly to that found in Boston, Ellen's life as an advocate entered a resurgent stage. I first met Ellen under her guise as self-appointed advocate. I did not know Ellen the mother, Ellen the daughter, Ellen the adventurous traveler, or Ellen the wife of an equally strong and independent individual with a disability, Bill.

Without using the term *medical model*, Ellen described what it was like growing up, receiving services in the form of treatment, and perceiving herself as disabled from a medical viewpoint. Ellen acquired a physical impairment in 1953 when the medical model was the only perspective of describing and treating a disability.

From being an unknowing participant in the medical model of disability, Ellen developed a personal perspective of disability. She feels that full inclusion for individuals with physical impairments in school is not always the best or most appropriate. She feels strongly that the schooling and socialization that she received at a segregated school/rehabilitation center/hospital for individuals with physical impairments met her

developmental, social, educational, and physical needs. Ellen explains, “A lot of it has to do with we all went to one school—the Massachusetts Hospital School. So we knew each other, dated each other and married each other. Everybody was disabled. A lot of people met in those places and married from those places. It worked for us and for many other disabled people.”

She met her future husband at the hospital school and many of her life-long friends are from the hospital school. My interpretation is that she thinks that a continuum of services is indicated for individuals with physical impairments and that each person should have an active, authoritative voice in making the determination about what placement is best.

Chapter 7

BILL: "I'M NOT CRIPPLED"

Bill is 63 years old and was born with cerebral palsy. He lives with his wife, Ellen, who is paralyzed from the waist down as the result of a fall when she was fifteen. Both Bill and Ellen use motorized wheelchairs for mobility. They have a wheelchair accessible van with a power lift for transportation. Bill lives with his extended family (wife, daughter and her husband and their daughter) in a wheelchair accessible home that they had built 17 years ago. They had to take out a second mortgage on the house to buy the wheelchair accessible van two years ago. They are both on disability income.

"Wit turned inwards is cynicism," (author unknown) seems to best describe Bill. Even at an early age Bill's cynical outlook appeared pervasive throughout his personality. When asked what his life was like when he was growing up, Bill's response was, "It sucked. I was in the hospital most of the time. Once they found out something was wrong with me, I was in the hospital all the time, until my father ran out of money and couldn't borrow any more money. Then they said, 'well, he's going to die before he's 21, take him home, and forget about it.'"

Family and the Early Years

Bill has a brother who is three years younger. Bill's sister is five years younger than Bill. Bill describes his mother as, "...nice. But you had to know my mother. She was a different kind of a person, always cheery, smiling. It didn't seem like it took much to make her happy." Bill seems unsure of what his parents had in common. Bill relays:

I don't know where my parents met. Their backgrounds are completely different. My father was a college graduate and my mother never went to high school; she probably never went past the eight or ninth grade.

My father was a biochemist, but he didn't make a lot of money. He was the director of a big laboratory at Walden Fewes Fishery. In 1940 he was one of five scientists in the country picked by the government to do research on vitamins. He used to go all around the country giving speeches on nutrition and vitamins, but he hated to travel.

Bill was born with cerebral palsy in 1935 and knew at an early age that his life was going to be different:

Well, at that time they called it spastic paralysis. That was the dark ages, you know. Nobody knew much about it; nobody knew what to do with it. They think it was caused because the doctor was late and they held me back with forceps. A lot of CP's (cerebral palsy) are born with CP because of forceps. It's tender on the brain and when you use forceps you can do some damage, which is what happened to me.

It became obvious. I couldn't stand up. I went on the floor on all fours up until the age of seven years old. So it was always the life of looking at knees. I had terrible problems with my knees at that age. I used to have water on the knee all the time. They used to have to drain them. They used to have to put these stinky hot pads on. That would suck.

They didn't think there was anything wrong with me mentally. They didn't associate mental retardation with the physical impairment because I could communicate at a very early age. I was able to say a lot of things, big words. I could talk. Most of the spastics couldn't verbally communicate.

Bills' early demonstration of language foreshadowed his mental abilities and facilitated changes in his life:

Because of my apparent intelligence, two things happened: the first was extensive surgery at Sinder's hospital. When I was seven years old my father happened to be talking to somebody where he worked who owned the fishing piers in Boston and was a Shriner. He set us up with the Sinder's Hospital in Springfield, Massachusetts, the Sinder's hospital for that area. So we went up there. Of course my father would have taken me anyplace to try to find somebody that could do something.

When he took me up to Sinder's, they said, "well, there's only so much we can do; but we can have you standing and walking with crutches probably within a year." As far as my family was concerned, that was unbelievable.

The second thing that happened because of my intelligence was being enrolled in the Massachusetts Residential Hospital School when I was 12. We had an interview. You had to take a mental test before they would allow you in there. You had to have an IQ that was high enough. You had to show that you could be taught, that you had the capacity to increase your mental powers before you could get in there. You were given away to the state. I was there for nine years. I came home for summer vacation. My parents knew it was better than what I was getting.

The Medical Model

Like his wife, Ellen, Bill grew up in a society that defined physical impairments as handicaps and treated these disabilities as medical conditions that required intervention. Bill describes what it was like to be the subject of well-meaning interventions:

I had surgery twice. Nine months, almost a year each time. I was in the hospital; I stayed right there. They released my knees in the back—cut them. They stabilized my ankles. My ankles were turned under; they brought them out and stabilized them. And they released the cords in the groin. After they released my knees, my legs would cross over, so they had to release those.

And then my hands—this one here used to be something like this one. It didn't work. So what they did was they cut the cord from underneath and brought it back over the top. In fact, you can see where they did it. However, they didn't

realize it at the time that if you put a CP in a cast for almost nine months, when you take that cast off, that's where whatever you've done is gonna' stay. So when they took the casts off my legs, my legs were stiff. And when they took the cast off my arm, the wrist just sprung right back up here because the pull here was more than the pull there. It pulled the fingers in and pulled the hand out.

So they did some of it (the surgery) first, and then I went back and they did the rest. It was terrible because I had my legs out straight, way out wide because they did the release here and straightened the knees and I had a cast from my stomach all the way down to my toes with a bar in between with my legs out as far as they could go. And this arm here was up by my side like this with a bar here. For nine months. It was fun when they had to turn me because they didn't turn the top part as fast as they turned the bottom part so the pain was unbelievable. And they had to hang half of me off the bed because this arm was stuck way out. It was fun.

One of my favorite stories from Bill relays how he perceived himself and how he related that perception to other people:

You should have seen me when I was younger. I absolutely terrorized people when getting back to my seat on the airlines. I would swing one leg up and way out and then swing the other leg up. Like going into the subways—I used to be able to go up and down steps. I'd fall down big flights of subway stairs, and people would just step right over me. And then I'd be going up a four inch curb

and five people would grab me and try to help me, and I'd be down on the ground.

I used to jump off the buses because the buses didn't kneel down like they do now. So I would get one foot down, and the other foot would be up in the bus, and I'd throw the crutches and I'd jump and land on the crutches and I'd be off. They said the bus driver would cringe every time. Sometimes I didn't make it. They say that walking is a series of controlled falls. For me, every step is a controlled fall.

Education

Prior to attending the Massachusetts Residential Hospital School when he was twelve, Bill had been at home "...going to 'opportunity classes.' These classes were for handicapped and problem kids and everything from young to old all in one class with one teacher. You made baskets and you colored and you raised hell and got the teacher crying ten times a day."

Because of his varied educational experience of attending 'special classes' in his hometown and matriculating at a residential vocational preparatory school, Bill has definite ideas about education. Bill explains:

I don't think mainstreaming is for everyone. There should be options. Everybody cannot be taught in a mainstreamed school, I don't care what they say. Massachusetts is the only school that did what it did in the world. It combined medical with education. The education was not just a simple show up and do this

and that. The school was accredited by the state of Massachusetts the same as any other school in the state. Any kid there that passed, that graduated from the Massachusetts Hospital School, had no problem getting a job.

What hurt Massachusetts Hospital School more than anything is when the law came down that you would be mainstreamed into the education program if you were disabled. That hurt the disabled a lot more than helped them, as far as the hospital school was concerned. The downfall of the hospital school is when they started allowing mentally handicapped there.

