ABSTRACT

Title of Document: CONSTRUCTING A DISABLED IDENTITY: THE INFLUENCE OF IMPAIRMENT, SOCIAL FACTORS AND REFLECTED APPRAISALS

Heather Ridolfo, Ph.D., 2010

Directed By: Dr. Melissa Milkie, Department of Sociology

The claiming of an identity as disabled has important implications for impaired individuals' interpersonal interactions and well-being, however not all impaired individuals claim a disabled identity. In this dissertation I build upon social and medical models of disability by extending the work in two key ways using multi-methods. First, using a symbolic interactionist frame, I examine how individuals' experiences are mediated through self processes in shaping their identity claims. Second, I assess how the identification process is influenced by individuals' social statuses. Data used in this study is from the 1994-1995 National Health Interview Survey on Disability, a large nationally representative sample of individuals with impairments. In addition, I supplement this analysis with data from 30 qualitative interviews.

Results underscore prior research showing that not all individuals who experience impairment identify as disabled. The qualitative interviews illuminated a

third group not obvious in the quantitative analysis - those in the process of negotiating a disabled identity. Experiences of socially constructed barriers have important implications for claiming an identity as disabled; however experiences of impairment also have strong effects on identity claims. In depth interviews also showed social barriers, but not environmental barriers, and impairment affect impaired persons' identity claims as disabled.

Self-processes perform an important role in helping impaired individuals understand their positioning in society and verify their identity claims. Reflected appraisals of being disabled increased the likelihood of claiming a disabled identity and these appraisals mediated the relationship between the experiences of socially constructed barriers, impairment and the self. In the qualitative analyses, social comparisons and self presentations were also found to be an agentic tool used by individuals to assert their identities as disabled/not disabled and in shaping others' views of them.

Finally, social statuses have important implications for the construction or rejection an identity as disabled. Those with higher social statuses were *MORE* likely to claim disabled identity, all things equal. In the qualitative analyses, women's disabled identity claims were often disregarded, perhaps underscoring their more difficult experience verifying their identity claims. Consistent with this, interactions between social statuses and the social and medical models were identified.

CONSTRUCTING A DISABLED IDENTITY: THE INFLUENCE OF IMPAIRMENT, SOCIAL FACTORS AND REFLECTED APPRAISALS

By

Heather Ridolfo

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Advisory Committee:
Professor Melissa Milkie, Chair
Professor Katharine Abraham
Adjunct Professor Barbara Altman
Associate Professor Jeffrey Lucas
Assistant Professor Kris Marsh

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Table of Contents

Acknowledgements ii
Table of Contents iii
Chapter 1: Introduction 1
Chapter 2: Review of the Literature 7
Medical Model of Disability 8
Social Model of Disability 14
Environmental Barriers 15
Stigma and Social Barriers 17
Self Theories: Social Comparisons, Self Presentations and Reflected Appraisals 26
Social Comparisons 26
Self Presentations 28
Reflected Appraisals 29
Social Statuses, Inequality and Disability 37
Gender 39
Race 41
Social Class 44
Age 45
Summary and Research Questions 47
Chapter 3: Data and Methods 50
Quantitative Data and Methods 50
Dependent Variable 53
Independent Variables 54
Interaction Terms 60
Controls 60
Qualitative Data and Methods 60
Analytic Plan 63
Chapter 4: Experiences of Environmental and Social Barriers, Impairment, and Identity Claims 67
Quantitative Findings 67
Qualitative Findings 70
The Negotiators 70
Experiences of Environmental Barriers, Social Barriers, and Impairment 72
Claiming a Disabled Identity: The Relationship between Experiences of Environmental Barriers, Social Barriers, and Impairment 85
Summary of Findings 87
Chapter 5: Claiming a Disabled Identity: The Centrality of the Self 90
Quantitative Findings 90
Qualitative Findings 92
The Identifiers: "I can't imagine somebody calling me -- an amputee -- not disabled" 95
The Disidentifiers: "It's just a bump in the road." 106
The Negotiators: "I can do everything…I'm just weak on the left side" 113
Summary of Findings 123

Chapter 6: Social Status and Disabled Identity Construction 125
Effects of Gender, Race, Social Class, and Age: Findings from the Quantitative Data 125
Gender Inequalities in Claiming a Disabled Identity and Gender Enactments: Findings from the Qualitative Data 127
Questioning Women's Disablement - "Mom shouldn't get sick" 128
Questioning Women's Disablement – "The leg still hurting 'cause you gained all that weight." 132
Gender and Femininity/Masculinity: Becoming Unattractive and Undesirable 134
Loss of Athleticism: "I used to be an athlete. Now I just watch guys." 136
Social Statuses and Identity: Status Differences in the Impact of Social and Medical Model Indicators on Claiming a Disabled Identity 138
The Social Model: Employment Status 139
The Medical Model: Severity of Movement Difficulty 140
Medical Model: IADLs 141
Summary of Findings 146
Chapter 7: Discussion and Conclusion 148
Limitations 155
Implications 158
Conclusion 163
Tables 164
Figures 179
Appendices 180
Appendix A: Criteria for Selection in the NHIS-D Phase 2-Adult Followback 180
Appendix B: Advertisement Flyer 185
Appendix C: Qualitative Interviews Telephone Screener 186
Appendix D: Informed Consent Form 190
Appendix E: Demographic Information Form 194
Appendix F: Cognitive Interview Protocol 196
Appendix G: Descriptive Statistics 205
Appendix H: Glossary of Terms 207
References 208

List of Tables

Table 3.1: Descriptive Statistics from the Quantitative Sample……....164

Table 3.2: Demographics of Qualitative Interview Respondents……..……165

Table 4.1: Descriptives of Impaired Individuals who Self-Identified as Disabled and Not Disabled……..166

Table 4.2: Identifying as Disabled Regressed on Environmental and Social Barriers, and Impairment……..……167

Table 4.3: Environmental Barriers and Social Barriers, and Impairment Experienced by Respondents from the Qualitative Interviews……...168

Table 5.1: Claiming an Identity as Disabled by Reflected Appraisals.....169

Table 5.2: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, and Reflected Appraisals……...170

Table 5.3: Claiming an Identity as Disabled by Reflected Appraisals……..171

Table 5.4: Self Processes from Qualitative Interviews……..172

Table 6.1: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, Reflected Appraisals, and Race Interactions…….173

Table 6.2: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, Reflected Appraisals, and Age Interactions……..174

Table 6.3: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, Reflected Appraisals, and Education Interactions……..…175

Table 6.4: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, Reflected Appraisals, and Gender Interactions…….……176

Table 6.5: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, Reflected Appraisals, and Poverty Interactions……....177

Table 6.6: Summary of Interactions……...……178

Table A1: Descriptives of Analytic Sample with Missing Data Retained……..…205

Table A2: Descriptives of the Final Analytic Sample with Missing Data Removed……206

List of Figures

Figure 1: Conceptual Model……..…….179

Chapter 1: Introduction

The identification process for impaired persons is complex. However, identifying as disabled has important implications for impaired persons' interpersonal interactions and well-being. For example, it may be necessary for impaired individuals to claim a disabled identity in order to advocate for their own needs, such as accommodations in both the physical environment and social interaction (Taub, McLorg, and Fanflik 2004), as well as to be able to receive social benefits (Reeve 2002; Wendell 1996). The label "disabled" also legitimizes individuals' experiences of pain, fatigue, and decreased functionality, and the recognition of these experiences as resulting from a disability may lead others to be more understanding of their physical limitations than they would if these limitations went undiagnosed or unnamed (Wendell 1996). Furthermore, identifying as "disabled" may help impaired individuals better understand their experiences of impairment and allow them to identify with others who are similarly impaired and possibly lead to a collective identity through which political action can take place (Wendell 1996). However, being disabled is a highly stigmatized status, and claiming a disabled identity may lead to the internalization of negative stereotypes regarding all aspects of an "impaired" person's life (Watson 1998).

In fact, not all individuals who meet the criteria for disability will claim it as an identity (Priestley 1999; Watson 2002; Taub, McLorg and Fanflik 2004; Watson 1998; LoBianco and Sheppard-Jones 2007; Iezzoni et al 2000). In a nationally representative study of U.S. non-institutionalized adults, only 72 percent of adult respondents with "major mobility difficulties" (which included the inability to walk,

climb stairs, or stand, or the use a wheelchair or scooter) reported that they considered themselves disabled (Iezzoni et al. 2000). In addition, only 66 percent of these same respondents reported that they believed others would consider them to be disabled (Iezzoni et al. 2000). The rejection of a disabled identity by individuals with a range of impairments and across different age groups is documented in other studies as well (Watson 2002; Priestley 1999; Skar 2003; Connors and Stalker 2007).

In order to understand why some impaired individuals claim a disabled identity and others do not, it is important to define disability. Within the disability literature there are two competing models that are used to establish definitions of disability and explain the disablement process. A more contemporary model of disablement is the social model. In this model, disability is defined as a socially constructed phenomenon that is imposed on individuals with impairments (Shakespeare and Watson 2001). That is, disability occurs when physical barriers in the built environment (environmental barriers) and social barriers prevent impaired persons from fully participating in society. This model arose in opposition to more traditional models of disability, which are often referred to as medical models. The medical model of disability defines disability as an outcome of functional limitations or psychological losses (Oliver 1996), and therefore locates the problem of disablement within the individual.

While the social model of disability broadens our understanding of the lived experiences of impaired individuals, it is criticized within the disability literature for overlooking the very real implications of impairment itself, which individuals experience independent of socially constructed barriers (Shakespeare and Watson

2001). However, proponents of the social model contend that the model does not completely ignore impairment, but instead attempts to explore the ways in which issues of impairment can be addressed through a social sphere (i.e., collective action) rather than a medical context (Oliver 1996). Oliver (1996) further cautions that neither the medical nor the social model of disability is perfect and no single model can explain the total experience of disability. Researchers are in agreement that a broader model of disability, one that encompasses the multiple experiences of disablement, is needed to fully understand the lived experiences of those with impairment (Oliver 1996; Shakespeare and Watson 2001). To understand disabled persons' experiences we must look at the full picture which includes "bodily, psychological, cultural, social, political, rather than claiming that disability is either medical or social" (Shakespeare and Watson 2001).

Research has begun to examine how both social and medical factors of disability shape the disablement process, and has produced evidence to support arguments for a more encompassing model (LoBianco and Sheppard-Jones 2007; Watson 2002; Priestley 1999). Additionally these studies find self-processes (i.e., reflected appraisals and social comparisons) play an important role in the identification process; however, they do not discuss how self processes and socially constructed barriers are related, nor do they explicate how barriers ultimately influence identity, or address variability in identity construction from social stratified positions. Two frameworks used here, symbolic interactionism and a social statuses perspective, will help elucidate the identity processes further.

In order to facilitate an understanding of how socially constructed barriers, impairment and social statuses influence identification of one's self as disabled, a symbolic interactionist approach is necessary. Individuals come to understand their self and their position in the social structure as a result of the feedback they receive from others during social interactions (Mead 1934; Cooley 1902). This process is recognized as occurring through three self mechanisms: social comparisons, self presentations and reflected appraisals (Rosenberg 1986). Individuals make social comparisons between themselves and others to understand their self and their position in society (Rosenberg 1986; Festinger 1954). Additionally, individuals' self-presentations are a mechanism through which individuals present their identities and social roles to others and in doing so, provide important information on how to interact with one another. Finally, reflected appraisals provide feedback to individuals regarding not only how significant others view them, but also how society as a whole views them. In terms of disability, these processes are important in determining whether or not impaired individuals claim an identity as disabled. Whether or not they do so is dependent upon the types of messages they receive, which then either reinforce or undermine their identity claims.

Furthermore, disability research, particularly studies which focus on socially constructed barriers in society, is critiqued for failing to address the experiences of disability from stratified social positions, such as gender, race, class, and age (Vernon 1998, 1999; Morris 1991). Individuals from varying stratified positions may experience their impairment in distinct ways as a result of the other oppressions they may experience because of their race, gender, age, and class status (Vernon 1998).

While research has increasingly examined the experiences of disability from a single standpoint, such as the experience of being male and disabled (Charmaz 1994, 1995; Gerschick and Miller 1995; Valentine 1999), female and disabled (Zitzelsberger 2005; Dyck 1999), an older adult and disabled (Kelley-Moore and Ferraro 2004), or black and male and disabled (Devlieger, Albrecht, and Hertz 2007), very few studies make comparisons among people in different social locations (Miner 1997; Kelley-Moore and Ferraro 2004; Bender 2006; Hanna and Rogovsky 1991; MacDonald, Keys and Balcazar 2007).

In order to gain a better understanding of the development of a disabled identity, it is necessary to develop a more expansive model of disability. Rather than assessing disability from either a social or medical model approach, we need a model which encompasses the complex experiences that impaired persons face, which includes socially constructed barriers and bodily factors, such as, type of impairment, level of functionality, as well as self theories, (i.e., social comparisons, self presentations and reflected appraisals) and their social statuses, such as race, gender, age, and class.

The goal of this dissertation is to assess how impaired individuals develop a conceptualization of self as disabled. In order to do this, I will address three research questions: How do environmental and social barriers versus physical impairments affect the claiming of a disabled identity among adults with physical impairments? How do self processes (i.e., reflected appraisals, social comparisons, and self-presentation) inform the embracement or rejection of a disabled identity? How is this process influenced by social statuses, such as gender, race, social class and age?

Using a symbolic interactionist frame, and more specifically, the reflected appraisal process, I examine how individuals' experiences with environmental and social barriers and physical impairment are mediated through self processes in shaping their identities as disabled, and how this process is influenced by individuals' race, gender, social class and age.