Bill's formative years were spent at the Massachusetts Residential Hospital School. According to Bill, this is where he "came into his own:"

That's where I became...that's where things started happening. I moved out of seclusion into the daylight. I developed my own little world there, my own system at the hospital school. I had a reputation. It was one way to get rid of people that you didn't want around you, keep people at a distance, keep from letting them in. I came up through other ages, through other leaders that were there, and then eventually they would drop off and others would take over and so the last few years that I was there, it was sort of my turn as overseer of the campus. I got my own way.

Bill describes the hospital school:

You had a couple of hundred kids there; girls on one side, boys on the other in cottages, and a big hospital. The place was like a college campus. There were a lot wheelchairs, bed carts, everything like that.

The education was the best you could get because your class sizes were five, six, ten at the most, you know, one-to-one. Besides regular school subjects, they had shop, shoe-making, brace-making, watch repairing, and printing. Canyon (Massachusetts Hospital School) was an unbelievable place. It was unbelievable for the people who went there and for what happened to them after they left there.

There was the whole thing of building relationships. Year after year, even after I left, there was a connection there to when you got outside. You still had friends. You built on those friendships. After we got married we went to weddings of other kids who were at Canyon. There were more married handicaps in Massachusetts than any place in the country. There was a whole bunch of us. We had clubs, we had meetings.

But it wasn't always the ideal setting for Bill. During the polio epidemic in the 1950's, attendance at the residential school was at a premium. Bill relays:

I was almost thrown out of there during the big polio outbreak in 1954. That place was loaded. We had iron lungs all over the place. They brought more polios into there; it was unbelievable. A lot of them that were there had to leave. I was almost one of them. They just didn't have the room. I was in vocation then. They wanted to watch me. And I was staying there part of the summer after the school year to put more time into learning watch repair.

Bill's tenure at the Massachusetts Hospital School may have been partly attributable to his cleverness:

Of course I got campused [restricted to campus] a lot. But I pretty much got around that any time I wanted. When kids were campused, when they wanted to go out, they'd try to sneak out through the back and over the fence and stuff like that. And they'd get caught.

What I did is, I went into the front office where the telephone and all that stuff is, where the board is, and I'd call a taxi, walk out the front door and get in the taxi. And nobody questioned it. The others would get caught all the time and I'd just walk out.

Vocation and Employment

Watch repair is not the first vocation that a new acquaintance would associate with Bill, mainly because Bill's hands are usually held in a tight table-top position due to the surgery he underwent at an early age. And yet, watch repair is the exact vocation Bill chose to pursue. Bill explains:

It's kind of ironic, working in watch repair with these hands, handicapped with cerebral palsy and surgery, and yet I can do watch repair. Not for assembly line or speed, but they work real well for the delicate stuff. I can work with this hand under a microscope using tweezers on the tiniest thing and I hold things with these fingers.

I made up devices that hold stuff. I made up a thing that when you're working under a microscope and you've got two things that you have to solder together and neither one is bigger than a hair and you're reaching for your

soldering iron and you're trying to put the soldering iron back into the stupid holder—that's a real deterrent to what you're doing. So I took the case out and just took a piece of metal and put a thick round magnet on it. Then I could just rip the soldering iron over there and hit the magnet. I didn't have to screw around trying to fit the soldering iron into the case; I just threw it over there. On the small vices that I used, I replaced the bar handle tightener with a thumbwheel tightener and that worked great.

Bill's assessment about being disabled doesn't seem to apply to himself. Bill stated that, "your choices when you're disabled and handling things are limited a lot more than when you are not disabled. You've got parameters when you're disabled that really tie you in." It appears that Bill set out to deliberately overcome the parameters that limited him as a person with a disability. Perhaps that is because Bill perceived his mental abilities as a major strength and considered them as an avenue for success when he was very young. That perception persisted when Bill pursued employment after graduating from the Massachusetts Hospital School. Bill explains:

As far as getting a job, the more handicapped you are, the harder it is getting a job. It boils down to brainpower, if you haven't got that, there's no way you're going to get a job. It's still the same, the discrimination is still there; it's the same as it has always been. The worse you are, the less you're going to be wanted. That's it.

The big fallacy of 504 or ADA and all that stuff is that it claims it has made a difference in employment and it hasn't. It's made a difference in the

education and it's made a difference in accessibility. The numbers on employment are exactly the same as they were before ADA and 504. Everything else has changed—accessibility and education; but the employment has not. It's still around 50% among disabled.

According to Bill, problems arise once you are employed as an individual with a disability and you lose employment:

The real difficulty if you're handicapped and you're getting any kind of help like from Developmental Services or Medicaid and you get a job and then lose the job, is getting that help back. You have a harder time getting that help back after you lose it if you are unemployed again. So you think about that a lot before you go out and look for a job. Because then trying to get what you had before is very difficult.

Civil Rights and Advocacy

Bill and I discussed the comparison between the civil rights movement and the disability rights movement. As with every other topic we discussed, Bill had a definite opinion and perspective:

I think that handicapped are the last minority that are discriminated against. We are the last ones. The blacks always bitched that they had to drink from separate fountains. Well we couldn't drink from any damn fountain. They had to sit in the back of the bus. We couldn't get on the damn bus. So if you go

along those lines, we are the most discriminated against than any of them that's lasted the longest.

The discrimination that Bill feels may be partly due to terminology associated with individuals with disabilities. Everyone has particular terminology and attitudes with which they take exception. Bill is no different:

Another thing that's always bugged me is being called crippled. I was never a *crippled child*. I was always able to do something. A car is crippled at the side of the road and it won't move. If it's handicapped, you've got a couple of bugs in it, but you're still moving.

I got pissed off one time with The Rehabilitation Center when they said the handicapped there were happy, they never complain, they were always smiling. I called them and said that's a bunch of crap. You don't think I want to go out and swim and ski and do all that stuff, even if I haven't done it before? And they said, "well, you've never done it before, others are handicapped after they're 20 or 30; they've done it." I don't know about that. If someone came up to me and said that, I'd say, "well at least you had 20 or 30 years." Dumb. I haven't had any of it. Although I've tried most of it. Tried going off a ski jump; almost got killed. Used my crutches as ski poles; didn't work.

First-hand knowledge of disabilities has made Bill a strong advocate within the disability movement. He has become somewhat disenchanting over the years:

Over the years I got out of advocacy because I found that you couldn't tell the difference between the handicapped and the county or state department that

you were trying to change. They had become one. When I went in to do something I'd get shot down as much by the handicapped as by the department. So I said to hell with you all; I don't want anything more to do with it. When you can't tell the difference between the handicapped and what you're fighting, it's time to get out.

Handicapped aren't always the best for the handicapped either, you know, they can be jerks just like everybody else. There are good ones and bad ones. I know some of the biggest jerks in the world who are in wheelchairs and are handicapped. You are your own advocate. Your best advocate is you.

If the handicapped community isn't more together then that will make us go backwards. In Florida, that's the way it is. One group fights another group and they get nowhere.

Politics

According to Bill, programs for people with disabilities are tied directly to politics:

The liberals create all the programs and the conservatives take it all away. So we see cycles when the Liberals are in power, programs expand. When the Republicans take over, the programs are cut back. You wouldn't have social security or ADA without Liberals.

With four more years of Republicans, you're going to see a lot of that stuff disappear. The thing that I have (Developmental Services, part of Health and

Rehabilitative Services) is now being privatized under Jeb Bush. You might as well consider that gone. Okay, so what's that tell you? There's nothing to it. You're not going to get anything. People that are handicapped are not going to get anything.

The Future

Bill has grave economic and social concerns for the future as a person with a disability. Bill thinks, "It's harder. It's almost impossible now. I don't know what's going to happen, which is why we try to go where we want to go and do what we want to do, next week I may not be able to move."

Self Description

Like his wife Ellen, Bill describes himself as "fiercely pro-independent as far as people's rights go, especially disabled." Bill sees himself as "helpful to other people." Bill "likes to have fierce discussion or debates," and he "likes perfection." According to Bill, these four phrases best describe him. The fifth descriptive phrase that Bill used in the Self Data Survey reflects his sardonic humor. Bill says that he is "a helluva nice guy." It is easy to observe Bill's humor on life as he traced his life history, describing his exploits as a teenager in finding ways to get off campus from the hospital school where he lived,

Again like Ellen, Bill chose his daughter as the person who knows him best. Bill feels that his daughter would describe him as, "independent," as "self-sufficient as

possible,” stubborn,” “grouchy,” and “a nice person.” The qualities that Bill sees in himself are reflected in how he perceives others see him. Bill effectively describes how he fits into his chosen environment.

Reflections and Response to Bill

I have known Bill for over 25 years. I know him to be bitingly caustic, but poignantly accurate about issues and interests of individuals with physical impairments. I found Bill to be directly eloquent.

At this stage of the study, I was forced to confront the fact that while I thought I was empathetic and understanding of what it is like to be an individual with a physical impairment, I was deluding myself. Bill gave me indications that I had been pretentious about what it is like to be a person with a disability when he talked about adopting their daughter.

Like Bill and Ellen, my wife and I had adopted. But our side of the story was what Bill had talked about, “When we went to the adoption agency, they asked me all the questions, what kind do you want? Well, blond, blue-eyed, all those things.” For Ellen and Bill, the rejoinder from the adoption agency was “well, how are you going to do that in a wheelchair?” For my wife and me, the response was, “Would you be able to receive the baby in ten months?”

Bill further emphasized my delusion of understanding what it is like to be an individual with a physical impairment. We discussed our options for old age.

Bill: it’s like I told her; I’m not going into a nursing home.

Pete: yeah, but realistically what will you do?

Bill: yeah, realistically.

Pete: at some point, I'll be too infirmed and the only place that can take care of me is in a nursing home.

Bill: that's right. Do you have insurance? Will you have insurance for it or will you have Medicaid? Will you go into a good nursing home in a retirement situation or will you go in a dump? It makes a hell of a difference. I'll be in a dump. I don't want to be in a dump.

Pete: so what happens when you can't physically get up anymore?

Bill: I don't know.

Pete: will they send in caregivers?

Bill: down here, no.

Pete: so how are you going to stay here if you can't get out of bed to take care of bodily functions?

Bill: I told you. I just told you.

Pete: you gonna' die?

Bill: yeah

Pete: is this going to be self-administered?

Bill: sure.

Pete: and how does Ellen feel about that?

Bill: I don't know. She didn't say too much about it. I've told her over and over that I'm not going into a nursing home.

Pete: I can understand that. Even the nice nursing homes don't appeal to

me, and we have plenty of nice ones down here.

Bill: yeah, for money. You do not have plenty of nice ones for me. In fact, you don't have any nice ones for me.

Pete: it requires money.

Bill: there was talk about that up north—that we were going to start our own (nursing home). Because we could get the money for it up there and we were going to start our own nursing home, run by us (the disabled). This would give us a lot better control. We just didn't get together. People moved. And it depends on how it's run as to how good it is.

I was again confronted by my tendency to assign stereotypical attributes of nobility to people with disabilities. Just as I had assigned noble characteristics to Theresa, I wanted to assign those same characteristics to a program that was run by individuals with impairments. I made an assumption that a nursing home run by people with impairments would automatically be better than one run by people who are able-bodied. Bill had corrected my misconception.

One of my favorite sayings is, "I reserve the right to dislike anyone I choose. Just because you happen to be in a wheelchair, doesn't mean you can't be a jerk." My interpretation of that is that I am forced to look at the person and not the device surrounding or encompassing the person. Perhaps I am not as egalitarian as I would like to think I am. When the time comes that the wheelchair or assistive technology device does not register when I form an opinion of someone, then I will be that much closer to equality. That has happened only

once. I remember working for Linda Simpson, whose interpersonal and management skills were exemplary. It wasn't until years later when someone asked me to describe her that I discovered that I included a wheelchair in the description of her. Up until that point, I had never thought of Linda as being in a wheelchair.

Bill, more than the other three contributors, has forced me to draw a parallel between my self-interpreted liberalism about individuals with physical impairments and how I felt about being a pediatric physical therapist working with parents who had kids with disabilities. I considered myself to be very caring, understanding and empathetic of parents who had a child with a disability. When I would include a home program as part of the physical therapy treatment for their child, I would try to be considerate of the time and effort it took to complete the home program. I would try to include the home program into regular day activities, such as doing range of motion for an affected arm or leg as part of the bathing activity. Or I would try to make a game out of the home program so that it could be included in a daily play activity. It was not until after I had babies of my own that I came close to understanding what I was asking of the parents of a child with a disability. For many of the parents, getting through a 24 hour day was all they could manage; forget about the luxury of a play time.

While I am not saying that I would have to experience a permanent physical impairment to truly understand what it is like to be an individual with a physical impairment, although a case can be made for that; I am saying that Bill would be the same caustic, acerbic outspoken individual he is regardless of his physical attributes. It's

because Bill and I share such similar viewpoints on so many topics that I can so easily identify with him. Through that projected identity, Bill has helped me feel what it is like to be him. Perhaps our mutually mellowing age has contributed to the increase in understanding on my part. Regardless, I have a better understanding of what it is like to be an individual with a physical impairment because of Bill. But, more importantly, I better understand that I will never completely know what it is like to be an individual with a physical impairment, I can only approximate that experience through propinquity and juxtaposition.

Chapter 8

SUMMATIVE RESPONSES

In this chapter I review the area of interest for each participant that appears to have been the most influential in their respective creation of self. In so doing, I address the first research question, “How do persons with physical impairments understand and give meaning to their lived experience?” I include the parameters of interest for the study—family life, culture/race/ethnicity, gender, age, and assistive technology. I include additional areas of interest that contribute to the formation of self that arose from each participant’s life history. I also relate the responses to the research questions to both the literature and the disability movement.

I then address the second research question of how individuals with congenital physical impairments understand and give meaning to their lives compared to individuals with acquired physical impairments. I offer observations of how and why the differentiation between individuals with congenital physical impairments and those with acquired physical impairments are maintained. As the fifth participant in this study, I describe the effect and impact the study has made on me. I conclude with implications and recommendations for future study regarding individuals with physical impairments.

Understanding and Meaning to the Lived Experience

Family Life

How does giving meaning to lived experience differ from person to person for individuals with physical impairments? The parameters of interest that contributed to the formation of self had different import for each participant in the study. Of the five areas of interest—age, gender, race/culture/ethnicity, assistive technology and family life, Ellen demonstrates through her life history that family life is a primary force in her life. “(My parents) were good when I had my accident when I was 15.” “My sister came home on emergency leave, and my brother came, they all came. And they were there with me. And my brother Bill came back.” “My uncle, who had died before I was born, was born with infantile paralysis and muscular dystrophy. And he died by age 17. My father used to tell us about him. They used to put him in a wagon and take him every place with them. My father was used to people with disabilities.” “(My father) did whatever I wanted and needed to have done.” “My mother came in to visit one time, and she could see that my legs were going to fall and she knew that I was worried about my legs falling out, so she tried to grab my legs to hold them.”

Ellen has lived directly with, or geographically close, to her extended family her whole life. When she married Bill they lived with her parents for two years and then bought a house two blocks away. When she moved to California, it was near her husband’s brother and his wife. They moved back to Massachusetts a short while later to be near family. When they finally made the big move to Florida, they moved within a mile and a half of Ellen’s grandparents and close to her aunt and uncle.

Presently Ellen and her husband have an extended family in their own home. Ellen's adopted daughter and her husband and their daughter live together in a three bedroom house. Ellen is very protective of her family: "I couldn't dream of letting my kids walk because of what's out there today. I walk Donna (Ellen's granddaughter) to the bus stop because of what's around."

While family life plays a large part in defining who Ellen is, family life was also important in the formative years of Mike's life: "Wouldn't have changed a thing when I was a kid, I had a hell of a good time. I did. I had a good time when I was a kid. I had a lot of fun. I wanna go back and do that all over again." Although Mike is not married, family is still important to him. He takes his role as uncle very seriously and remains close to his mother and father. While family life does not appear to be the dominating factor in determining who Mike is, it is difficult to pin down one area that is the most influential in the defining of self for Mike, although being handicapped is certainly one area that receives a lot of emphasis from Mike. Mike relays, "The best place for a handicapped person to be is in Canada, (because of socialized medicine)." And even though "things have gotten better for handicapped people; who gets stuck holding the bag?—The people in wheelchairs again." Mike appears to relate to the concept of social discrimination (Barton, 1996; Oliver, 1996a). Mike's response to the felt discrimination is to create an equal living environment:

Take this building for example—this is a building filled with handicapped people. Okay? Once again, segregated. I never, ever, would have built the building like this. It's a very good idea. It gave some people who need a home, a

home. And I'm not against that, that's a very good thing. But why did you do it this way? Why can't you just build a great big apartment complex and have some of the apartments handicapped and some of them not? Why do you have to segregate the people? That's my whole point—don't segregate the people, and you won't have this problem. At college I wasn't segregated; I rarely had the problem. You don't segregate, you don't have the problem.