Data used in this study are from the 1994 National Health Interview Survey on Disability (NHIS-D), a large nationally representative sample of non-institutionalized U.S. residents with impairments. In addition, I supplement this analysis with qualitative data from 30 in-depth interviews with adults aged 18-67 who have mobility limitations. Environmental barriers include environmental barriers in the home, general environmental barriers outside the home, and transportation barriers. Social aspects of disability include the following factors: social activity level, satisfaction with social activities, barriers to social activities, work experiences (employment and discrimination in the workplace), and marital status. Medical indictors of disability will be examined using the following factors: severity of movement difficulty, ADLs (limitations in activities of daily living, such as bathing, dressing, eating) and IADLs (limitations in instrumental activities of daily living such as housework, meal preparation, and shopping), and use of assistive devices. In addition, using a symbolic interactionist approach, I examine the importance of others' (both significant others and the generalized other or "society") views of the individual. Moreover, I examine the interactions of race, gender, class and age and indicators of disability from the social and medical models of disability.

Chapter 2: Review of the Literature

Definitions of disability vary greatly among academics, policy makers, medical professionals and laypersons (Altman 2001). However, how we define disability has important implications for social policies, research, and how impaired individuals comprehend their 'disability' and subsequently, develop identities (Altman 2001; Morris 1991). Although disability has traditionally been conceptualized as a deficit in the person and a social problem that was to be eradicated, more recent scholarship has begun to define disability as a socially constructed phenomenon (Oliver 1996). The social model of disablement developed in opposition to models of disablement that located the source of disablement in the person (Oliver 1996). These models were labeled "medical models" (Oliver 1996). Proponents of the social model challenged the notion that disability resides in the individual and instead propose that disability emerges from the barriers in the built environment and social barriers in society that prevent impaired individuals from fully participating in society (Oliver 1996; Shakespeare and Watson 2001).

While scholars using the social model of disability contend that impaired individuals' encounters with both environmental and social barriers contribute to the conceptualization of the self as disabled (Oliver 1990; Shakespeare and Watson 2001; Hughes and Patterson 1997), others maintain that impairment itself has real implications for self-identification as disabled (Morris 1991). In examining how disabled identities are constructed, it's important to keep both of these paradigms in mind as they both are likely to shape societal responses to disability and therefore have an impact on the daily social interactions of impaired persons (Oliver 1996). The

following section will briefly outline each paradigm, beginning with the medical model, and then introduce two contributions of this dissertation to our understanding of disabled identity: 1) the symbolic interactionist approach, with focuses on reflected appraisals as a conceptual expansion of the disablement process and 2) a social status/inequality approach, with an examination of how environmental and social barriers interact with social statuses in the disablement process.

Medical Model of Disability

Medical models of disability are models which locate the source of disability in the individual. Models of disablement that are characterized as falling under this umbrella term "medical model," include the World Health Organization's (WHO) International Classification of Impairment, Disability and Handicap models (i.e., ICIDH-1, ICIDH-2), Nagi's model, the Institute of Medicine at the National Institute of Medicine models (i.e., IOM-1 , IOM-2), and Verbrugge and Jette's model. These models serve a number of purposes, such as administrative (i.e., determining who should receive social benefits and legal protection), epidemiological research, and clinical assessments; however they all define disability in a similar way (Altman 2001). That is, they define disability as emerging from pathology or disease,[1] which then leads to impairment,[2] followed by functional limitations,[3] which then prevent individuals from fully participating in society (Altman 2001). These models are described in more detail below.

[1] Pathology can be generally defined as an interruption in the body's normal functioning while the body attempts to restore its normal state (Altman 2001).
[2] Impairment can be generally defined as bodily abnormalities and losses (Altman 2001).
[3] Functional limitations can be generally defined as restrictions or inability to perform usual roles or everyday tasks as a result of impairment (Altman 2001).

The ICIDH-1 was developed in the 1980s by the World Health Organization as a way to classify and measure health and disease internationally. This model describes a causal relationship between disease onset and becoming "handicapped" (WHO 1980; Gray and Hendershot 2000).[4] The four main components of this model are 1) disease, 2) impairment, 3) disability and 4) handicap. Disease, which is defined as an intrinsic pathology or disorder experienced by an individual, is conceptualized as leading to impairments or the loss or abnormality in an individual's psychological, physiological or anatomical structure or functioning (WHO 1980). Impairment can then lead to disablement, which is defined as a restriction or lack of ability to perform activities. Finally in this model, handicapped is identified as the possible end result of impairment and disablement. Handicapped is defined as a limitation resulting from impairment that prevents an individual's fulfillment of survival roles (WHO 1980; Gray and Hendershot 2000). There are several limitations to this model, including inattention to the role of the environment in the disablement process, as well as a lack of clear distinction between some of the components, such as impairment and disability and disability and handicap (Gray and Hendershot 2000). Additionally, the relationship between the components of the model was not fully developed (Gray and Hendershot 2000). In 2001, the WHO published the ICIDH-2 to address some of these limitations.

One notable improvement to the ICIDH-2 was the incorporation of social experiences into the model. In the ICIDH-2 the process of disablement begins with health conditions such as experiences of disorder and disease. Health conditions are

[4] This pattern is described by Gray and Hendershot (2000) as typical, but not necessarily causal pattern of health outcomes.

recognized as possibly leading to impairment, which is defined as "problems in body function or structure such as a significant deviation or loss" (WHO 2001:10). Next, impairment is conceptualized as leading to activity limitations at the personal level, such as moving around, performing self-care, performing domestic activities, among others (WHO 2001; Gray and Hendershot 2000). Activity limitations can then cause the individual to experience participation limitations, which are measured based on an impaired individual's ability to fully participate in life. It is noteworthy that this component of the model is assessed by comparing an impaired individual's involvement is life activities to the participation levels of non-impaired persons (WHO 2001; Gray and Hendershot 2000). The final component of this model of disablement is contextual factors, which include both personal and environmental factors that interact with the individual's health condition in determining the extent of their functioning (WHO 2001). Examples of personal factors are not classified in the model due to cross-cultural differences in these factors (Gray and Hendershot 2001) but can include things such as an individual's race, gender, age, fitness, etc. Environmental factors include such things as attitudes of society and physical environmental barriers (WHO 2001). The WHO contends that the ICIDH-2 integrates aspects of both the medical and social models of disablement (WHO 2001), however it still locates disability as stemming from the individual (Shakespeare and Watson 2001). Additionally, the usage of social and environmental as determining criteria of disablement remains ill-defined (Gray and Hendershot 2001).

Another model that can be characterized as a medical model is Nagi's (1965; 1991) model of disablement. This model begins with pathology that causes an interruption with normal bodily processes and the simultaneous efforts of the body to return to a normal state of functioning. In this model, pathology can then lead to impairment, which is defined as "a loss or abnormality of an anatomical, physiological, mental or emotional state" (Nagi 1991:314). Nagi also defined three types of impairment – losses that are condition of pathology itself, losses that are residual following the control or elimination of pathology, and losses that are not associated with pathology, such as congenital formations (Nagi 1991). The third component of Nagi's model was functional limitations. That is, limitations in an individual's abilities to perform his/her usual roles that result from impairments. According to Nagi (1965; 1991), disability is the culmination of impairments and functional limitations that prevent or limit an individual's ability to perform his/her socially defined roles, such as family roles work roles, interpersonal relationships, or other aspects of social life. Unlike other medical models of disablement, Nagi does note that the degree to which one is impaired is also contingent upon how an individual make sense of his/her daily interactions, how others define the interaction, as well as characteristics of the environment itself and the degree to which an individual can move about freely (Nagi 1991). Like the ICIDH-2 model of disablement, Nagi's model incorporates aspects of the social world into its conceptualization of disablement, however, like other medical models it locates disablement as stemming from individual level factors.

Another medical model, the Institute of Medicine model of disablement (IOM), was prefaced on the Nagi model. The IOM model of disablement was developed as a model to guide prevention of disablement. Drawing on the Nagi model, this model identifies a relationship between pathology, impairment, functional limitations, and disability. Similar to the Nagi model, this model identifies disability as stemming from pathology - or molecular, cellular, or tissue changes which can be caused by a number of factors including, among others, disease, congenital condition, and injury (Brandt and Pope 1997). Pathology can then lead to impairment, which is defined as losses or abnormalities in functioning. As in Nagi's model, impairment can then lead to functional limitations, which is simply defined as the inability to perform tasks (Brandt and Pope 1997). Finally, disability can occur if these experiences lead to a limitation in an individual's ability to perform expected roles in society. That is, if there is a gap between the individual's capabilities and the demands of the social and/or physical environment (Brandt and Pope 1997). Although this model indicates that disability is not conceptualized as inherent in the individual, but rather the outcome of the interaction of the individual and his/her environment (Brandt and Pope 1997), it is still considered to be a medical model as it focuses on deficiencies in the individual that affect the ability of the individual to interact within his/her environment. Additionally, the discussion of the role of the environment and societal limitations in the disablement process is underdeveloped (Brandt and Pope 1997). These criticisms were somewhat addressed in the revision of this model.

In the IOM-2 model of disablement, the definitions of pathology, impairment, and functional limitations remain the same as in the first IOM model; however,

significant improvements were made to the final step – disablement. Using a three-dimensional element in the model to represent the potential for disablement, this model hypothesizes that the effect of impairment and functional limitations on disablement is dependent upon the degree to which these factors interact with the social and physical constraints (or lack of) of the environment (Brandt and Pope 1997). In other words, disablement is contingent upon the degree to which persons with impairments and functional limitations experience support in their physical and social environments (Brandt and Pope 1997).

Finally, another popular model of disablement that can be classified as a medical model is Verbrugge and Jette's model of disablement. Verbrugge and Jette's model of disablement also begins with pathology, which they define as "biochemical and physical abnormalities that are detected and medically labeled as disease, injury or congenital/developmental conditions" (Verbrugge and Jette 1994:3). Like other models, this model conceptualizes pathology as leading to impairment, which is defined as significant disruptions in the body's systems. In this model, impairment is modeled as leading to functional limitations, which Verbrugge and Jette (1994) define as limitations or inability to perform physical actions, such as walking, climbing stairs, etc. Disability is then viewed as occurring when an individual cannot perform activities in any domain of life that are specific to his/her age and gender (Verbrugge and Jette 1994).

Although, the ICIDH-2 model, the Nagi model and the IOM-2 model recognize the individual's interaction with his/her social and built environment as influential in the disablement process, they do not define disablement as a social

oppression and they do not distinguish between that which is biological (i.e., impairment, functional limitations) and that which is social (i.e., disablement) as does the social model (Shakespeare and Watson 2001). As mentioned above, the medical model approach to defining disability has been highly criticized in the disability literature for locating disability as residing in the individual, rather than social forces (Oliver 1996; Oliver 1990; Hirsch and Hirsch 1995). This view of disability perpetuates stereotypes of individuals with impairments as enacting a "sick role" in society (Hirsch and Hirsch 1995) and disability scholars posit that as long as disability is viewed as an individual tragedy, disabled persons will continue to be treated as individual victims who need to be rehabilitated in order to participate in society, and that this treatment would continue to shape social interactions as well as social policies (Oliver 1990). Conversely, if disability is defined as a social oppression, disabled persons would be viewed as "collective victims of an uncaring and unknowing society," which could lead to a shift in social policy away from rehabilitation to focus on alleviating oppressions (Oliver 1990:2).

Social Model of Disability

The social model of disability emerged from the British Disability Movement in the 1970s in response to the limitations of the medical model of disability (Thomas 1999). Based on the Union of the Physically Impaired Against Segregation (1976) publication "Fundamental Principles of Disability," where a redefinition (and separation of) impairment and disability was offered, the social model of disability is centered on the idea that disability is a socially constructed phenomenon imposed on individuals with impairments (Oliver 1990; Shakespeare and Watson 2001; Hughes

and Patterson 1997). In this model, impairment is disability is separated from impairment. Impairment is defined as "lacking all or part of a limb, or having a defective limb, organism, or mechanism of the body" (Oliver 1996:22). Disability is defined as "the disadvantage or restriction of activity caused by a contemporary social organization which takes little to no account for people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (Oliver 1996:22). Instead of viewing disability as a sole outcome of impairment, it is viewed as emerging from the interaction between impairment and the social environment (Thomas 1999). In other words, disability is dependent upon an impaired individual's integration in his/her community, his/her ability to socialize, work and be independently mobile (Oliver 1996).

In the remainder of this dissertation, when I refer to impairments I am referring to the social model definition of impairments. Additionally, when I refer to disability, I am referring to the social model definition of disability. In recognizing disability as a social oppression, the term "disabled people" is used instead of "people with disabilities," a term that is deemed more politically correct in the United States.[5]

Environmental Barriers

Impaired persons' encounters with environmental barriers have been well documented in the literature. Living in a world designed for able bodied persons presents constant obstacles to persons with mobility impairments. Because the built

[5] The term "disabled people" was adopted by supporters of the social model of disablement as a way of recognizing the fact that disablement stems from social oppression, rather than from individual level factors, such as impairment (Shakespeare and Watson 2001). Supporters of the social model contend that using language such as "people with a disability," although politically correct in North America, perpetuates the image of disability as a causal factor of impairment (Shakespeare and Watson 2001).

environment is often not accommodating to those with physical impairments, being physically impaired changes individuals' subjective experience of space and often performing everyday tasks becomes an act of thoughtful planning and anticipation of potential difficulties (Toombs 1995). As a result, impaired individuals are less likely than able-bodied individuals to participate in their communities, and this gap increases the more impaired a person is (Hendershot 2003). Based on data from the 2002 National Health Interview Survey, when it comes to participating in the community, which includes things like getting together with friends, going to church or temple, going to movies or shopping, 43 percent of disabled persons studied reported that building design was the number one reason given for why they did not participate more (Hendershot 2007). Respondents who were disabled also reported crowds, lack of transportation, difficulty with sidewalks and curbs, sound, and poor lighting as other reasons why they do not participate more in their communities (Hendershot 2007). Additionally, data from the 1994-1995 National Health Interview Survey on Disability found that impaired individuals often need a number of accommodations in the workplace in order to effectively get to and perform their jobs, such as accessible parking and transportation, elevators, accessible work stations, handrails and ramps (Zwerling et al. 2003).

These findings are supported by personal accounts and ethnographic studies, which demonstrate difficulty navigating the built environment. For example, disabled individuals frequently encounter problems when shopping, dining out, and attending other social events, such as limited parking, broken elevators, inaccessible entrances, lack of handicap fitting rooms and bathrooms (and lack of *accessible* handicap fitting

rooms and bathrooms, even if provided), lack of places to rest, crowded floor spaces and narrow aisles, as well as lack of transportation (Kaufman-Scarbourough 2001; Toombs 1995; Connors and Stalker 2007; Watson 1998).