Theresa's family life, while not the dominating influence in the definition of self, is still a major part of her life. She was raised by her grandmother and respects her, but wanted to move out after her accident so she "could raise my children the way I wanted to and give them the values that I thought were important." Theresa sees her role as mother to her children not as a "handicapped woman that can't do everything that a 'normal' mother could do," but as a role model for her children. It is important to Theresa that she and her 15 year old daughter are "best of friends so we can talk about anything, including sex. She doesn't need to get pregnant when she is 15 like I did. I lost my virginity even before I knew what it was." She wants more for her kids than she has. "They don't need to just see me get a 'check' every month, not work for it, and not earn it. That's why I work—to be a role model for them."

Just as Priestley (2003) expanded upon in his life course approach to disability, Theresa manages to intertwine many issues surrounding disability into a common thread of conversation. Priestley talks about the commonality of life's stages between individuals with impairments and individuals without impairments. Theresa discusses racial issues and disability while referencing gender and family life issues. Listening to

Theresa is like listening to scholarly works on disability by Oliver (1996b), Marks (1999), or Barton (1996), but with the simple eloquence of a story told by the person living the life of an individual with a disability:

I think it's something totally as a black community that we're not exposed to. So you don't know how to embrace a person with a disability; so you are totally caught off guard. You're totally caught off guard, you don't know what to expect.

I think when it comes to the white community, there's a different embracing there. There's a different push there.

Like, for instance, a kid that is born with a disability, you have a different motivation for getting that child to be as normal as possible, when they're born with it. They want them to be normal, they want them to be accepted, they want to let them know that "they can do everything that everybody else can do, they just do it differently." I think that goes whether it's black or white, as far as if it's a congenital disability. But when it's an acquired disability, you're fighting a different battle because especially when it comes to age differences—at what age were they hurt? At what age did they get the disability? What are their support systems going to be like? Do they have a support system? A totally different fight. In the black community, that support system may be absolutely, positively zero. Whereas in the white community you have that parent that financially or socially will stick by you to the end. So, it is totally different how it's done and the way it's done (in the black community as compared to the white community).

That's just what we were taught all our life. It's just been driven into our heads that people want to make women the lesser equal, but we have to make ourselves the one that's more valuable. And we get that driven into our heads and we get this attitude about it even.

Theresa further intertwines the discussion by making the comparison between the civil rights movement and the disability movement:

I think it's just something that's been driven into our heads for so long. You see it in school where they talk about slavery where the black woman was treated. They want to fight for this because somebody fought for this, and somebody fought for that. But at the same time, we, as individuals have to realize that we have to fight our own battles. We can't go off and expect that somebody else fought the battle for us 50 or 60 years ago. We can't want something because of something that somebody else did. No, you have to make your own. You have to stand on your own feet; you can't stand on somebody else's fight. "I deserve this because Harriet Stowe had the Underground Railroad." No, I don't. If I deserve it, it's because of what I've done, because of what I've accomplished, or because of what I've put forth. Not because of what Martin Luther King did, or not because of what this person did. They thought that they gave me the right and they gave me the opportunity to do it, but if I don't stand on my own and go forth with it, I don't have a right to it. That's just my personal take on it, the way that I look at it.

Theresa operationalizes the concept of individual responsibility combined with unity effort that Priestley (2003) describes when he calls for a forward movement for the individual rights of the disabled without risking the progress that has been made for the disabled as a unified front.

Bill's family appears more important in defining who he is in later life than in his formative years. What Bill didn't say about his family spoke volumes. Bill became "a ward of the state" at 12 when he was sent to live in a residential hospital school in Massachusetts. According to Bill, the hospital school was where "I became...that's where things started happening. I moved out of seclusion into the daylight." Bill's formative years were spent in a residential hospital school. As a result, he has strong opinions about education and the facility he attended:

The Massachusetts Hospital School was the only one of its kind in the world. Massachusetts is the only school that did what it did in the world. It combines medical with education. Any kid that graduated from the Massachusetts Hospital School had no problem getting into college. They were automatically accepted. That's how good their record was. It was fantastic.

I don't think mainstreaming is for everyone. There should be options.

Everybody cannot be taught in a mainstreamed school, I don't care what they say.

Today, Bill is the head of the household of an extended family that includes three generations. He feels responsible as the patriarch of the family. It is obvious in his carriage and demeanor about his house that he deserves the respect that his family accords him.

Race/Culture/Ethnicity

Of the four participants in this study, Theresa speaks the most eloquently about race/culture/diversity and disability. She feels strongly about her race and culture and her role in it. Theresa's role as a black woman in a matriarchal society is closely tied to her family life:

I think it's a lot like my grandmother. She didn't want to have a man over her children because if something happened where he did something wrong, it would be him out the door. I just remember her putting her life on hold a lot for us, for her children, for her grandchildren; she just wanted to raise the children in her household. And I think as far as in the black community, when it comes to a black woman in a household, we take on this attitude that if we don't do it, it won't get done.

Theresa thinks that in the black community there is more of a tendency to hide a person with a disability or to blame the mother for the child's handicapping condition:

I have a friend whose son is 16 now. He was born with hydrocephalus—he had water on the brain. But because “she was afraid of what her friends would think” and all kinds of stuff, she never had him tested. She never sought out the help he needed until he was older, until he was three and couldn't sit up by himself. But she wouldn't admit it to herself. A lot of the kids that are born with (disabilities) are probably being raised by grandparents.

Not so in the white community. Theresa feels that “there is a different embracing, a different push” in the white community. A lot has to do with a higher socioeconomic

status in the white community compared to the black community. Theresa relays that “in the white community, they have the money to get the help they need; so they seek it out.” “It’s not as much the mother’s fault if the child is handicapped.” “Those kids are raised mainly by their parents, not their grandparents.” “It’s different in the white community compared to the black community for the disabled.” As Theresa says, “I’m the first black woman I have known in a wheelchair.”

Mike relays that he has no perspective on race and disability. “We were just kids; we didn't pay any attention to that kind of stuff. We were just kids, having a good time. Who was faster in their wheelchair, that's all we thought about. As for as racism, I don't know.” Although Mike went to school with kids who had physical impairments and were from differing cultural backgrounds, his current friends are all of European descent.

Previous to attending the hospital school, Bill had very little interaction with differing cultures when he was growing up:

I didn't have that many contacts with blacks. I come from a town where the only time that you saw a black was when the summer people came with their chauffeurs and maids. Gloucester wasn't black, Rockefeller was snowy white. I don't think there was a black in the whole town. Most of the Northeast corridor all the way up to New Hampshire was white. The only place there were blacks was in the big cities. At that age we never went to the big city.

I asked Bill if there were any black kids in the hospital school that he attended.

Bill: yeah, why?

Pete: I was just wondering what discrimination was like back then.

Bill: this was Massachusetts.

Pete: what's that mean? More liberal?

Bill: yeah.

Pete: so there's no bigotry in Massachusetts?

Bill: yeah, there probably is, but...bigotry is every place. But I think it's lesser there.

Even from this brief interlude there are indications that race/culture/ethnicity do not play a significant role in identity formation for Bill. Like Mike and me, Bill is part of the dominating social class—white and male, and, as such, is not forced to deal with prejudicial issues based on race. That doesn't prevent Bill from having an opinion on racial issues:

Yeah, well I mean a lot of blacks bring it on themselves. I think Bill Cosby got it right on the nose—dumb and black, themselves, the way they talk. There is no reason in this day and age for people that are black to talk stupid. And he got in all kinds of trouble for that. Well, they're just trying to be white. That's got nothing to do with it, he says. He says talk, just talk. There's no reason why you people can't talk good English. Speakin' in this two-bit black. Why do they talk that way? Did you hear the big controversy about him and everything? He's really pissed off at the blacks and the way they handle themselves. He thinks that they dumb down. And other blacks that see blacks moving up and doing the same thing, they call them whiting out. He said it's terrible from both ends. You're

dumbing down and whiting up. What the hell chance you got? You bring it on yourselves.