Stigma and Social Barriers

Impaired individuals' experiences with social barriers have been recognized in the sociological literature for many years, most notably in the work of Goffman (1963). According to Goffman (1963), impaired individuals experience stigma when they possess an attribute marked as unusual and different from the norm (impairment) and a stereotype(s) attached to that attribute that serve to discredit the individual who carries that attribute. Goffman identifies two kinds of attributes, those that are *discrediting* and those that are *discredible*. Persons with mobility impairments often possess what Goffman (1963) described as "discrediting attributes." These are attributes that are often visible, or if not, are readily evident during social interactions. Goffman (1963) contended that individuals with these types of attributes must work to manage the tensions that these attributes introduce into the social interaction in order to reduce experiences of stigmatization and discrimination. However, depending on the visibility of their impairment, persons with mobility impairments may also possess discredible attributes. In these cases, impaired persons must manage the information regarding these attributes during social interactions in order keep from disclosing, as Goffman puts it, their "failing."

Although Goffman's work is credited with demonstrating that it is not the attribute of the individual that prevents him/her from fully participation in society, but the relationship between that attribute and societal responses to it (Susman 1994),

others posit that Goffman's conceptualization of stigma further perpetuates the stereotype of impaired persons as passive, helpless victims (Fine and Asch 1988) and for locating the source of stigma as residing within impaired individuals rather than the actions of those who oppress (Finkelstein 1980). Finkelstein argues that Goffman's emphasis on the need for impaired persons to manage the interaction so as to limit the tensions between themselves and able bodied others removes the responsibility of oppression from able-bodied others and places it directly back on those who are being oppressed. Also argued to be missing from Goffman's work is the ability of impaired individuals to confront, reject, and ignore stigma as a strategy for managing stained interactions (Oliver 1990).

Modified labeling theory offers another an alternative conceptualization of the stigmatization process that takes into account the role of the stigmatized (Link, Cullen, Struening, et al. 1989). This theory contends that during socialization individuals take on the generalized others' attitudes toward the stigmatized (e.g. disabled), and when/if these same individuals possess stigmatizing attributes these attitudes become personally relevant and individuals are likely to feel devalued or discriminated against. Expectations of devaluation and discrimination can affect social interactions in terms of interpersonal relationships and job opportunities, among others, as those who are stigmatized engage in behaviors such as hiding their stigmatizing attributes, withdrawal, or education of others in an attempt to alter attitudes (Link et al. 1989). In the remainder of the dissertation when I refer to stigma I am referring to the discrediting attitudes toward persons with physical impairments., and when I refer to social barriers I am referring to the outcomes of stigmatization,

which can include discrimination, strained interactions, and social exclusion, among others.

Impaired individuals' encounters with discrimination and oppression during daily interactions have been widely noted in the literature (Morris 1991; Cahill and Eggleston 1995; Connors and Stalker 2007; Toombs 1995; Kaufman-Scarbourough 2001; Harris Interactive, 2000). In studies which rely on disabled persons' personal accounts of social interactions with able-bodied persons and participant observation, disabled persons are often found to be treated as "non-persons" in which they are often stared at, ignored, talked to in a degrading manner or subjected to inappropriate, and sometimes hostile comments and gazes by able-bodied others (Morris 1991; Cahill and Eggleston 1995; Connors and Stalker 2007; Toombs 1995). For example, Kay Toombs, a professor of philosophy who uses a wheelchair as result of MS, recalls a comment made to her by stranger in a shopping mall who stated, "Why don't you change places and let me ride in your wheelchair for a while and you walk. My legs are tired!" (Toombs 1995:18). Similar reactions are found in other studies as well. For example, one study which documented the experiences of wheelchair users when out in public, found numerous experiences of being ignored, talked over, or treated as a burden by able-bodied others (Cahill and Eggelston 1995). One participant in this study recounted her experiences when dining out: "You go to a restaurant, and you're with your able-bodied friends, and the waitress says 'What will she have?' And like I've gone to a restaurant and they don't know where to put you. They make such a big deal out of it. They even talk right in front of me, about me, as

if I'm not there. 'Well, where are we gonna put her?'" (Cahill and Eggelston 1995:684).

Additionally, disabled individuals must also deal with unsolicited help from able bodied others and overt sympathy when out in public (Connors an Stalker 2007; Toombs 1995; Kaufman-Scarbourough 2001; Morris 1991; Cahill and Eggleston 1995), as it is often assumed that because they are impaired they need assistance (Fine and Asch 1988). For example, disabled persons recount numerous incidents in public when complete strangers will begin pushing their wheelchairs without first asking their permission, (Toombs 1995; Morris 1991; Cahill and Eggelston 1995), or go out of their way to hold open doors, or help them with placing their wheelchairs in their car (at times damaging the chairs in the process) (Cahill and Eggelston 1995). Toombs (1995:17) describes one such experience with unsolicited help from strangers: "For example when I'm wheeling myself around the shopping mall, strangers will (without my permission) start pushing my wheelchair, explaining they are "helping" me. On one occasion, in order to get from the cab to the curb, a taxi driver simply picked me up (with no warning or no inquiry as to whether I would like him to do so!)."

Impaired individuals are also frequently subjected to stigma and stereotypes regarding their impairment and are not afforded the same kind of privacy rights as are able-bodied persons (Wendell 1996; Morris 1991; Cahill and Eggelston 1991). For example, able-bodied others often assume that disabled people want to be "normal" or able-bodied, or that they are ashamed of their bodies and that they feel their life is not worth living because on their impairments (Morris 1991). They also experience

frequent infringement of their privacy (Cahill and Eggleston 1995; Morris 1991). For instance, in a study of wheelchair users, one respondent stated "Another thing that people tend to ask me about is that they see me out near the van, and they'll stop me when I'm getting in my van and [say] "Well gee, where did you get this?" Or "how much did it cost?" No one would stop you and ask you have much your car cost. But they feel like they can stop me and ask me how much my life or my chair or whatever cost." (Cahill and Eggleston 1995:685).

Finally, despite advances made with the 1990 Americans with Disabilities Act, impaired individuals continue to report difficulty finding work, though they have many capabilities. Using data from the 1994-1995 National Health Interview Survey on Disability, Loprest and Maag (2003) found that more than half of impaired individuals who were not working cited difficulties finding work, which included lack off appropriate jobs, lack of transportation, and need for workplace accommodations. Similar findings were also found in the 2000 Harris Survey of Americans with Disabilities. Based on findings from this study, 32 percent of disabled adults work full- or part-time compared to 81 percent of adults without disabilities and 36 percent of disabled adults who are employed reported that they have encountered some form of discrimination in their workplace (Harris Interactive, 2000). The most common type of discrimination reported was not being offered a job for which they were qualified, followed by being denied workplace accommodations, being given fewer responsibilities than fellow coworkers, being paid less, being refused promotion and refused a job interview (Harris Interactive, 2000). In terms of education and employment, disabled persons are often assumed to be unable to perform particular

duties that were considered essential to the job for which they were applying (Vernon 1996). Additionally, disabled individuals also report experiencing a number of environmental barriers before they ever get to job interviews, particularly those with mobility impairments. In one study, respondents recounted numerous incidents of going to interviews and not being able to get in the buildings, despite being assured in advance that the buildings were accessible (Vernon 1996).[6]

The social model of disability is important for understanding the self as it shifts the meaning of disability away from medical contexts and into the social context. In doing so, it allows impaired individuals (and able bodied others) to challenge the assumption that disability stems from impairment. This allows impaired individuals to define for themselves what it means to have impairments and the agency to make their own identity claims.

Although the social model of disability broadens our understanding of how disability is socially constructed, it has been critiqued for overlooking the reality of how impairment itself impacts the lived experiences of disabled persons (Morris 1991, 1996; Hughes and Patterson 1997; Crow 1996; French 1993; Thomas 2004; Hughes 2004). Critics claim that even if all barriers in society were removed, impaired persons are likely to continue to experience physical and emotional symptoms such as pain, fatigue, chronic illness, and depression as a result of their impairment and these experiences are argued to have a significant impact on their daily lives (Crow 1996; French 1993; Morris 1991). While the social model was very successful in enabling impaired people to confront and cope with daily encounters of

[6] Experimental studies have found physically impaired job applicants are evaluated more positively than their able bodied peers with comparable skills and interview performance (Nordstrom, Huffaker, & Williams 1998; Cesare, Tannebaum, & Dalessio 1990).

exclusion and discrimination, it leaves them without a platform with which to cope with bodily experiences of impairment (Crow 1996; Morris 1991) and may perpetuate feelings of shame and isolation among impaired persons (Morris 1991).[7] In fact, despite the vast success of the social model in complicating our conceptualization of disability, individuals often experience their impairment and their *disability* from an individual, bodily level (Higgins 1992; Watson 1998; Wendell 1996). For example, despite recognizing barriers in society that limit their ability to actively participate, impaired individuals continue to discuss how they could personally adjust to their environment, rather than how the environment could adjust to their needs (Higgins 1992).

Furthermore, although it is theoretically possible to separate out the effects of individual level factors (impairment) from social factors of disability, individuals are likely to experience these things simultaneously. This is because individuals ultimately experience the world through their bodies (and minds); therefore experiences of social disablement will be processed through individuals' experiences of impairment (Hughes and Patterson 1997; Giddens 1991). These limitations of the social model have led some scholars to call for a model that integrates both individual level experiences of impairment and social experiences of disablement (Crow 1996; Hughes and Patterson 1997). Crow (1996) contends that in order to gain a better understanding of the effect of impairment on individual's lives we need to examine impairment in three ways: 1) objective experiences, such as lacking a limb, or having

[7] Proponents of the social model contend that that the model is not a theory and cannot serve as such, nor was it intended to capture all aspects of the disablement process. Rather its purpose was to serve as a mechanism for collective action and to empower impaired individuals to challenge socially constructed barriers that disable them (Oliver 1996).

a defective limb or bodily mechanism 2) subjective experiences, such as the meaning individuals apply to their impairment and 3) the wider social context, such as social exclusion, discrimination, and barriers in the built environment that disable people.

More recent research has begun to examine both social and individual/medical factors of disability and the subjective meaning of these two things to the individual, and has produced evidence to support arguments for a more encompassing model (LoBianco and Sheppard-Jones 2007; Watson 2002; Priestley 1999). Indicators of disability from both the social and medical models of disability are found to predict whether or not an individual claims a disabled identity (LoBianco and Sheppard-Jones 2007; Priestley 1999). For example, having a visible functional limitation, the use of mobility aids and the inability to independently perform daily tasks are found to increase the likelihood that individuals with impairments will identify as disabled (LoBianco and Sheppard-Jones 2007; Priestley 1999; Zitzelsberger 2005). However, being in accommodating physical spaces, the ability to engage in social activities, such as spending time with friends and participating in entertainment activities, are found to decrease the likelihood that individuals with impairments will identify as disabled (LoBianco and Sheppard-Jones 2007; Zitzelsberger 2005). In addition, one study found that individuals who recognized social barriers as disabling them, and not their impairment alone, were capable of rejecting the stigma associated with their impairments, and able to make other identity claims for themselves (Watson 2002).

Finally, social and medical model indicators of disability are both found to affect how individuals with impairments perceive others to view them (LoBianco and Sheppard-Jones 2007; Watson 2002; Priestley 1999). Using a nationally

representative sample from the National Health Interview Survey, one study found indicators of disability from the social model (i.e., social activities, marital and employment status) and indicators of disability from a medical model (i.e., activity limitations and use of mobility aids) both significantly predict whether impaired individuals perceive themselves as disabled and their perceptions of others' views of them as disabled (LoBianco and Sheppard-Jones 2007). However, this study does not connect the relationship between reflected appraisals and identity, nor does it meaningfully address social status location, two major contributions of this study. Using a small sample convenience samples two others studies also found social and medical model indicators of disability affect one's claiming of a disabled identity (Watson 2002; Priestley 1999). Although one study focuses on the narrative as an important tool in maintain identities (Watson 2002), neither draws on other self theories to explain how these identities are constructed.

Though all of the studies cited above provide some insight they into how experiences with socially constructed barriers and impairment are related to identities as disabled/able-bodied, they leave out an important component of the identity process; that is, how these factors ultimately affect identity through self-processes. Although these studies find relationships between environmental and social barriers, impairment, and identity, the process by which these factors come to shape identity is unknown. In order to understand the relationship of socially constructed barriers, impairment, and identity, this dissertation builds a more expansive model, one which draws upon Self theories and a social status and inequality perspective.

Self Theories: Social Comparisons, Self Presentations and Reflected Appraisals

In order to understand the process by which individuals negotiate and/or internalize an identity as disabled, it is important to utilize an interactionist approach to identity construction. The symbolic interactionist perspective contends that identity construction (and self-concept construction more generally) occurs through social interaction. The self is innately social, meaning that individuals come to understand their self as a result of the feedback they receive from significant others and "the generalized other" regarding their identity enactments. Three key elements that form identity are social comparisons, self-presentations and reflected appraisals (Rosenberg 1986).

Social Comparisons

Social comparisons are an important mechanism individuals use to learn about their self and their place in society. Individuals compare themselves to others and in doing so make evaluations of their self based on standards set by internal idealizations regarding the object they are comparing (Rosenberg 1986; Festinger 1954). In Festinger's (1954) original theory of social comparisons, he argued that social comparisons consisted of unidirectional upward drives, in which individuals engage in upward social comparisons in order to evaluate their abilities and opinions against a standard (i.e., those who are marginally better off than themselves). Depending on whether individuals compare favorably or unfavorably to others, individuals can experience a positive or negative view toward their self and subsequently an increase or decrease in their self-esteem respectively (Rosenberg

1986; Festinger 1954). This process serves as a motivational mechanism to improve oneself (Festinger 1954).