Like Bill, Ellen grew up in the Northeast and had very little interaction with other kids from varying backgrounds. She only remembers one student at the hospital school who was black and she “never went out with him; we were just friends.” Ellen implies through her life history that race has no particular bearing on disability, either as having a disability, or how people view an individual with a disability. But then, Ellen would “obviously rather be white. They’re still having a lot of problems with blacks and we were fortunate to be born white.” The only participant in the study who had an acknowledged position on culture/race/ethnicity and disability was Theresa, who defines herself as being part of the black community.

Gender

What starts out as a gender issue becomes a personal defining position for Theresa:

I think so far as “black woman in a wheelchair,” men, black men, white men, I think its men period; they have a certain stereotype or persona that they're looking for. And as a man, most men see the wheelchair and the girl in the wheelchair. They don't see the woman as a person. Which is not all men. But I tend to push men away. Which is probably a bad thing, but my whole thing is... it's so funny because there's this one guy that wanted to date me before and the whole time that he was talking to me, I was saying to myself “what's wrong with

you that you want to date a person in a wheelchair?" It wasn't that he saw things so differently than me, it was that, "what's wrong with you, are you alcoholic, do you have a drug problem? Do you think that I'm just this lonely person that maybe you could... You see me going to work every day so maybe I got an easy ride here—I can make her think I love her type thing." You know, there are so many guards up for me, when it comes to relationships. But man, I'm going to have to break them down so I can start meeting people. I mean, there are just so many people that are totally in the dark.

For Theresa, gender and disability are tied to race and disability:

I think white men accept all aspects of disabilities, as far as urinating on themselves, as far as being incontinent of bowels, all that kind of stuff. Black men—Nah. To be with a woman that somebody else has to come in and help in the morning, get up to bathe, and so forth or even if the man had to get up a couple of hours early to help his wife and get her up in the morning—I just don't see a black man doing that. There's probably one out there, but he's not in Florida. I could be totally wrong; I may just not have ever met that man that has that side of him where it's unmanly to love someone like that. But I just haven't been positioned with that person. And when it comes to dating, I'm not really open with the total aspect of my disability either. Because, to me, that's a very guarded issue, it's very personal.

But I think a black woman will take on the disability of the black man easier. She'll be more able to take care of that man, and clean his butt and do all

the kinds of things that he can't do. If you look at it, you're better off being disabled as a man to find a healthy woman. A woman will help a man with that kind of thing, whereas a man wouldn't help a woman do that.

Ellen, on the other hand, felt a disparity of privileges awarded to students at the hospital school based on gender:

They got the privilege to smoke and females weren't allowed to. Even though I had my father's permission, I still wasn't allowed to smoke. It turned into a big issue. I was president of the senior class and I met with the superintendent of the hospital school at breakfast and I wanted to smoke and I brought it up. And the boys just wanted me to be quiet because they didn't want to lose the privilege. But I wouldn't. We never were allowed to smoke the whole time I was there. It was really unfair.

Because Ellen is experienced and because we have known each other for a long time, I felt I could ask her directly about gender and disability.

Pete: do females look on disability differently than males? Do they get services differently? Are they treated differently? Is there a gender issue with disabilities?

Ellen equated her response with the services that she and her husband, Bill, respectively receive secondary to their disabilities:

I don't know. Because Bill and I go through different agencies for different things. And I have to say, except for a few times up in Massachusetts when I had problems with Vocational Rehabilitation. Other than that, I've never had problems with the agencies I deal with.

When asked if he thought females looked at disability differently than males, Mike's response was, "I don't know. I've tried to figure that out."

Age

Ellen: "I'd like to be young. Who wouldn't? There are too many problems. You have enough problems being disabled and then it adds to it because of age. But ours are added to more because we're disabled."

Mike: being older is a disability, in and of itself. Now combine that with being disabled, then what happens?

When I was a kid, I really didn't look at it differently, I didn't really see it differently, but it was different. You know when you're a kid, you're a kid. All you think about is, what's in my lunchbox, you know, why can't I go outside and play?

But now I think of things like I'm still on my dad's insurance for very practical reasons. Cause way back when, my dad and I discussed it, and we decided unless I got really, really lucky and found the right job with really, really good insurance; there was no way that I was ever going to be able to get on somebody's insurance policy, cause they'd never insure me, in spite of the fact that I'm healthy as a horse.

So I look at things from that perspective. I always have to make sure that I have insurance. Do I have enough money coming in to cover myself if I do something to myself and I get laid up? Because the odds are more in my favor that

I'm gonna' hurt myself and do something and get laid up than the average guy.

Even though, technically, they're not. That's the way it's looked at in the world. So

I have to do the same thing.

Getting a job is tough. That's why I work for myself. Cause it doesn't matter how smart you are, they're not looking up here (points to head). And when I was a kid, I figured, all I gotta do is make sure I'm smart. Because no matter what happens, I don't have legs anyway, I can use my head to get me through. Well that kind of logic works great when you're a kid. Doesn't really apply to the way things work out in real life.

Theresa's perspective on age and disability is from the viewpoint of a person who acquired a disability later on in life:

If you are a teenager and get disability, you'll be motivated differently. It strictly depends on the person. Your motivation motivates the people around you that want to help you. An adult who has an acquired disability, can't be pushed away as easily. Take me as an example—as a 32-year-old woman, if I had a very nasty attitude, always negative, I think a therapist would give up and say, “well I'm going to teach you what I'm going to teach you, and then I'm going to go home.” Versus, I'm that 32-year-old woman who comes in there with an attitude of “I've gotta' do this.” They're more motivated to help you. They're going to help you; they're going to work harder for you because you are putting forth to be better. Versus that teenager who is going to be pushed from day one, cause he's got his whole life ahead of him and they're going to push him the hardest. Until

they just totally shut down on themselves out of rebellion. And then when they don't want to do anything, the therapist is going to say, Okay, I'll leave them here for their parents.

Bill thinks his marketable skills have diminished as a result of age:

Well, the worse you are physically, the less you're going to be wanted. That's it. I could never get back into what I was doing before. It's harder now than it was before because I'm older and am able to do even less physically now than I was before. And accessing stuff is getting harder too. It's harder. It's almost impossible now. I don't know what's going to happen. I can't get a wheelchair. Ellen can't get a wheelchair. VocRehab shot her down too. The only way you can get a wheelchair is if we go out and work.

Assistive Technology

Theresa best describes how she feels about assistive technology and disability: Don't judge me because you see this hardware attached to me. It's the type of thing where the wheelchair doesn't define who I am; I define the wheelchair. It's not the "oh, you see the wheelchair right there with the girl in it?" It's "the girl in the wheelchair." I'm not just the wheelchair. I'm the girl sitting in the wheelchair. The wheelchair is not who I am. I'm the person in it. It's the same as "look at that person in that car." You don't want me to judge you by the car you drive—don't judge me by the wheelchair; it's really one and the same.

Although Mike, Bill and Ellen are equally dependent on assistive technology for mobility, none acknowledge assistive technology as contributing to how each thinks of himself or herself. Mike's perspective on assistive technology and disability is related to whether the person has an acquired or a congenital disability. "It's all according to what you need and if you're smart enough to use it. It's not so much a matter of who uses assistive technology more, or who knows more about it; it's a matter of who can afford it. So from that standpoint, I guess guys with acquired handicaps use it more because they have better access to funding."

Congenital Versus Acquired

According to Mike, who has a congenital disability, individuals with acquired disabilities have it easier:

People feel sorry for people in an accident in a different way than they feel sorry for guys like me. I, as the victim (of a handicapping condition), become the accused; I am somehow responsible for my handicapping condition. But he's not; he's a victim of circumstances. And he's taught things that we didn't know. The first thing they taught him in a rehab hospital was how to deal with his limitations—how to manage, how to handle the wheelchair, up-and-down. They never taught us that, ever.

And it's easier for him to get financial aid than it is for guys like us. Because they will spend as much money as needed, even supplanting his income, to rehabilitate him to get him back in the work force. At the same time, they won't

spend 1/20th of that amount to habilitate us to get us into the work force, unless it's for a job that they've pre-determined that's all we can do because we're gimps.

Mike recognizes the anger that is associated with having an acquired disability, "he was angry because he couldn't do what he was doing before. It doesn't mean that he was angry about being disabled, he was just angry because he couldn't do what he was able to do before." Mike feels that it is partly due to "having two different frameworks, because you have two different realities that you're looking at, and one is crashing into the other."

Ellen, who also has an acquired disability, thinks that "a lot of people that were born with disabilities didn't have much knowledge of the outside world. I think that people that were born with disabilities were certainly a lot different because they were in institutions most of their lives and never saw the difference until they got out of there." However, individuals with acquired disabilities may not fare that much better, according to Ellen. "People that are newly disabled don't know anything. People that are newly handicapped or older people that get handicapped don't know anything or you can't get them to do anything. You see some stupid things that they do and you say, 'Why?' When it's out there and you go looking for it, and you ask for it; you don't just go and live without it without trying to get some kind of help or asking someone about it." Whether one has an acquired or congenital disability, "it's knowledge and what you do with it."

Before Theresa acquired her disability, she had occasion to compare two students with disabilities at her school. One student had a congenital disability, the other had an

acquired disability. Theresa relates, “as far as the one that was acquired—I think he was embraced by more people just because of the fact that people knew him.” “But you have to look at that person who is born with that disability too. How far can they push him? How much can he do?”

Bill believes that “discrimination is still out there.” It’s not based as much on whether the person has an acquired versus a congenital disability as much as it depends on the person’s mental abilities and how motorically limited he or she is. “Yeah, it’s strictly brainpower. It’s still the same. The discrimination is the same as it’s always been. The worse you are physically, the less you’re wanted.”

Bill, who has a congenital disability, and Ellen, his wife, who has an acquired disability, applied for jobs at the same place of employment. Bill thought Ellen had a distinct advantage in getting hired because, “she had two good hands, and she looked less handicapped.” But Bill recognizes that “a lot of people that get hurt after they’re able-bodied have a harder time accepting it.”

Self Description

Each of the four participants described themselves and how they fit in their environments. The commonalties among the four participants are intriguing. Each is strongly independent and has developed into a strong advocate for others. Mike, Ellen, and Bill display a cynical sense of humor that helps keep some of their perceived inequities like discrimination for employing individuals with physical impairments in a workable perspective. Theresa’s humor is much more subtle.

When Theresa described five phrases of how a person who knew her best would describe her, she responded with, “girl, better you than me” and “ain’t nothing wrong with her.” Theresa feels that people don’t always think she really is disabled, and she deals with that through humor.

Overall, the commonalities that I perceived in the five participants (the researcher is included as the fifth participant) are: an intelligence reflected in a quick wit, which was often cynical; a sense of humor that is used to keep untoward perceptions in a balanced perspective; a fierce sense of independence; a dedication and commitment to cause; and a stubbornness that preferred to be perceived as perseverance.

Medical and Social Model

Perhaps the age in which individuals grow up has something to do with how they define themselves. Ellen and Bill are 62 and 63. The fact that they met in a hospital school and both underwent extensive surgeries and hospitalizations certainly contributes to their definition of self in terms of the medical model of disability. A good part of each of their life histories is detailed descriptions of the trauma each underwent in an effort to maximize their function. Ellen describes herself as a “para” and Bill remembers he was a “spastic” when he was a kid.

Like Bill, Mike was born with cerebral palsy, but 30 years later. He has named his company P.M.I.G., which is “gimp” backwards. This social term appears to be a reflection of the period in which Mike grew up. The disability movement was well underway when Mike was born (Fleischer & Zames, 2001) and there was a transition of

moving from the medical model of disability to the social model (Oliver, 1996a; Tursumani, 2003).

Social terms within the disability movement developed during this transition period. Both Theresa and Mike refer to able-bodied individuals as TAB's (Temporarily Able Bodied). Theresa explains, "They are a person within disability; they are a person first. They have just acquired something that you haven't acquired yet." Bill finds the derogatory term *spas* in today's teenage vernacular to be offensive. Just as many schoolyard names such as *idiot*, *imbecile*, and *moron* had their beginnings as medical designations (Linneman, 2001; Trent, 1994), so too with designations for individuals with physical impairments (Barnes, 1996; Holmes, 2001). The medical terms of *cripple* and *spastic* found in Bill and Ellen's day have given way to defining *handicap* and *disability* in social terms. Bill describes what crippled means: "I was always able to do something. A car is crippled at the side of the road and it won't move. If it's handicapped, you've still got a couple of bugs in it, but you're still moving."

Theresa explains:

I think that when people talk about being handicapped, and I always refer to myself as being disabled; I'm not handicapped, I'm disabled. Disabled is a compound word—dis is a prefix of able. I no longer am able to do what I used to do; I'm disabled. I think of a person who is handicapped as being born with it. They're handicapped; this is something they've always had, and they're trying to

get past; they're handicapped. You got it from God. When you get a handicap, it's something you have; you try to get past that handicap, you have to deal with it and go on.

Individual Model

Theresa continues, "I just think if people stop looking at a disabled person as a handicapped person, if you stop defining people by the situation, and define the person first, all of us would be better off. As a disabled person, don't try to define us, let us evolve, let us become who we want to be, let us be ourselves first. When you define a person with a disability, you put a limitation on them." "Everybody's not going to be the same just because they are in a wheelchair. You can't expect every person in a wheelchair to have the same abilities as me, to have the same drives as me, to have the same attitude or personality as me."

Mike relays striving to achieve recognition as an individual at an early age. He remembers in junior high school what it was like to be talked about as if he was not even there, being forced to a position of liminality as described by Murphy (1988). "When I was with somebody, occasionally, some guy would come up and say, 'yeah, what's his name?' I'd look right at him and go, 'Oh God, I don't know. You wanna know my name? Ask me, for God's sake.' No, they'd talk to somebody else."

In college, Mike was accepted as an individual. "Not, oh there's the guy in the wheelchair, none of that crap. It's just, Mike. And Mike happens to be in the wheelchair; if you can't deal with it, then too bad, because that's the way it is."

Priestley (2003) discusses the social model of disability, but puts that model in the perspective of the individual first. Each of the four participants in the study said, in many different ways, and in many different forms, “look at me as an individual, don’t pass judgment on me based on how I look or on the hardware that is attached to me; judge me by who I am and what I present to you.” I thought that was what I was doing when I started this study. I now know that I am just beginning to understand what it is like to be Mike, what it is like to be Theresa, what it is like to be Ellen, and what it is like to be Bill.

Lessons Learned

I have incorporated my responses and reactions directly and indirectly throughout the study. I defer to Mike, Theresa, Bill and Ellen on the perceptions of disability related to age, gender, race/culture/ethnicity, family life, and assistive technology. Therefore, I include in this section only thoughts and responses that have not heretofore been mentioned.

Mike’s concept of integrated community housing struck a cord with me. Egalitarian housing is certainly not a new concept, but it took Mike’s perspective and description for the concept to develop into a realistic construct for me. Bill later relayed that Massachusetts had such a working model in operation. Although I intellectually accepted that Florida was at the dismal end of providing services to individuals with disabilities, it took Mike and Bill to make me feel what it is like to be at the bottom of the social food chain.

Ellen's graphic descriptions of living the medical model of disability made me appreciate how the treatment of individuals with physical impairments may not have evolved into the social model of disability as I would like to believe. Comparing Ellen's description of living the medical model in the 1950's with Sacks' (1998) recounting of his experience of being physically impaired in the 1990's drew many similarities. As a physician and advocate for individuals with disabilities, Sacks found himself at the mercy of the medical community for several months following an accident that left him with a temporary physical disability. Sacks' description of that account belies a social model of disability. Quite the contrary, Sacks recounts feeling helpless and dependent because of his medical condition and diagnosis.

Bill reinforced the experience of the medical model as he unfolded his life history. I am chagrined to learn that Bill feels that the employment rate for individuals with physical impairments is no better now than it was before Section 504 and ADA were enacted. Bill believes that only 50% of individuals with disabilities who are eligible for employment are, in fact, employed.

Bill, Ellen, Mike, and Theresa helped me understand that there is a difference between individuals with congenital physical impairments and those who acquire physical impairments. The *system* perpetuates that difference. Theresa explains the system:

But if you want to use the system to better yourself and not be in the predicament that you're in, you wouldn't accept disability (payment). You can't get disability and make a living at the same time. It's like, forget about disability

and just work on trying to better yourself. My biggest dream is to make enough money where I can hire somebody to come in, pay them two hours a day just to help me take care of my daily needs like getting out of bed and bathing. Just not have to deal with the disability and all that. If I could win the lottery today, that's the first thing I'd do. If I never had to call VocRehab again to help me get wheelchair repairs, that's the biggest dream that I could ever have; that's the goal.