However, the claim that social comparisons are unidirectional has been challenged and discredited by subsequent empirical research (Wills 1981; Taylor and Lobel 1989). Instead, individuals can be agentic in deciding with whom they will compare themselves (Rosenberg 1986; Singer 1981). For example, studies show individuals are more apt to make downward social comparisons when they feel their self is under threat and thus are motivated to view the self more favorably (Wills 1981; Gibbons and Gerrard 1991; Wood and VanderZee 1997). That is, they compare themselves to others who are less fortunate. By comparing oneself to others who are more disadvantaged, individuals are able to make more positive self-evaluations (Wills 1989).

Social comparisons are particularly important when examining social identities, such as disabled. Social identities are dependent upon that ability of in-group and out-group members (e.g., disabled vs. not disabled) to make social comparisons between themselves and members of opposing groups in order to verify their own group membership (Hogg 2000). However, social identity theory posits that when group boundaries are viewed as permeable, members of low status or stigmatized groups will often try to pass into higher status groups (Hogg and Abrams (1988). In order to pass from one social identity group to another it may be necessary to make downward social comparisons between oneself and their in-group members (Hogg 2000).

Social comparisons have been cited in the disability literature as an important part of the process of self-identification as disabled (Watson 2002; Priestley 1999). Impaired individuals make upward social comparisons by comparing their self to able-bodied others in order to understand their impairments and "differentness," (Watson 2002; Priestley 1999), as well as downward social comparisons by comparing themselves with other impaired persons in order to make sense of their standing within the disabled community (Priestley 1999).

Self Presentations

In addition to making comparisons between themselves and others, individuals maintain self-presentations of themselves during social interactions. Self-presentations serve to define the interaction as they provide information to others regarding how to interact and, in particular, what behavior is appropriate (Goffman 1959). Self presentations can include both verbal assertions regarding the self and non-verbal cues, such as physical appearance and behavior (Goffman 1959). Appearances and mannerisms are both functions of what Goffman (1959) referred to as "personal fronts" or characteristics of the individual that are always present. However, note that individuals may alter these fronts depending on the context of interaction, and the reactions they wish to receive from others. During social interactions individuals learn information about the others with whom they are interacting based on these others' personal fronts, and often these fronts contain symbolic cues that inform individuals of each others' social roles.

Individuals may give self-presentations that are not necessarily in line with how they themselves view their self (Goffman 1959; Rosenberg 1986). However,

these performances may serve to ease the interaction and/or to maintain one's self-esteem (Rosenberg 1986; Goffman 1963). In the case of mobility impaired persons, things like mobility aids, movement difficulty, and immobile or missing limbs cue others of their impairment. However, mobility impaired individuals, who wish to reject a disabled identity, may alter their mannerisms or behaviors in a way to contradict or alter others' views of them as impaired, despite the fact that they themselves view their selves as impaired. This may entail hiding their impairment (Goffman 1963) as mentioned above or behaviorally demonstrating their abilities (Watson 2002; Taub and Greer 2000).

Reflected Appraisals

Another key mechanism that is more neglected in the disability literature, but which is important to the process of identity development is the reflected appraisals process. There are three important components to this process that emerge out of social interactions: 1) actual appraisals 2) perceived appraisals and 3) the generalized other (Rosenberg 1981).[8] *Actual appraisals* are what Rosenberg considered to be "the social self," meaning how others actually see us. *Perceived appraisals*, which are often referred to as "reflected appraisals" are individuals' perceptions of how particular others view them. The generalized other is individuals' perceptions of the attitudes of the community as a whole. The generalized other can be further broken down into subcultural groups within society. For example, as described above, impaired individuals may hold perceptions for how disabled others and able bodied others view them. Rosenberg (1986), drawing on the work of Mead (1934) and

[8] In other writing Rosenberg refers to these terms as "direct reflections" and "perceived selves" respectively (Rosenberg 1986).

Cooley (1902), contends that as individuals interact, they receive information from others regarding their selves. But because others do not always tell us how they view us, others' actual appraisals of the individual are believed to be mediated through individuals' reflected appraisals, which in turn affect *self-appraisals*, that is, how individuals view their self (Rosenberg 1986).

While the reflected appraisal process has been widely accepted in the self-concept literature, it has also been critiqued over the years. One criticism, in particular, is that the reflected appraisal process, and Mead's general theory of taking the role of the other, falsely assumes that individuals openly communicate their attitudes toward others in the social interaction (Felson 1980). Another criticism is that reflected appraisals more accurately reflect one's own self-appraisals than others' actual appraisals (Ichiyama 1993; Felson 1981; Felson 1989). In fact numerous studies have shown that individuals' perceptions or reflected appraisals do not accurately reflect others' actual appraisals (Shrauger & Schoeneman 1979; Felson 1989; Felson 1981; Felson 1985; DePaulo et al 1987). However, it is argued that the concept of reflected appraisals was never meant to serve as a measure of how others actually see us; rather how we *think* others see us (Rosenberg 1981). Another criticism of the reflected appraisal process is that reflected appraisals may better represent our perceptions of how the generalized other or "society" views us, rather than how significant or specific others view us, and some support for this is found in the literature (Felson 1985; DePaulo et al 1987).

Many scholars argue that the reflected appraisal process is critical to understanding self-processes, as reflected appraisals bridge the relationship between

social structure (and social interaction) and the self-concept (Rosenberg 1986). Furthermore individuals may be more agentic in selecting and integrating evaluations of themselves into their self concept than the above studies indicate (Franks and Gecas 1992). In fact, findings from some studies suggest that individuals are capable of playing an active role in selecting with whom they interact, usually those whose appraisals they view as most meaningful, thus affecting others' actual appraisals toward them (Gecas and Burke 1995; Rosenberg 1986; Kaufman and Johnson 2004; Milkie 1999; Ichiyama 1993).

One theory that explicates how these self processes come to shape identity is Burke's (1991) Identity Control Theory (ICT). According to Burke (1991), the self is an occupant of a role, which interacts within the larger social structure and in accordance with shared cultural meanings prescribed to that role. Therefore roles are viewed as the link between the self and the social structure. Given that experiences vary from person to person, any role could have multiple meanings, causing identities associated with that role to vary as well (Turner 2003). That is, roles have different meanings for different people. Identities are self-meanings that develop out of the roles or statuses one holds, and subsequently identities only predict behavior when the meaning of a behavior (role enactment) matches the meaning of an identity (Stryker and Burke 2000).

The main goal of Burke's ICT is to attempt to explain the internal dynamics of the self as individuals seek to verify the identity that is associated with the roles they enact. Burke's theory consists of four main elements: identity standard (criterion for whether or not an identity is verified), inputs (reflected appraisals regarding an

individual's enactment of an identity), comparison (comparison between the inputs and the identity standard), and behavior outputs (behavior based on the congruency between inputs and the identity standard). Burke argues that when an identity standard is achieved, individuals experience positive emotions and they will engage in behavior that further forms their commitments to others in their interactions, however when an identity standard is not achieved, individuals experience negative emotions and will attempt to alter their behavior to bring others' responses to their enactment of an identity back in line with the individual's identity standard (Burke 1991).

However, a limitation of Burke's theory is that it does not take into account social identities, which can be differentiated from role identities or personal identities (i.e., those tied to institutions like work or family). Burke's identity theory focuses on roles and whether role performances are reflective of the meanings and expectations associated with that role (Stets and Burke 2000). In identity theory, emphasis is placed on the negotiation of role performances in the interactional setting, and less attention is given to social identities, which (according to Social Identity Theory) can be claimed and maintained outside of the interactional context (Stets and Burke 2000). "Disabled" is a social identity, meaning that it is defined by "categorical representational meaning systems shared by large segments of society that can provide expected characteristics for those who belong to that category as well as perceptions for their behavior and narrative history of group membership" (Deaux and Martin 2003: 105). While social identities are often claimed subjectively by those who exhibit characteristics fitting of that social category, social identities are

also often objectively ascribed to persons who exhibit characteristics of a known social group (Deaux and Martin 2003). Ascription of a social identity is particularly likely when individuals display physical characteristics or visual cues as indications of their "belonging" to that group (Deaux and Martin 2003; Killian and Johnson 2006; Waters 1990). This brings me to the second limitation of Burke's theory – it presumes that individuals have an establish identity that they wish to maintain.

Although social identities are often ascribed based on physical appearances or other visual cues, individuals who possess these characteristics may wish to disidentify from a given social identity or claim an alternative identity for themselves. A small body of literature recognizes identities that develop in opposition to other, often stigmatized social identities (McCall 2003; Killian and Johnson 2006; Pyke and Johnson 2003). McCall's (2003) "not-me identities" are characterized as identities that emerge in reaction against others' ascriptions of identities on the individual. Evidence of individuals adopting "not-me identities," or "disidentifying" from stigmatized social identities is found in the literature (Killian and Johnson 2006; Pyke and Johnson 2003). However, although individuals may wish to claim or reject a particular social identity, and correspondingly desire others to accept their identity claims, it is not always possible to affectively change how others' view them, particularly if markers of one's membership to a social identity group is visible. (Hunt 2003; Killian and Johnson 2006)

One way to resolve this missing piece of "social identities" in Burke's ICT is to integrate the aspects of ICT with aspects of social identity theory. Deaux and Martin (2003) contend that identities are developed within two types of contexts:

broad social categories and the interpersonal network; and it is the interplay of these two contexts from which different forms of identities (i.e., role identities and social identities) are formed. Individuals' ability to claim or reject an identity is dependent upon the social context. The degree of support one gains for the enactment of an identity during social interactions will determine the likelihood of that identity being maintained or abandoned. Furthermore, the social categories may shape or constrain participation in everyday networks, which can have important implications for those who wish to reject particular identities and take on new ones. Finally, Deaux and Martin contend that social categories that individuals identify with often include others with whom one have never met and may never meet. In these cases the enactment of these social categories is largely based on what one gleans from popular discourse and others' reactions to their enactment of that identity.

Taking this interactionist approach into account, it would then follow that impaired individuals develop an identity as disabled depending upon the types of messages they receive from others regarding their self during social interactions, as well as the messages they receive through social discourse regarding impairment, and other aspects of their environment (inaccessible buildings, transportation, social exclusion) that send messages to the individual regarding their self. This claim is supported in the literature by studies which claim that frequent experiences of social exclusion and environmental barriers produce feelings of shame and frustration among people with impairments and send the message that they do not belong (Reeve 2002; Toombs 1995; Morris 1991). These experiences also shape how individuals with impairments believe others to perceive them (Skar 2003; Lobianco and

Sheppard-Jones 2007), and affect their likelihood of accepting or rejecting a disabled identity (Skar 2003; Watson 2002; Reeve 2002; LoBianco and Sheppard-Jones 2007). Impaired individuals who experience numerous barriers in society are found to engage in destigmatizing behaviors, such as taking on other roles to distract from their impairments (Skar 2003), and to reject their disabled identity, which claiming other identities for themselves (Watson 2002).

However, the process of negotiating an identity is highly dependent upon one's social environment and with whom one interacts and the degree to which these others produce "spoiled identities" for individuals with impairments (Higgins 1992). For those who are physically impaired, their "disability" is often viewed by others as a master status (Barnartt 2001; Higgins 1992; Fine and Asch 1988). A master status can be defined as an ascribed social status possessed by an individual, which supersedes all other statuses held by that individual during social interactions (Barnartt 2001). However, unlike others master statuses (e.g., race and gender) the status "disability" is more likely to occur later in life, is not always visible, and can vary in terms of its manifestation (both between and within individuals) (Barnartt 2001). The degree to which a disability is visible and whether or not a person discloses their disability has important implications for social interactions, as there are shared norms within society regarding how interactions between disabled and able-bodied others should go – disability presupposes how interactions will go (Barnartt 2001).

However, this is not to say that all disabled persons integrate these negative messages into their self concept. In fact there are acts of resistance (Reeve 2002). A

common finding in the literature is that claiming a disabled identity is a fluid process, which is highly dependent upon one's social context (Priestley 1999). In some contexts, impaired individuals may be better able to reject their disabled identity and claim other identities that are more meaningful to their sense of self. Individuals must evaluate the costs and benefits that result from claiming a disabled identity within their current social context (Priestley 1999; Reeve 2002). If maintaining identities that run counter to their disabled identity becomes too exhaustive, individuals may end up relinquishing those identities (Charmaz 1995). It is also important to consider individuals' reference groups. That is, whose perceptions the individual considers most meaningful (Rosenberg 1981; Frank 1988).

Finally, it is important to also take into account individuals' other social statuses and how these social statuses affect the disablement process. Not only may individuals' experiences of impairment be shaped by their privileged or subordinated status as a result of their race, gender, age, and class status, but the salience of these statuses to their individuals sense of self may also shape how they cope and identify with their impairment. Social status is argued to play an important role in individuals' identity claims (Hunt 2003; Killian and Johnson 2006; Waters 1990). Two studies, in particular, have demonstrated how social status advantages some groups in disidentifying from stigmatized identities. In their research on North African immigrants' rejection of an immigrant identity in France, an identity that is highly stigmatized, Killian and Johnson (2006) found some women were able to draw on resources gained through education and social class to shape others' perceptions of them. Social statuses may have important implications for impaired individuals'

claiming of a disabled identity as well. Conversely, Waters (1990) found West Indian immigrants in the US sought to verify their immigrant identity as a way to distance themselves from the stigmatization of being seen as American blacks and West Indians of higher class status were better able to do so than their lower class peers.

Social Statuses, Inequality and Disability

The relationship between disablement and other social statuses has been largely missing from models of disablement. Disability research, particularly research which focuses on socially constructed barriers in society, is often critiqued for treating disabled persons as a homogenous group (Hughes 2004; Vernon 1998, 1999; Morris 1991; Shakespeare 1996). Advocates argue that impaired persons experience varying degrees of oppression, beyond their degree/type of impairment, and socially constructed barriers in society, as a result of their stratified social positions, such as gender, race, class, and age (Hughes 2004; Vernon 1998, 1999; Morris 1991).

Black feminist theorists have long contended that social statuses, such as race, class and gender are constructed within larger macro level systems of racism, patriarchy, and capitalism, which constitute what is referred to as 'interlocking structures of oppression' (Collins 1993). These systems of oppression shape our daily interactions and subsequently the development of our self-concept. However, while it is argued that one's race, class, and gender are always present and active in any given social interaction (Collins 1993), a single status may be more salient in a given situation (King 1988), and not all statuses may be equally visible and/or important in terms of individuals' self-concepts (Collins 1993).