But as Bill points out, Vocational Rehabilitation is generally considered to be limited to individuals with acquired disabilities. Bill had very little luck with VocRehab when he was trying to get a job, as did Mike. Ellen and Theresa have both used VocRehab extensively. Ellen and Theresa, on the other hand, are not eligible for services from Developmental Services (D/S), a division of Health and Rehabilitative Services (HRS) as are Mike and Bill. The services and funding provided by D/S is based on the medical model of disability and is limited to individuals with congenital disabilities with diagnoses of mental retardation, cerebral palsy, spina bifida, epilepsy, or autism.

Combine the delivery of services based on the type of disability with society's reaction to individuals with significant congenital physical impairments, and the reason for the continued differentiation between individuals with congenital physical impairments and those with acquired physical impairments becomes evident. In the study done by Green et al (in press), individuals with acquired physical impairments such as quadriplegia secondary to auto accidents were less stigmatized than individuals with spastic quadriplegic cerebral palsy. The social aesthetics of an individual who is paralyzed are easier to identify with than a person who is disfigured due to a birth defect.

Mike initially highlighted this concept during his oral life history and each participant, in turn, reinforced that perception during their life histories.

Theresa's culture perspective is invaluable. I think again of what it may have been like being in the black community and not seeing any other individuals with physical disabilities. After an interview session with Theresa, I had written in my journal:

I had not appreciated the lack of exposure that individuals with physical impairments receive in the black community. I have been to many patients' houses in the black community, yet I was never made to appreciate that I was seeing these individuals in their home, behind closed doors. I did not know that the black community considered the mother to be at fault if the child was born with a disability. Nor did I realize that I saw very few adults with disabilities out in the community. As Theresa said, "I'm the first black woman with a disability that I know." Theresa was also the first black woman that I knew with a disability. In that respect, my eyes have been opened to discrimination that occurs within a culture against individuals with physical impairments.

Theresa summarizes for all of us: "It boils down to being yourself, being who you are. Respect me first because I'm Theresa, then respect me because I'm a mother, then respect me because I'm disabled. Those things are more important than respecting me as a black woman. And that goes back to being a person, being who you are."

Co-Construction

The method of research selected for this study proved the most efficacious because of the extensive personal and professional relationships I had with each of the participants. That foreknowledge was essential to achieve the depth and understanding of what each participant was willing and capable of sharing. Future studies wishing to incorporate similar topics using similar methods would do well to assess the extent to which participants are known to the researcher when selecting a research method.

Our co-constructed narrative is unique to this study. The mix of the five participants with their respective constructs contributed to the creation of who we are individually and who we became collectively (Fransella, 2003; Kelly, 1991). The merits and pitfalls of that co-construction are the same--that it is unique. Only the combination of these five participants would have yielded these results. The study has the potential of transferability through identification with one or more of the participants in the study.

The pitfall of the co-construction is its replicability. While the process and participants with similar characteristics can be replicated, the dynamics of the co-construction may yield an entirely different interpretation. The value of the study is what these participants present individually and collectively. The depth to which the participants were willing to share because of our mutual friendship encourages a better understanding of what it is like to be an individual with a physical impairment. Understanding decreases discrimination.

Following the interviews and at the culmination of the life history project, Bill spoke for all of the participants when he said that 'there was no way in hell' that he

would have been nearly as forthcoming if there had been another interviewer present. However, an additional interviewer might have proven helpful to develop additional areas of interest through more in-depth, probing questions, thereby adding another layer of interpretation to each life history.

A more regimented questionnaire might have produced more consistent results between and among the participants. A format could have been followed and consistent responses could have been obtained. Such would be the case if this study incorporated only an oral history or any other time limited method of data gathering. Using life history as a data gathering technique that contributes to an overall ethnography (Angrosino, 2002) of individuals with physical impairments discouraged the use of a limiting interview technique such as a script. The questions needed to be layered and complex. Because each participant had a different story to tell, different questions, different prompts, and different facilitory measures were required that would allow each participant the latitude to describe himself or herself in terms and parameters that were the most meaningful to that person.

It was the dynamic process of interviewing, of sharing stories and perspectives, that when combined with everything that I had come to know about each of the participants led to questions and probes specific to that individual. Immediate feedback was essential in the interview process. Non-verbal feedback was particularly critical in dealing with sensitive areas. Friendship and intuition helped guide the discussions. My friendship with each of the participants seems to have magnified as the result of the

study. I believe that life history is the best data gathering technique to gain an understanding of what it is like to be an individual with a physical impairment.

For me, the life history process emerged as a research tool that contributed to the ethnography of a subculture within our society. The process taught me that each researcher assimilates the life history interview process as a tool for research, and the skill for conducting these interviews develops with preparation for the interview, practice of the interview, and precision of knowing the right question to ask at the right time. Life history is an intuitive skill that develops over time.

Future Considerations

Several questions and concerns have arisen because of this study. The last survey that was done to assess how individuals with physical impairments perceived themselves was done in 1973. Having transitioned from the medical model of disability toward the social model of disability, complete with social descriptions of handicap, disability, and impairment by the World Health Organization, it may well be time to re-assess if individuals with physical impairments perceive themselves differently in light of the social construct of disability. It would be interesting to see what impact the individual model of disability as alluded to by Priestley (2003) has made on the identity construct of individuals with physical impairments.

Most of the research on sexuality and disability is from the medical model perspective and concentrates on individuals with acquired disabilities, specifically quadriplegia and paraplegia. In addition to expanding the issue of sexuality for

individuals with congenital physical impairments, studies should also focus on the social perspective of sexuality while including the necessary medical background.

Bill's impression that there has been no improvement in the employment rate for individuals with physical impairments following the implementation of Section 504 and ADA requires validation. The causes for the interpretation of this disparity need to be examined and corrected. Part of our true sense of identity of who we are is integrally centered on what we do for a living. If individuals with physical impairments are to make strides towards equality, their sense of purpose and identity needs to be bolstered by meaningful employment. Research to help achieve that goal is essential.

Priestley's (2003) agenda for future research for the disability movement includes race and disability. Theresa's glimpse into the life of a woman who is black and disabled eloquently relays that much more could, and should, be written and described concerning other cultures, ethnicities, races and disabilities. Just as there has been a parallel drawn between the civil rights movement and the disability movement, the language and the cultures of each minority are beautifully interwoven and need to be shared to develop mutual understanding.

The societal institutions that perpetuate polarization for individuals with physical impairments should be explored to develop a further understanding of the reason for their creation and retention. Bureaucratic agencies that provide services to, rather than with, individuals with physical impairments should be examined to determine their rationale for populations served. For example, why does Vocational Rehabilitation primarily serve individuals with acquired disabilities and Developmental Services provide services only

to those with congenital medical diagnoses? What can be done to eliminate the disparity of services? (According to Bill, it is fairly common knowledge in the disabled community that VocRehab has much more money than anyone else and if there is any way possible to get on V/R's rolls, one should jump at the chance).

What other social institutions intentionally, or unintentionally, perpetuate discrimination against individuals with physical impairments? When I began this study, I thought that individuals with physical impairments were on the cusp of acceptance and equality in our society. Bill proved me wrong, maintaining that, "handicapped are the last minority that are discriminated against. We are the most discriminated against and that has lasted the longest." Just as this study has attempted to do, future studies should be designed to decrease discrimination of individuals with physical impairments.

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Appendices

Appendix A: Self Data Template

(Morse) 262.16M

1. Write out five phrases (or sentences) which best describe "you."

a.

b.

c.

d.

e.

2. Consider the person who knows you best. What five phrases would you expect that person to use in describing you?

a.

b.

c.

d.

e.

3. What person or persons (parents, siblings, other) are you most like? _____ In what ways?

4. What was your role growing up in your family at:

a. Preadolescence

b. Adolescence

c. Now (if pertinent)

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Appendix B: Mike's Self Data

1. Write out five phrases (or sentences) which best describe "you."

- a. Warped sense of humor
- b. Not quite what others expect
- c. Loyal
- d. Smart
- e. Cynic

2. Consider the person who knows you best. What five phrases would you expect that person to use in describing you?

a. Interesting question as I have not seen her for some time, but she probably would say the same as above. She used to say to me that she wished I could see myself the way that she does.

3. What person or persons (parents, siblings, other) are you most like? Oh, you need to ask my mom for a good answer to that one. But, I have traits of my grandparents and parents. In what ways?