Theorists argue that the impact of any given status on an individual's life experiences varies depending on the situation in which we are examining, and the reference group to whom we are comparing the individual (King 1988; Collins 1993). In other words, social statuses (i.e. gender, race, social class, and age) in reality are dynamic, and the salience of a particular status is largely shaped by the social context and the social issue under consideration.

In terms of disablement, one's social statuses are embedded within systems of domination and subordination which shape their opportunity structures and their access to resources (Collins 1993). In the disability literature, some researchers contend that we need to examine the interaction of disability and other social statuses in order to understand the diversity of experiences (Stuart 1992; Hanna and Rogovsky 1991). These researchers argue that impaired individuals who hold other devalued statuses, such as female or a minority race, experience simultaneous oppressions as a result of disablism, racism, and sexism. However theorists are in disagreement regarding how the interaction of race and disability should be examined. For example, Stuart (1992) contends that in order to examine the unique experiences of black disabled people, we need to examine the simultaneous oppressions this group faces. Other researchers contend that the use of the term "simultaneous oppression" to describe black disabled people's experiences is overly simplistic (Vernon 1999). Vernon (1999, 1998) claims that this approach overlooks diversity within black disabled peoples' experiences, particularly class differences and does not fully capture black disabled people's experiences. She argues that black disabled people experience oppression singularly, multiply, and simultaneously (Vernon 1998).

Despite the theoretical contribution of these critiques of disability studies, there continues to be a lack of strong empirical evidence to support these claims (Oliver 1990; McDonald, Keys and Balcazar 2007). While research has increasingly examined the experiences of disability from a single standpoint, such as the experience of being male and disabled (Charmaz 1994, 1995; Gerschick and Miller 1995; Valentine 1999), female and disabled (Zitzelsberger 2005; Dyck 1999; Thomas 1997), black, female and disabled (Petersen 2006) or black, male and disabled (Devlieger, Albrecht, and Hertz 2007; Ostrander 2008), very few studies make comparisons among people in different social locations (Miner 1997; Charmaz 1994; Hanna and Rogovsky 1991; Bender 2006; MacDonald, Keys and Balcazar 2007). The following section will briefly outline findings in the literature regarding the relationship between gender, race, class and age and disability.

Gender

Studies on gender and disability tend to focus on two relationships between gender and disablement: 1) the ability of disabled person to enact gender roles, 2) the role of gender in the disablement process. The research in this area point to different predictions about whether or not men or women would be more likely to claim a disabled identity, all things equal. First, it is argued that impairment differentially affects men's and women's ability to enact gender. For men, impairment runs counter to hegemonic masculinity, such as being strong, physically fit, youthful, independent, self-reliant and rational (Gerschick 2000; Morris 1991; Robertson 2004; Valentine 1999), whereas impaired women face the convergence of two devalued statuses (Gerschick 2000; Hanna and Rogovsky 1991). However, some argue that impaired

women are also denied traditional female roles, as they are stereotyped as lacking resources necessary to be a suitable partner, mother and to achieve female beauty ideals (Sheldon 2004; Gill 1996; Oliver 1990; Vernon 1999; Zitzelsberger 2005; Thomas 1997; Asch and Fine 1992; Hanna and Rogovsky 1991).

Studies suggest that impaired men face a greater risk of identity loss when it comes to their gendered identities than do women (Charmaz 1994; Miner 1997). Numerous studies have found that when impairments prevent men from enacting their masculine identities, they are likely to experience an identity crisis (Valentine 1999; Gerschick and Miller 1995). Men are also found to engage in various behaviors in order to reclaim or renegotiate their masculine identities (Gerschick and Miller 1995; Charmaz 1994). Men are more likely to try to disguise their impairments, in order to put forth a public persona of someone who is independent and strong (Charmaz 1994). Doing so allows them to reclaim their masculine identities either by engaging in past behaviors that marked their masculinity or through creating alternative masculine identities for themselves (Gerschick and Miller 1995). Women on the other hand are found to be more resilient than men in terms of adopting new identities when their gendered identities are threatened by impairment (Charmaz 1994; Miner 1997) and unlike men are less likely to try to recapture their former selves. Based on these findings, it is possible to hypothesize that men might be less likely than women to claim a disabled identity, particularly when faced with threats to their gender identity.

Second, gender has been found to have implications for the disablement process. Empirical studies have shown that disabled women are more likely to be

socially isolated than are disabled men. For example, disabled women are less likely to marry, more likely to divorce, less likely to have children (Hanna and Rogovsky 1991; Bureau of Labor Statistics 2009) and are less likely to be employed than are disabled men (Hanna and Rogovsky 1991). Additionally, women are less likely to have access to resources as they are less likely than their male counterparts to have a high school education (Hanna and Rogovsky 1991), less likely to be college educated (Fine and Asch 1992) and when employed, earn significantly less money than disabled men (Hanna and Rogovsky 1991). Therefore, women may have more to gain from claiming a disabled identity, in terms of accessing financial resources, than do men. However, women may be less inclined to identify as disabled as they may view it as having negative ramifications.

However, it is difficult to understand how gender impacts the disablement process as the majority of studies examine the relationship of gender and disablement from the perspective of a single gender, or reference comparisons between genders only in passing without looking at systematic differences between the two (Charmaz 1994; Charmaz 1995; Gerschick and Miller 1995; Valentine 1999; Zitzelsberger 2005; Dyck 1999; Thomas 1997). Additionally, very few of these studies utilize nationally representative samples, making it difficult to make generalizations from the data.

Race

In addition to issues of gender, disability researchers contend that experiences of disablement are also affected by one's race (Stuart 1992; Vernon 1999), with almost all research focusing on the minority group African Americans. As a result of

experiences with disablism and racism, black disabled people are argued to have limited access to resources, to be isolated from their communities and families, and subsequently have limited to no ability to form an identity as a black disabled person (as they are excluded from disability politics and from the black community) (Stuart 1992). However, as with gender, few studies make direct comparisons between races when examining the effect of race on the disablement process (see MacDonald, Keys, and Balcazar 2007; Bender 2006). Instead, studies often focus on single standpoints, such as being a black male (Ostrander 2008; Devlieger, Albrecht, and Hertz 2007) or black female (Petersen 2006) and disabled.

Additionally, the limited research that has been done suggests that race may not have as significant of an impact on disability experiences as does gender (Bender 2006; Ostrander 2008; Devlieger, Albrecht, and Hertz 2007; McDonald, Keys and Balcazar 2007). Studies which have examined race and disability often find that respondents' gender identities play a more salient role in their conceptualization of self as disabled than do their race identities (Bender 2006; Ostrander 2008; Devlieger, Albrecht, and Hertz 2007; McDonald, Keys and Balcazar 2007).

In a study of black men who were paralyzed as the result of gunshot wounds, Ostrander (2008) found similar identity dilemmas as did previously cited research on masculinity and disability. The men in this study discussed experiences of diminished masculinity as a result of their impairment, as they were no longer able to enact behavior that was symbolic of masculinity within their social contexts, such as walking with a swagger, standing tall, having impromptu sexual relations, and being in physical fights. The men in this study did not feel that their impairment challenged

their racial identities. In fact, a couple of respondents commented that it was almost normal to be black and disabled because it was seen as a normative outcome of gang related activity. However, these men did express concern over others' reactions toward their impairments and also discussed concerns for their own safety as they were returning to violent neighborhoods unable to physically protect themselves.

In another study of black males who became impaired as a result of violence, respondents did in fact experience dramatic changes in their social relationships as a result of their impairment, such as loss of family support, loss of friends who were in gangs, and the making of new friends during rehabilitation (Devlieger, Albrecht, and Hertz 2007). While this particular study provides insight into black males experiences, particularly men who become impaired as a result of violence, there is little discussion of how race shapes their disablement process. However because these studies do not use a comparison group, it is difficult to know the extent to which men's experiences were shaped by their race, beyond the social contexts in which their lives were embedded (i.e., inner city and gang participation).

In a study of 10 white men and 10 black men with physical impairments Bender (2006) found masculinity to be a more salient identity following impairment than was race. Overall, Bender found more similarities than differences in how the men in this study constructed their understanding of self as disabled and their views of how this status constrained their participation in society. Both black and white men reported feeling constrained within a structural context of ability, in which their access to employment, the built environment, and marriage was limited. Furthermore, these men discussed having to forgo traditional social expectations of masculinity

within these three contexts, and this in turn led to feelings of emasculation as a result of their impairment.

Finally, one study of learning impaired adults found mixed results when it came to the effect of race on disability experiences (McDonald, Keys, and Balcazar 2007). While some respondents felt their impairment was accepted within their racial/ethnic communities, and did not further isolate them from social interaction, others contended that they were further disabled when interacting with non-disabled others within their racial and ethnic communities, as a result of stigma attached to their impairments. Additionally, as in other studies, marked differences were found in the effect of gender on disablement experiences. Men in this study felt that their impairment prevented them from fulfilling traditional masculine roles, whereas women reported more often than men receiving pity from others. However, unlike in other studies (Sheldon 2004; Gill 1996; Oliver 1990; Vernon 1999; Zitzelsberger 2005; Thomas 1997; Asch and Fine 1992; Hanna and Rogovsky 1991), these women did not receive messages that they should not partner and/or become mothers.

Social Class

Social class is also argued to have a significant impact on the disablement process. It is argued that social class shapes experiences of impairment and the degree of exposure to oppressive social relations (Shakespeare 1996). Social class should have significant implications for the disablement experiences, as one's class should determine the amount of resources one has access to. However, social class is largely overlooked in disability studies (Shakespeare 1996).

Age

Age should also have a significant impact on the disablement process, particularly in conjunction with the timing of the onset of impairment. Experiences with disablement vary greatly across the life course and have different meaning for impaired individuals' lives. Having bodily imperfections is viewed as more problematic during childhood and young adulthood, a time when being physically fit and healthy is valued and normal, particularly for young adults, seen as necessary for labor force participation and reproduction (Priestley 2004; Macfarlane 1994). Furthermore, it is argued that older adults are less likely to be perceived as disabled than are younger adults, as impairment is seen a normative part of aging (Priestley 2004).

However, as with social class, it is difficult to find studies which examine experiences of disablement (and the construction of a disabled identity) across the life course. Among the studies that have been done, some findings suggest that individuals who experience impairment may be different depending on where one is in their life course.

Experiences with impairment earlier in life can shape life course trajectories for young adults. For example, disabled young adults with early onset of impairment are less likely to be employed than those who experience late onset of impairment; a finding the authors partially attribute to the increased likelihood of finishing high school among adults with late-onset impairment (Loprest and Maag 2003). Furthermore, it is argued that barriers to participation in normative age-graded events

such as marriage, parenting, and employment denies impaired persons the premise for building adult identities (Priestley 2004).

While older adults make up a large proportion of mobility impaired adults, they are rarely viewed as "disabled" (Townsend 1981), as impairment is often seen as a normative aspect of aging (Priestley 2000). The belief that impairment is normative in old age may have important implications for identification as disabled among older adults. Individuals who experience the onset of impairment later in life may be less likely to develop an identity as disabled (Zink 1992; Langlois et al. 1996). Using a convenience sample of older adults, aged 65 or older, Langlois and colleagues (1996) found that 21 percent of adults who did not perceive themselves to be disabled were unable to perform at least one ADL and 40 percent had difficulty with at least one ADL.

However, older adults who are impaired also have to contend with ageism, which may impact their experiences of disablement. For example, older adults who are impaired are often denied independence and are likely to experience more social barriers in forms such as unsolicited help from others (Zarb and Oliver 1993; Zarb 1993). Experiences such as this may shape their identification as disabled. In fact, findings from one study indicate that the disablement process among older adults may be similar to that of other age groups. Increased impairment, receiving home health care, and stopping driving increase the likelihood that older adults identify as disabled (Kelley-Moore et al. 2006). Conversely, having social support, satisfaction with their level of social activities decreased the likelihood that older adults identified as disabled (Kelley-Moore et al. 2006). Additionally, this study found older women to

be more likely than older men to identify as disabled, independent of their health status (Kelley-Moore et al. 2006). A limitation of this study is that it does not compare the disablement experiences of older adult to other age groups. Therefore it is difficult to draw conclusions regarding how the disablement process is affected by age.

In sum, despite theoretical claims that experiences of disablement are shaped by larger structural systems, such as racism and sexism, there are limited empirical studies in the literature that provide evidence to support this claim. However, it does appear that gender may operate in distinct ways in shaping the disablement experiences for men and women, and one's gender may be more salient in shaping disability experiences than is race. Social class and age may also be likely to shape disability experiences, however very little is known about the relationship between these statuses and the construction of a disabled identity.

Summary and Research Questions

The goal of this dissertation is to gain a better understanding of how impaired individuals develop a conceptualization of themselves as disabled. As an identity, "disabled" is constructed based on a complex relationship between biology, society, and the individual (Shakespeare 1996). In order to capture how these different processes come together to shape an understanding of self as disabled, a more expansive model is needed.

While the social model of disability added an important contribution to our understanding of disability as a social construction, it has its limitations. First, the model does not provide insight into how bodily experiences of impairment impact the

self. Second, the model was not designed to be a theory of self and therefore cannot operate as such. Third, it fails to integrate other aspects of self, such as race and gender, into the process of disablement.

Using both quantitative data from a nationally representative sample of impaired individuals and data from qualitative interviews with 30 respondents, I will address three research questions: How do environmental and social barriers versus physical impairments affect the claiming of a disabled identity among adults with physical impairments? How do self processes (i.e., social comparisons, self-presentations and reflected appraisals) inform the embracement or rejection of a disabled identity? How is this process influenced by social statuses, such as gender, race, social class and age?

First, I will examine how indicators of disability from the social model of disability, which include environmental barriers in society, measures of social inclusion/exclusion, and indicators from the medical model of disability, which include severity of movement difficulty, activities of daily living (ADLs), instrumental activities of daily living (IADLs), and the use of assistive devices affect the claiming of a disabled identity. Second, I will examine how social and medical indicators of disability are mediated through the self processes to affect the claiming of a disabled identity. In other words, do social and medical indicators of disability affect impaired individuals' perceptions of how others view them in terms of being disabled, and does this in turn affect how they view their Self? Finally, I will examine how gender, race, social class, and age influence this process as a whole.