My mom: I have what you can call "kid stuff." She likes super heroes, magic, fun, etc.

My dad: I have my ability to stand my ground and my temper.

My paternal grandfather: I have the ability to control my temper, a health dose of street smarts, "common sense," and a sense of humor.

My paternal grandmother: I have my sense of order (anal), sternness, and a lot of "backbone."

Appendix B: (Continued)

My maternal grandmother: I have moxy, eclectic nature, intelligence.

My maternal grandfather: I never knew him, but from the stories I have been told—he has got to be in here too.

4. What was your role growing up in your family at:

a. Preadolescence: I was a kid. I did kid stuff.

b. Adolescence: I was a teenager. I did teenage stuff.

c. Now (if pertinent): I am an uncle. I do uncle stuff.

Appendix C: Theresa's Self Data

1. Write out five phrases (or sentences) which best describe "you."
 - a. Always deep in thought
 - b. Never put off tomorrow what can be done today
 - c. Taking nothing for granted
 - d. Never say never
 - e. Don't try and categorize me
2. Consider the person who knows you best. What five phrases would you expect that person to use in describing you?
 - a. Girl, better you than me!!!
 - b. Ain't nothing wrong with her
 - c. Treat me like everyone else
 - d. Never feel sorry for her
 - e. Just as stubborn
3. What person or persons (parents, siblings, other) are you most like? The person I am most like is my grandmother. In what ways?

Being raised by her, I have always been a very strong, independent woman with enormous faith. To raise six of her own children and 5 of her grandchildren all alone with no husband. She always taught me to put my faith in God. Through all the things that life has dealt me, I know that help is just a prayer away. He puts no more than I can bear.

Appendix C: (Continued)

Everything I go through is for a reason. I may never know the reason, but I know God is with me

4. What was your role growing up in your family at:

a. Preadolescence: Spoiled Brat

b. Adolescence: I was a teen mother and the oldest grandchild. I had a lot of responsibility towards my brothers and sisters.

c. Now (if pertinent: A lot of family members and friends call me for advice and sometimes to just have someone to listen to their problems. I never judge them. I'm just there for them. I may not always agree, but I try to be what they need at that time, whatever it may be. To my children, I try to be Mom and best friend. My children and I talk about all subjects. I am learning when to be mom and when to be friend.

Appendix D: Ellen's Self Data

1. Write out five phrases (or sentences) which best describe "you."

a. Independent

b. Self Sufficient

c. Controlling

d. I like to see things that are started, finished

e. A spur of the moment person, when I think of something, I want to do it now.

2. Consider the person who knows you best. What five phrases would you expect that person to use in describing you? Well let's say that if I ask my kids, they will say that I am:

a. grouchy

b. mean

c. The thirteen year old hates me a lot, and the 32 year old, probably thinks more than she will say, probably that:

d. I expect more out of her than she is willing to do

e. Bill will say, I shop too much

3. What person or persons (parents, siblings, other) are you most like? Mother

_____ In what ways?

I look like her. We both liked to play Bingo, and she was a terrific dancer, and as was I, before I had my accident.

4. What was your role growing up in your family at:

Appendix D: (Continued)

- a. Preadolescence: I was the baby of the family
- b. Adolescence: I had to get dinner started, as my mother worked (Like peel potatoes, etc.)
- c. Now (if pertinent): I am the sister, or the aunt that lives far away.

Appendix E: Bill's Self Data

1. Write out five phrases (or sentences) which best describe "you."
 - a. Fiercely pro-independent as far as people's rights go, especially disabled
 - b. Helpful to other people
 - c. Like to have fierce discussions or debates
 - d. Like perfection
 - e. A helluva nice guy
2. Consider the person who knows you best. What five phrases would you expect that person to use in describing you?
 - a. independent
 - b. As self-sufficient as possible
 - c. Stubborn
 - d. Grouchy
 - e. A nice person
3. What person or persons (parents, siblings, other) are you most like? Father In what ways?

Lost hair like him, his humor
4. What was your role growing up in your family at:
 - a. Preadolescence: I was the eldest
 - b. Adolescence: Spent my adolescence in a hospital school
 - c. Now (if pertinent): Brother, and Dad

Appendix F: IRB Approval

FWA 00001669

IRB Number: 10257

From 12/11/03

Thru 12/09/04

Informed Consent

Social and Behavioral Sciences

University of South Florida

Information for People Who Take Part in Research Studies

The following information is being presented to help you decide whether or not you want to take part in a minimal risk research study. Please read this carefully. If you do not understand anything, ask the person in charge of the study.

Title of Study: Understanding Individuals with Acquired and Congenital Physical Impairments

Principal Investigator: Pete Marsh

Study Location: Respondent's Residence

You are being asked to participate because you are an individual with an acquired or congenital physical impairment.

General Information about the Research Study

The purpose of this study is to determine how an individual with an acquired physical impairment defines him/herself as compared to an individual with a congenital physical impairment. For individuals with physical impairments, are there other factors involved

Appendix F: (Continued)

that markedly impact their perception of what they can and can't do, such as age, gender, race and culture?

This study also hopes to determine if individuals with an acquired physical impairment view and use assistive technology differently than individuals with a congenital physical impairment?

Plan of Study

A life history will be conducted with you using open-ended interview questions. Three to four separate interviews will be scheduled at your convenience in your home, each session lasting 3-4 hours. The interviews will be audio-recorded; the recordings transcribed, and the audio recordings destroyed. Following analysis of the transcriptions, all electronic and printed copies will be kept by the primary researcher in a secured, locked office environment. Your identity will remain confidential and will not be disclosed. All names, locations and identifying nomenclature will be changed to eliminate possible identification.

Payment for Participation

You will not be paid for participation in this study

Benefits of Being a Part of this Research Study

By taking part in this study you will be given the opportunity to help others better understand the experience of disability and provide a better understanding of how individuals with physical impairments use assistive technology.

Risks of Being a Part of this Research Study

Appendix F: (Continued)

There are no known risks associated with this study.

Confidentiality of Your Records

Your privacy and research records will be kept confidential to the extent of the law. Authorized research personnel, employees of the Department of Health and Human Services, and the USF Institutional Review Board and its staff and other individuals, acting on behalf of USF may inspect the records from this research project. The results of this study may be published. However, the data obtained from you will be combined with data from others in the publication. The published results will not include your name or any other information that would personally identify you in any way. Code names will be used to protect confidentiality. All data will be kept by the primary investigator in either locked files and/or locked office.

Volunteering to Be Part of this Research Study

Your decision to participate in this research study is completely voluntary. You are free to participate in this research study or to withdraw at any time. Your decision to participate or not to participate will in no way affect your personal or professional status.

Questions and Contacts

If you have any questions about this research study, contact Pete Marsh at 941 378 2295

If you have questions about your rights as a person who is taking part in a research study, you may contact the Division of Research Compliance of the University of South Florida at (813) 974-5638.

Appendix F: (Continued)

Consent to Take Part in This Research Study

By signing this form I agree that:

* I have fully read or have had read and explained to me this informed consent form describing this research project.

* I have had the opportunity to question one of the persons in charge of this research and have received satisfactory answers.

* I understand that I am being asked to participate in research. I understand the risks and benefits, and I freely give my consent to participate in the research project outlined in this form, under the conditions indicated in it.

* I have been given a signed copy of this informed consent form, which is mine to keep.

Signature of Participant

Printed Name of Participant

Date

Investigator Statement

I have carefully explained to the subject the nature of the above research study. I hereby certify that to the best of my knowledge the subject signing this consent form understands the nature, demands, risks, and benefits involved in participating in this study.

Signature of Investigator

Printed Name of Investigator

Date

About the Author

James Peter Marsh is a non-traditional doctoral student at the University of South Florida. After earning Bachelor's and Master's Degrees in Health Education from the University of Florida in 1975 and 1976, Mr. Marsh received a post-graduate degree in Physical Therapy in 1977. Following retirement from the Sarasota County School District as Program Specialist for Students with Physical Impairments, he returned to higher education in pursuit of a Ph.D. in Special Education in 2002.

Having served as President of the Board of Directors for United Cerebral Palsy of Sarasota-Manatee for 15 years and as Chair of the Florida Developmental Disabilities Council for three years, Mr. Marsh maintains an avid commitment to advocacy for individuals with physical impairments. His areas of interest continue to be centered on individuals with physical impairments, and, most recently, the assistive technology that improves the lives of individuals with physical impairments.