Examining the construction of a disabled identity using this model may provide a more nuanced picture of impaired persons' experiences and how they come to self-identify as disabled or able-bodied. As illustrated in Figure 1, indicators of disability from the social model of disability should have a direct effect on identification as disabled/not disabled. Additionally, medical model indicators of disability should also have a direct effect on identification as disabled/not disabled. However, some of the effect of both social and medical indicators of disability may be mediated through reflected appraisals (and other self processes). Individuals' daily experiences with environmental and social barriers in their environments, as well as with impairment should provide them with information regarding their position within the social structure, which in turn should affect how they view their self. Finally, this entire process may be affected by individuals' other social statuses, such as their gender, race, social class and age.

[Insert Figure 1 about here]

Chapter 3: Data and Methods

Quantitative Data and Methods

The NHIS-D is a federal survey managed by the National Center for Health Statistics (NCHS). The NHIS-D was initially administered along with the 1994 and 1995 National Health Interview Survey (NHIS) core questionnaire. The NHIS is a cross-sectional household survey used to monitor the health of the U.S. population. The NHIS-D emerged out the 1990 Americans with Disabilities Act, which brought about a need for policy relevant data on persons with disabilities at the national level. The goal of the NHIS-D was to collect data on the medical, social and administrative needs of persons with impairments. The survey was administered to a nationally representative sample of the civilian non-institutionalized U.S. population.

The NHIS-D was conducted in two phases. Collecting the data across two phases was not done to produce longitudinal data but rather to reduce respondent burden due to the large amount of content being collected (Hendershot, Larson, and Lakin 2003). Phase 1 of data collection took place over a two year period. The questionnaire was administered to any available adult in the household who was knowledgeable about household members' health status. Data from Phase 1 served as a screening tool for which respondents were selected to participate in Phase 2. Criteria for selection into Phase 2 were based on responses to items on the Phase 1 questionnaire, the NHIS core questionnaire and the supplemental questionnaire on family resources. Based on these responses, it was determined if respondents fit into policy relevant categories of disability. These categories included a wide range of indicators of impairment, such as, being a disabled child, having polio, using assistive

devices, have ADLs/IADLs/functional limitations, being mentally ill, receiving supplemental security income or receiving social security disability income, and so on. There were over 200 response patterns used to identify disabled persons and flags were placed on these persons' data from Phase 1 to indicate that they were disabled (Hendershot, Larson, and Lakin 2003). A summary of the screening criteria for Phase 2 can be found in Appendix A.

In Phase 2 the questionnaire was administered to any household member identified in Phase 1 as being impaired. If this person was not available or unable to respond for themselves, then a proxy respondent was used to collect information on that person.

The sample for the current study was limited to mobility impaired respondents who answered for themselves in Phase 1 and Phase 2. Mobility impaired individuals were identified as persons who met any of the following criteria: unable to walk, have difficulty walking for a quarter of a mile, walking up 10 steps without resting, standing or being on their feet for about 2 hours, sitting for about 2 hours, stooping, crouching or kneeling by their self or without the use of aids OR if they use assistive devices, such as a walker, scooter, wheelchair, cane or crutches to get around. Because my research questions focus on claiming a self-identity, it is necessary to limit the analytic sample to respondents who self-reported on all measures.

The analytic sample was limited to ages 18-64. Data for respondents aged 17 or younger was collected using a proxy respondent and these cases were subsequently dropped when the data was limited to self-respondents. Additionally, I excluded

respondents who were 65 years of age or older in order to eliminate respondents who were more likely to be disabled as part of the aging process.

There was a were a total of 107,469 respondents who participated in Phase 1 of the 1994 NHIS-D and among these respondents 16,114 also participated in Phase 2. Among the respondents who participated in both Phase 1 and Phase 2, 10,141 respondents were identified as mobility impaired. The sample was then limited to respondents who gave self-reports in both Phase 1 and Phase 2 (N=6,227). The sample was also limited to respondents between the ages of 18-64 (N=3,327). Blacks and whites make up an overwhelming number of cases in the sample (628 blacks and 2,529 whites). The remainder of the sample consisted of Asians, Native Hawaiian or Other Pacific Islanders, American Indian/Alaska Natives (N=170). Because there were so few races other than blacks and whites, it would not be possible to do race comparisons among these other race groups and therefore they were dropped from the sample. The final sample from the 1994 data consisted of 3,157 respondents.

For the 1995 NHIS-D, there were a total of 95,091 respondents who participated in Phase 1 and among these respondents 9,691 also participated in Phase 2. Among the respondents who participated in both Phase 1 and Phase 2, 6,071 respondents were identified as mobility impaired. The sample was then limited to respondents who gave self-reports in both Phase 1 and Phase 2 (N=3,795). The sample was also limited to respondents between the ages of 18-64 (N=2,168). As with the 1994 data, blacks and whites made up a significant portion of the sample (330 blacks and 1,678 whites), therefore only these two race groups were retained. The final sample from the 1995 data consisted of 2,008 respondents.

Finally, the samples from 1994 and 1995 were combined (N=5,165). A standardized sample was created by removing all respondents who were missing any data for the variables of interest (1,807 respondents). The final analytic sample consisted of 3,358 respondents.[9]

Table 3.1 shows the descriptive statistics for the independent and dependent variables for the quantitative sample. Of the 3,358 respondents, approximately 48 percent identified as disabled and 43 percent perceived others to view them as disabled. The majority of the respondents were white (84.8%) and female (68.9%). In terms of education, 24.7% had less than a high school education, 38.9% had a high school degree, 22% had some college, 7.5% had a college degree and 6.8% had a professional degree beyond college. The average income was $17,000-17,999. The mean age of respondents was 46 years old.

[Insert Table 3.1 about here]

Dependent Variable

Disabled identity was measured during Phase 1 using a question which asked "Do you consider yourself to have a disability?" (0=no, 1=yes).[10,11]

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[9] Please see Appendix G for descriptive information on the analytic sample prior to dropping missing data, and the final analytic sample, in which all missing data cases were dropped.

[10] Because of the wording of this question there was some concern that this measure would not adequately capture an identity as disabled. In particular the wording "to have a disability" could be interpreted as merely asking about a social status. A more ideal identity question would ask "Do you consider yourself to be disabled?"or "Do you identify as disabled?" During the cognitive interviews, respondents were probed on their interpretation of this question and rewordings of the question, which placed more emphasis on identity. The majority of respondents interviewed did not recognize any difference in the question intent when asked "Do you consider yourself to have a disability?" versus "Do you consider yourself disabled?" Respondents interpreted both questions as asking about their identity.

[11] The measures for disabled identity, reflected appraisals, demographic data (race, gender, age, education, and income) and employment status were captured in Phase 1; however the remaining variables were measured in Phase 2. Although data collected in Phase 1and Phase 2 was not intended to be used as longitudinal data, but rather as cross-sectional, there is some concern that the lapse in

Independent Variables

Reflected appraisals were measured using a question which asked, "Would other people consider you to have a disability?" (0= no, 1= yes).

Indicators of disability from the social model – Environmental barriers

Environmental barriers in the home were captured using a series of question which asked respondents, "Because of a physical impairment or health problem, do you have any difficulty entering or leaving your home; opening or closing any of the doors in your home? Reaching or opening cabinets in your home; using the bathroom in your home? Responses to each item were coded 1 for yes and 0 for no. Affirmative responses to each of these items were then summed to create a summary measure of barriers in the home.

Environmental barriers outside the home were measured using a question which asked respondents, "Do you have any (other) problems getting around outside your home due to an impairment or health problem?" A dichotomous variable was created based on whether or not the respondent had any difficulty getting around (1=has difficulty, 0=does not have difficulty).

Transportation barriers were measured using a series of questions which asked about respondents' use of public transportation and any difficulties they experienced when accessing public transportation. All respondents were first asked "During the past 12 months, have you used local public transportation, such as a regular bus line, rapid transit, subway or street car?" Respondents who have used public transportation in the past 12 months were asked "Because of an impairment or

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time across phases could introduce potential error into the findings. In order to adjust for this time between interviews is controlled for in the regression analyses.

health problem, during the past 12 months, did you have any difficulty using the local public transportation service?" Respondents who did not use public transportation in the past 12 months were asked, "Does an impairment or health problem prevent or limit your use of the public transportation service?" Based on responses to these questions, a dichotomous measure of transportation barriers was created (0=no public transportation available/uses public transportation and has no difficulty/does not use public transportation and this is not because of their impairment, 1= uses public transportation and has difficulty/does not use public transportation because of impairment).

The availability of *paratransit* services was measured using a question which asked respondents, "Some communities have special bus, cab or van services for people who have difficulty using the regular public transportation service. When using this special service, people can call ahead and ask to be picked up. Is such a service available in your area? (1=yes, 0=no).

Indicators of disability from the social model – social engagement

Although there are no measures in the NHIS that directly measure social barriers, it is possible to examine respondents' levels of social engagement. I examine the number of social activities respondents participate in the previous two weeks, and their level of satisfaction with their social participation. Additionally, marital status and employment status are used as proxies for respondents' social engagement in society. These measures are not ideal measures, as individuals may or may not be less socially engaged because of the lack of opportunity for social engagement as a result of social barriers. More ideal measures would capture social exclusion resulting from

the stigmatization of impairment. Despite this, these measures have been used by others in the literature to capture social engagement among impaired persons (LoBianco and Sheppard-Jones 2007).

Social activity level was measured using a series of questions which asked about respondents' social activities and social relationships. Respondents were asked about activities they had done in the past two weeks. "During the past 2 weeks did you – get together socially with friends or neighbors? Talk with friends or neighbors on the telephone? Get together with any relatives not including those living with you? Talk with any relatives on the telephone not including those living with you? Go to church, temple, or another place of worship for services or other activities? Go to a show or movie, sports event, club meeting, class or other group event? Go out to eat at a restaurant?" (1=yes, 0=no) Responses to these questions were summed to create a measure of social activity level.

Three indicators of satisfaction with social activity level were created using a question which asked "Regarding your present social activities, do you feel that you are doing about enough, too much or would you like to be doing more?" Based on responses to this question, three dichotomous measures were created: *Socializing about enough; Socializing too much; Socializing too little.* The variable "socializing about enough" was omitted from the regression analyses.

Marital status was measured using a question which asked "Are you now married, widowed, divorced, separated, or have you never been married?" A dichotomous variable was created based on responses to this question to indicate whether or not the respondent was married and currently living with their partner (1=

married, 0= not married). Respondents who were married were allowed to indicate whether or not their spouse lived in the household. Because this measure was used in the analysis as an indicator of social inclusion, respondents who were married but not living with their partners were placed in the "not married" group.

Employment status was measured using a question which asked "Do you NOW work at a job or business?" Responses were coded (1= employed, 0= not employed).

Indicators of disability from the medical model

Although I do not directly measure "impairment" in this study, four measures serve as proxies for this indicator of disability: *severity of movement difficulty, ADLs, IADLs, and use of assistive devices.*[12]

Severity of movement difficulty was measured based on responses to questions that asked respondents about the difficulty they had in performing physical tasks. Respondents were first asked: "By yourself and not using aids, do you have difficulty, walking for a quarter of a mile (that is about 2 or 3 city blocks)? Walking up 10 steps without resting? Standing or being on your feet for about 2 hours? Sitting for about 2 hours? Stooping, crouching, or kneeling? Reaching up over your head? Reaching out (as if to shake someone's hand)? Using your fingers to grasp or handle? Lifting or carrying something as heavy as 25 pounds (such as 2 full bags of groceries)? (1=yes, 0=no). Respondents were then asked about the degree of difficulty they had in performing the tasks from the preceding questions: "How much difficulty do you

[12] Although severity of movement difficulty, ADLs, and IADLs may not be ideal measures of impairment, they are widely used indicators of functional limitations, which according to the medical model definition of disablement, stem from impairment. Additionally, previous research has found these indicators to be predictive of health disparities between disabled people and able bodied people (Altman and Bernstein 2008).

have (activity), some, a lot, or are you unable to do it?" In order to construct a measure of severity of movement difficulty, responses to these activities were first weighted to reflect how important these activities are in maintaining an independent lifestyle (Altman and Bernstein 2008). Difficulty sitting for about 2 hours, and stooping, crouching or kneeling were coded as one. Difficulty standing or being on your feet for about 2 hours and lifting or carrying something as heavy as 25 pounds were coded as two. Difficulty with walking up 10 steps without resting, reaching up over your head, and reaching out (as if to shake someone's hand) were coded as three. Difficulty walking for a quarter of a mile and using your fingers to grasp or handle were coded as four. All responses were coded to the level of difficulty and multiplied by the weight of that particular activity. This number was then totaled and divided by 9 (the number of activities). Scores higher than zero were divided into quintiles. The first quintile contained scores greater than zero but less than or equal to .45 and represented the least amount of impairment. The second quintile contained scores greater than .45 but less than or equal to 1.20. The third quintile contained scores greater than 1.20 but less than or equal to 2.23. The fourth quintile contained scores greater than 2.23 but less than or equal to 3.56. The final quintile, contained scores greater than 3.56 and represented the most severe impairment.

ADLs (activities of daily living) were measured using a series of questions which asked "Because of a health or physical problem, do you have any difficulty bathing or showering? Dressing? Eating? Getting in and out of bed or chairs? Getting outside? Using the toilet, including getting to the toilet?" (1=yes, 0=no) Responses to these questions were summed to create a measure of ADLs.

IADLs (instrument activities of daily living) were measured using a series of questions which asked respondents if they had difficulty preparing their own meals, shopping for groceries, managing money, using the telephone, doing heavy yard work, and doing light yard work (1= yes, 0=no). Responses to these questions were summed to create a measure of IADLs.

Use of assistive devices was measured using a series of questions which asked, "During the past 12 months, did you use any of the following medical devices or supplies? Crutches, a cane, a walker, a wheelchair, a scooter?" A dichotomous variable was created based on whether or not the respondent used any of these types of assistive devices (1=uses assistive devices, 0=does not use assistive devices).

Social statuses

Gender was recorded based on interviewer observation. It is a dichotomous variable, in which 0=male, 1=female. *Race* was measured by respondents' self report of their race (0=white, 1= black). Education and income served as measures of social class. *Education* is measured in years of schooling completed. Items were recoded so that 1= less than high school, 2= high school diploma 3= some college, but no degree, 4= college degree and 5= professional degree beyond college. *Income* is measured based on self-reported family income. The NHIS-D has constructed measures of income. The measure used in this study ranged from less than $1,000 - $50,000 and over (0= less than $1000, 26=$50,000 and over). There were 645 missing cases for income, and these were imputed using the mean income level for education. *Age* is measured in number of years.

Interaction Terms

Two-way interactions terms were created by interacting gender, race, poverty and age group with all indicators of disability from the social and medical models. In order to construct interactions the continuous age variable was replaced with a dichotomous measure of age, labeled *age groups* (0=persons between the ages of 18-44 and 1=45-64). Additionally, the continuous measure of income was replaced with a dichotomous variable which captures whether or not respondents were living in poverty. Persons living in *poverty* is measured using a dichotomous measure constructed by NCHS, where 1= income at or below the poverty threshold and 0=income above the poverty threshold.

Controls

Length of time between interviews is a variable constructed by NCHS based on the date of the Phase 1 interview and the date of the Phase 2 interview. This variable was measured in days.

Qualitative Data and Methods

Data from 30 in-depth interviews were also used to answer the research questions. The interviews were conducted in the Questionnaire Design Research Laboratory (QDRL) at NCHS as part of a larger cognitive interviewing study to develop new questions which ask about environmental and social barriers that lead to disablement on federal health surveys. Five researchers (4 women, including myself, and 1 man) conducted the cognitive interviews. Respondents were recruited through a newspaper advertisement placed in the Washington Express Newspaper. See

Appendix B for a copy of the recruitment flyer/advertisement. Individuals who were interested in participating in the study left their contact information (name and telephone number) on the QDRL answering machine. The QDRL Laboratory Manager then called the individual back and determined through a set of screening questions if the individual possessed the desired research characteristics which parallel those in the nationally representative sample. See Appendix C for a copy of the telephone screener. If the individual possessed the desired research characteristics and was willing to participate, he/she was scheduled for an interview.

The sample for the qualitative interviews consisted of people with mobility limitations aged 18 to 67. Mobility limitations are defined as the inability to walk or having difficulty walking for a quarter of a mile, walking up 10 steps without resting, standing or being on their feet for about 2 hours, sitting for about 2 hours, stooping, crouching or kneeling by their self or without the use of aids or using assistive devices, such as a walker, scooter, wheelchair, cane or crutches to get around. This sample differed from the quantitative sample in the two ways. First, unlike the quantitative sample, this sample consisted of an almost equal number of women and men. Second, while the quantitative sample was predominately white, the sample from the qualitative interviews was predominately African American. However, the two samples were fairly consistent in terms of education, income, and age. See Table 3.2 for information on the qualitative sample characteristics.

[Insert Table 3.2 about here]

Interviewers employed cognitive interviewing techniques, in which questions were administered, followed by in-depth probing regarding respondents comprehension of the question and their response processes. Cognitive interviewing is a method used to evaluate survey questionnaires, specifically, by examining the ways in which respondents interpret and processes survey questions (Willis 2005; Tourangeau, Rips and Rasinksi 2000). As a qualitative method, cognitive interviewing provides detailed insight into patterns of error as well as patterns of interpretation and calculation that respondents use to answer questions.

The purpose of using cognitive interviewing was twofold. First, as a qualitative method, it elicits respondents' narratives, which allowed me to gain insight into respondents' experiences with environmental and social barriers, physical impairment, and their self processes. Additionally, this method allowed me to test the questions that were used in the quantitative analyses, which provided me with a better understanding about how these questions were operating and whether they were capturing the kinds of information I intended to measure in the quantitative analysis.

Interviews were conducted in a private room in the QDRL at NCHS, and lasted 60 minutes. Prior to the start of the interview, participants were asked to read informed consent documents which allowed for recording of the interview. A copy of the informed consent form can be found in Appendix D. The interviewer then asked the participant to confirm that he/she understood the information in the informed consent, and were then asked again for permission to record the interview. Next, respondents were asked to fill out the demographic information form. A copy of the demographic information form can be found in Appendix E. Following this,

interviews began with an overview about the purpose of the study. Each interview was conducted using the same semi-structured questionnaire (see Appendix F for a copy of the interview protocol). After the interview, participants were given the thank-you letter signed by the director of NCHS, a copy of the consent form, and $40.

Analytic Plan

Three sets of analyses were conducted to answer the research questions. The first set of analysis examined the prevalence of indicators of disability from the social model and medical model among respondents who identified as disabled and those who did not. Independent sample t-tests were used to determine if respondents who claimed a disabled identity experienced more environmental and social barriers and greater impairment than did respondents who disidentified as disabled.[13] Additionally, t-tests were used to determine if respondents who claimed a disabled identity and those who did not varied in terms of demographic characteristics. Next, a series of logistic regressions were conducted, which examined the relationship between environmental and social barriers, and impairment, and claiming a disabled identity, controlling for social statuses. In the first model, claiming a disabled identity was regressed on indicators of disability from the social model. In the second model, indicators of disability from the medical model were entered into the analyses. The relationship between environmental barriers, social barriers, impairment and claiming an identity as disabled was also examined in the qualitative analyses.

[13]In all quantitative analyses, data were weighted for differential probabilities of selection and poststratification (Lee and Forthofer 2006).

In the second set of analyses, I examined whether reflected appraisals mediated the relationship between social and medical model indicators of disability and claiming a disabled identity, using logistic regression.[14] Sobel tests were used to determine if the mediation by reflected appraisals on the relationship between social and medical model indicators and identifying as disabled was significant (see MacKinnon and Dwyer 1993; Preacher and Hayes 2004). In order for mediation to occur three conditions must be met. First, claiming a disabled identity was regressed on the main independent variables (social model indicators and medical model indicators) (Path C). Next, reflected appraisals are regressed on social model and medical model indicators of disability (Path A). Finally, controlling for social and medical model indicators of disability, claiming a disabled identity is regressed on reflected appraisals (Path B). If the direction predicted appears, and the effect of social and medical model indicators on disabled identity is less when reflected appraisals is added to the model that when it is absent, a mediating effect is present (Baron and Kenny 1986). A SAS macro developed by Jasti and colleagues (2008) was used to calculate Sobel tests of mediation. Findings from the qualitative data were used to supplement these findings as well. In the qualitative analysis I explored not only the role of reflected appraisals in the construction of identities, but also the roles of two other self processes: social comparisons and self-presentations.

[14] To test for multicollinearity in the full regression model, two series of diagnostic testing was completed. First, VIF tests were calculated for each variable in the model. The results did not show signs of multicollinearity. Second, bivariate correlations were calculated among all variables in the model. Only two variables had correlation coefficient that could possibly suggest collinearity (ADLs and IADLs; $r = .730$). It is not surprising that these two variables were correlated as they are both indicators of functional limitations. In order to determine if multicollinearity was present in the model due to these two variables, I ran the full model once without the IADLs variable and once without the ADLs variable. This had no effect on the coefficient values or significance levels. Therefore, as they are commonly used as separate measures in past research (, I decided to keep both measures in the full model.

Finally, I examined whether the relationship between social and medical model indicators of disability, reflected appraisals and claiming a disabled identity varies depending on one's social statuses. Using a logistic regression I examined the main effects of social statuses on claiming a disabled identity. Next, separate regression models were conducted for the two way interactions between gender, race, class, and age and social model indicators of disability and medical model indicators of disability. In addition, regression models were run on subgroups of the analytic sample (i.e., women, men, blacks, whites, persons in poverty, persons not in poverty, low education, high education, young and old). Finally, using data from the qualitative interviews I examined the influence of gender on claiming an identity as disabled identity. Because of the nature of the qualitative sample, I was only able to examine the relationship between gender and the disablement process.

The qualitative data was analyzed using the constant comparative method (Lincoln and Guba, 1985; Strauss and Corbin, 1990; Creswell, 1998). The constant comparative method involves the simultaneous practice of performing a systematic coding of the data and analysis to generate theory. This process involved four steps. First, I reviewed the data and assigned codes to categories found in the data, while simultaneously comparing data that fell under the same categories. Through these comparisons I could then begin to see the dimensionality of categories, that is, the range of properties that fall under a particular category, as well as potential conflicts between items placed under the same category. Over the course of this process I could then start to see how categories were integrated to form a theory about the patterns found in the data. Finally, categories were then constructed into a working

theory (Glaser and Strauss 1980). Q-Notes, a qualitative analysis software program developed by NCHS, was used to organize and analyze the qualitative data.

Chapter 4: Experiences of Environmental and Social Barriers, Impairment, and Identity Claims

The first research question I examined was: How do environmental and social barriers in the environment versus physical impairments affect the claiming of a disabled identity among adults with physical impairments? In order to assess the relationship between environmental barriers, social barriers, impairment and claiming an identity as disabled, a comparison of means and logistic regression analyses were performed. In addition, narratives from the cognitive interviews were analyzed to supplement findings found in the quantitative analyses. This chapter will discuss the findings from each method.

Quantitative Findings

In the quantitative data, 1,618 respondents self-identified as disabled and 1,740 respondents did not identify as disabled. Significant differences were found between these groups in terms of their encounters with environmental and social barriers and level of impairment (see Table 4.1). Respondents who self-identified as being disabled were significantly more likely to have environmental barriers in the home ($t=12.38$, $p<.001$) than were respondents who did not identity as disabled. Additionally, respondents who identified as disabled were more likely to experience environmental barriers outside the home ($t=15.61$, $p<.001$), and transportation barriers ($t=7.90$, $p<.001$) than were respondents who did not identify as disabled.

[Insert Table 4.1 about here]

Respondents who identified as disabled were also less socially engaged than respondents who did not identify as disabled. Respondents who identified as disabled participated in fewer social activities ($t=-9.13$, $p<.001$), and regarding their satisfaction with their current social activity level, were less likely to consider themselves to be socializing about enough ($t=-2.72$, $p<.01$), and were more likely to consider themselves to be socializing too little ($t= 3.77$, $p<.001$) in comparison to those who did not identify as disabled. Respondents who identified as disabled were also less likely than those who did not identify as disabled to be married ($t=-2.72$, $p<.01$) or employed ($t=-16.34$, $p<.001$).

In terms of medical model indicators of disability, respondents who self-identified as disabled reported greater levels of impairment than did respondents who did not identify as disabled. Respondents who identified as disabled reported more severe movement difficulties ($t=21.52$, $p<.001$), more difficulty with ADLs ($t=14.3$, $p<.001$) and IADLs ($t=16.63$, $p<.001$), than did those who did not identify as disabled. Respondents who identified as disabled were more likely to use an assistive device ($t=9.04$, $p<.001$) than were respondents who did not identify as disabled.

In the next set of analyses, using a series of logistic regressions, I examined how environmental barriers, social engagement, and impairment, affected claiming an identity as disabled, controlling for social statuses (see Table 4.2). First, I examined the association between claiming an identity as disabled and environmental barriers and social engagement. As the number of environmental barriers in the home increased, so did the odds that respondents would identify as disabled (OR = 1.38, $p<.001$). Additionally, respondents who encountered environmental barriers outside

the home had an increased odds of identifying as disabled compared to those who did not experience these barriers (OR = 2.42, p<.001). Neither environmental barriers in transportation, nor the availability of paratransit, were significantly related to identifying as disabled.

[Insert Table 4.2 about here]

Social engagement was also related to whether or not impaired respondents identified as disabled. First, the more social activities respondents participated in, the lower the odds that they would identify as disabled (OR = .91, p<.01); however, no relationship was found between satisfaction with social activity level and identifying as disabled. Finally, no relationship was found between marital status and claiming an identity as disabled; however, respondents who were currently employed had lower odds of reporting that they were disabled compared to those who were not employed (OR = .42, p<.001).

The second model introduced medical model indicators of disability into the regression analysis. More severe movement difficulties (OR= 1.42, p<.001) and more difficulty performing IADLs (OR=1.24, p<.001) both increased the odds of identifying as disabled. The addition of these variables also decreased the significance of some of the social model indicators, and in some cases reduced the effects of those indicators to non-significance. For example, with the introduction of these measures, environmental barriers in the home were no longer significantly related to identifying as disabled and the relationship between social activity level and claiming a disabled identity decreased in significance (OR = .94, p<.05). Experiencing barriers outside the home continued to be positively and significantly related to identifying as

disabled; however, its effect decreased from the previous model (OR = 1.51, p<.01). The association between employment and claiming a disabled identity remained strong (OR=.48, p<.001).

The findings from the quantitative analyses support previous studies which found that not all impaired individuals claim an identity as disabled (Priestly 1999; Watson 2002; Taub, McLorg and Fanflik 2004, Watson 1998; LoBianco and Sheppard-Jones 2007, Iezzoni et al 2000). Additionally, these finding support previous research which show indicators of disability from the social and medical models influence the claiming of a disabled identity (LoBianco and Sheppard-Jones 2007; Watson 2002; Priestley 1999). In the next set of analyses I examined how indicators of disability from the social and medical model influence the claiming of an identity as disabled using data from 30 qualitative interviews.

Qualitative Findings

The Negotiators

A significant and unique finding that emerged from the qualitative interviews was that there were not two identity groups but three identity groups: the identifiers - those who identified as disabled (N=19), the disidentifiers - those who did not identify as disabled (N=7), and the negotiators - those who were still negotiating this identity (N=4).

Respondents who were placed in the identifier and the disidentifier groups were respondents who consistently throughout the interview discussed their own self-identification or disidentification with a disabled identity. Conversely, respondents

who were placed in the negotiator group vacillated between identifying as disabled and disidentifying as disabled during the interview. Some of these respondents simply could not give a definitive response to questioning of whether or not they considered themselves disabled. For example, when first asked this question one woman stated,

> "Yes and no. I do have a disability but I don't want to deal with it. I make myself go as far as I can. I don't like putting it out there." (Clair, a black woman in her 60s)[15]

Other respondents initially gave a definitive response; however, later during the interview they identified with the opposite identity and discussed why they identified as disabled and disidentified from a disabled identity. For example, a black woman in her fifties initially reported that she considered herself to have a disability because she has a diagnosed, debilitating condition that limits her ability to perform everyday tasks. However, upon further discussion she revealed that she doesn't always identify as disabled, and in fact at times she is very resistant to that identity. She ultimately described herself as "not totally disabled."

These respondents were labeled "negotiators," as identity theory dictates that individuals strive for self-verification (Burke 1991). In Burke's identity theory, it is theorized that individuals are likely to experience positive emotions when their identities are verified, however, when an identity standard is not achieved, individuals experience negative emotions and will attempt to alter their behavior to bring others' responses to their enactment of an identity back in line with the individual's identity standard (Burke 1991). If this cannot be done, individuals are likely to abandon their identity claims, and claim identities that can be verified. Therefore, individuals who

[15] All names used are pseudonyms.

do not have a stable identity as either disabled or not disabled, are likely to continue to negotiate this identity until they eventually receive enough verification for one identity or the other. However, because the data used in this study is not longitudinal I cannot determine which identity group these respondents will end up in, and therefore label them as the negotiators.

Experiences of Environmental Barriers, Social Barriers, and Impairment

In the following section I analyze the qualitative data using the integrated theoretical approach of social and medical models. First, I discuss the prevalence of encounters with environmental and social barriers across the three identity groups. In addition, I examine the degree to which respondents are impaired using indicators of disability from the medical model across the three identity groups. Finally, I examine how experiences of environmental and social barriers and impairment were meaningful in shaping respondents' identity claims.

Social model: Environmental barriers experienced by the respondents

Almost all of the respondents discussed experiencing environmental barriers in both their homes and outside of their homes on a daily basis. Environmental barriers within the home included things such as, heavy and/or manual doors, narrow doorways, steps/stairs, a lack of handrails along walkways, stair cases, and long hallways, as well as inaccessible bathrooms and kitchens. Additionally, some respondents also experienced barriers outside of their home, including inaccessible buildings, and barriers having to do with the landscape, including steep ramps and hills, uneven sidewalks, potholes in the street, curbs with no cutouts, incomplete ramps/curb cutouts, and slippery surfaces in the wintertime. Although these

respondents did note that although most buildings now have automatic doors and ramps to gain entry, once inside these building other areas are often not accessible.

> "They put ramps that I can gain entrance around if nothing else. I noticed that the old buildings, once I get in there, the bathroom isn't. You know, it just has the ramp. It's not full accessible. It's just I can gain entrance to the building….they don't have elevators. They might be like three stories and they just have a ramp so you can gain entrance to the building. But once you in there the elevators might be small. They're for three people to stand in or- I mean I've run into that a lot of times, unless they've been modernized. Once you gain entrance that's it. I can gain entrance but that's the only access I have." (Shawn, a black man in his 40s)

In terms of transportation, respondents also noted significant improvements in the DC area public transportation system which made transportation much more accessible. However, despite these improvements in accessibility respondents still experienced numerous barriers. The most common accommodation respondents cited when discussing transportation was the addition of lowering or kneeling capability to public buses that place the entrance to the bus at ground level, and/or lifts that lower down to accommodate those who cannot use the steps. Buses were one of the most common forms of transportation used among the respondents I interviewed and this feature was invaluable to them; however, when these features were not available on buses or were broken, accessibility was greatly decreased. One respondent describes here the difficulty and frustration he experiences when lifts are not available on public buses.

> "Some buses don't have a flat lift… some buses have steps and it's difficult for me to raise my leg up to step up on and carry my walker on. And some of them don't have that lift to bring the bus down and that can be more hard for me to get up on when they don't have that. I hate those buses with steps." (Lou, a black man in his 50s)

Although the subway system was one of the least common modes of transportation used among the respondents I interviewed, elevator and escalator outages at subways stations were actually the most commonly cited barrier to transportation. During elevator outages riders are forced to use escalator or stairs in order to gain entry/exit to/from the station, or they must take a shuttle bus to their desired destination.

Among respondents who drove, issues with the availability and accessibility of handicapped parking were common complaints. Although handicapped parking is provided in most places, respondents reported that it is at times difficult to find open handicapped parking spots, or handicapped parking is inconveniently located.

Respondents also discussed experiencing environmental barriers in the workplace, such as inaccessible bathrooms. For example, one respondent described how she often cannot access the bathroom at work because the door to the actual bathroom is so heavy.

> "I have struggled with the door by myself. I've ended up having to call or wait for somebody to pass by and ask them to open the door. Once I'm in I'm fine and getting out is okay 'cause you can just kind of kick it (the door). That's the only good thing about wearing a prosthesis. You can kick things really, really hard." (Beth, a white woman in her 30s)

However, once inside the bathroom, she has no problem accessing the stalls or sinks.

Many respondents reported that they quit their previous jobs as the work became too strenuous. These respondents were previously employed in a variety of sectors, including retail, manual labor, education (i.e., teachers, coaches), law enforcement (i.e., prison guard, crossing guard), healthcare (i.e., home health aide),

all of which required them to be on their feet for extended periods of times and/or perform manual tasks. In addition, their places of employment did not provide accommodations in terms of places to sit and rest, nor adequate breaks.

Finally, respondents also cited environmental barriers as reasons for why they do not participate in social activities. For some respondents the inaccessibility of the built environment prevented them from fully participating in activities that they once enjoyed. Respondents discussed wanting to go particular places, such as family members' homes, sporting events, restaurants, shops, theaters, etc., but because accessing these places often involved climbing steps these respondents are often unable to go. One respondent describes this experience,

> "I'm going to tell you about a place I like but I don't like going there because, 'cause all of the old buildings, Georgetown. Georgetown is an obstacle for a person in a wheelchair 'cause all those old buildings. And unless the entrance is right to the street you have to go up a lot of steps or it's going to be some work put in to gain entrance to some of those shops- a lot of those shops in Georgetown… A lot of those shops I would go in and spend some money but a therapist once warned me years and years ago just said 'if you can't gain entrance into a place or a residence by yourself don't get nobody to pull you up no steps because if something happened to you… it just be bad on my behalf to get in a situation like that." (Shawn, a black man in his 40s)

Crowds also limited some respondents' ability to participate in social activities. For example, one respondent who must rely on a wheelchair to be mobile feels anxious about his ability to be prepared and to feel safe in crowded places.

> "I don't like being around large crowds when I'm sitting in this chair. Like going out to clubs or big venues or big events I don't- I don't feel comfortable. 'Cause stuff happen too fast and the element of surprise I'm not ready for that sitting in this chair, no big event. So I turn down a lot of invitations to go hang out…" (Shawn, a black man in his 40s)

Respondents also cited inaccessible transportation as another environmental barrier to their social activities. As mentioned earlier, respondents often had difficulty accessing public transportation for reasons such as, broken lifts, elevator and escalator outages, and the availability and convenience of handicap parking. For some, these barriers in transportation limited their ability to be socially active.

Social model: Social barriers experienced by the respondents

The vast majority of respondents from the qualitative interviews reported experiencing some degree of social barriers. For some, this entailed strained interactions with able bodied others, or stigmatization. Many respondents also report a decrease in the amount of social activities they participated in since the onset of their impairment. Additionally, most of these respondents reported that they were not satisfied with their level of social activity and would like to be doing more. Respondents attributed their social exclusion to a number of factors, including environmental and social barriers and the impairment itself.

First, some respondents reported strained interactions when simply walking down the street or accessing public transportation. In particular, respondents discussed having to negotiate interactions with able bodied others who would become impatient with their limited mobility and slow pace.

> "Like walking down the street and people see you walking with a cane but they expect you to move out of the way. And they tell you sometimes 'hey, move out of my way!'" [He makes a face and lifts up his cane.] "Hey this hurts! …I could name a whole lot of specific events but… it's sort of like 'You're in the way. Get out of the way. You're moving too slow, move out of the way.' Here's a constant phrase, 'You see me walking with this cane, don't you?' That's a constant phrase… like number one on my hit list right now." (Ben, a black man in his 50s)

This same respondent discussed how able bodied others don't pay attention in general to those around them when walking down the street.

> "People don't pay attention. They talk on their cell phone, walk down the street and you have to stop and kind of put your cane out and poke them… you have to be like wait a minute, pay attention to where you're going. Because they will walk right over you or just stand there… they behind you, they get impatient. They're in front of you, they act like you're not there. There's all kinds of stuff. They're ridiculous."

Respondents also discussed strained interactions with able-bodied others when accessing public transportation. As in the case of one respondent who reported that on the day of her interview other riders were too impatient to wait for the lift to lower so she could access the bus. Instead these riders lifted her walker up onto the bus and then helped her up the stairs. Although she stated that she didn't mind this and considered these riders to be helpful, the interaction is interesting from a sociological standpoint. This interaction is a quintessential example of disabling interaction from a social model standpoint; however this woman does not recognize it as such. Additionally, this respondent mentioned that when the automatic lifts were not working on buses, she will often tell the driver to go on and that she will wait for another bus.

> "People are in a hurry to get home, so I don't even bother." (Phyllis, a black woman in her 60s)

Other respondents also discussed how other bus and subway riders, who were able bodied, grew impatient when respondents needed accommodations. For example, one woman with a prosthetic leg described herself as having balance issues even on "good days" and because of this she must plant her feet wide to stabilize

herself when riding the subway – a behavior that other riders do not always appreciate.

> "Metro can be pretty- I don't know if you take the metro but it's pretty rocky at times. And I'm not uber stable on my feet. So I really have to kind of like hang on to the rail, you know hang onto one of the poles or straps pretty solidly and kind of plant my feet pretty far apart, which in a crowded metro train some people don't appreciate. But I'm like that's fine, you can fall against my prosthesis. I'm not going to feel it, so knock yourself out. [Laughs]" (Beth, a white woman in her 30s)

Respondents also noted that even when accessibility services were provided, able bodied others did not respect impaired persons' essential need for these services. For example, some respondents noted that even when elevators at the subway stations are working it can be, at times, difficult to gain access to one, due the number of people, particularly able bodied others, using them.

> "The elevator (in the subway station) sometimes it says that people with disabilities and the elderly go first, and you know they just….sometimes waiting and waiting for the elevator and when it comes there are about six people on there, sometimes teenagers sometimes business people who just didn't want to walk the stairs… the escalator might be broken in the station so they use the elevator and they don't give people in wheelchairs priority to get on." (Diane, a black woman in her 50s)

A number of respondents also expressed frustration with able bodied others sitting in the priority seating on buses and subways and not giving up their seats for impaired or elderly persons.

> "Now on the front of the bus and the train there's a section that says seniors and persons with physical disabilities. And the people will sit there and just look at you. You know? And they see you having difficulty standing up…." (Rodney, a black man in his 50s)

Finally, although paratransit was the primary form of transportation for many of the respondents I interviewed, almost half of these respondents also found this

service to be extremely unreliable. Complaints about this service included being picked up too early, too late, or not being picked up at all, being left places, drivers getting lost, and witnessing drivers abandoning other riders when they could not find the pick-up location. Respondents described this service as "a headache to use," "the luck of the straw [*sic*] (in terms of reliability)," "a pain in the butt," and their "last form of transportation." Furthermore, in order to use these services respondents have to plan ahead and schedule rides, sometimes weeks in advance. Some respondents, who could have benefited from this service, opted out of it completely, as it prevented them from being spontaneous.

Respondents also experienced social barriers in the workplace. Several respondents were asked to leave jobs or felt they were denied jobs because of their impairment. For one respondent this occurred when he reapplied for his own job after taking a leave of absence for rehabilitation. This respondent reported that when he reapplied for his job he was told that his position, which he had held for 10 years, was no longer available but if wanted, he could take a different position beginning at starting salary. When asked if he thought this was due to his impairment he stated the following,

> "Yeah, for the simple fact that I wasn't the person that I was before. Because now I'm walking with a cane. And I couldn't do, well I could still do it but there are certain things that I couldn't do and I guess they felt like- well I was always in the public so I guess they had an idea that it didn't look good for a company image while I'm walking around with this cane and not able to do the things that I used to do. Plus I was on medication at the time because pretty much I wasn't strong as I was before I had the accident. They didn't come out and say it but I've heard it from a few people who still work for them…" (Ben, a black man in his 50s)

However, one respondent reported being told outright that an employer would not hire her due to her impairment.

> "I went to work at some fast food restaurant and I had on my brace and the lady was like 'well we would hire you but you might have problems keeping up with other workers.' That's discrimination! To me." (Patty, a black woman in her 50s)

Others also suspected that they could not find work because of their impairment, however they noted that employers are not going to out-right tell someone that they would not hire them because of their impairment. Others felt their impairment was so stigmatizing that they might not be able to find work, unless they could somehow hide the fact that they were impaired.

In terms of interpersonal relationships, respondents also discussed having difficulty maintaining their existing friendships following their impairment. Often this was the result of respondents' inability to participate in the same activities they engaged in with their friends prior to their impairment.

> "I am much less social than I used to be. Just because I tire so easily. I used to go out dancing. I can't do that. I can't dance period. But I can't stay standing in a night club for six hours straight anymore. And it's amazing how many friends you'll lose when you can't do that. I used the night club example but it could be friends who used to go on long dog hikes, you know, hikes through the woods with the dogs kind of thing. It is isolating." (Beth, a white woman in her 30s)

> "…my other friends I don't even care to be around too much. Because they basically like to do other things. They like to play ball, this and that. Saturday morning, this and that. Things that I normally used to do, I can't do. So I just prefer not to even, you know, to be in their way. Put it like that. But they still my friends and I still care for them. You know, they care for me but… you now it's not the same." (Jamal a black man in his 40s)

Some respondents expressed frustration with how their friends interacted with them following their impairment, as they perceived their friends' behaviors toward

them to be ignorant and demeaning. For example, the respondent cited above expressed frustration that he constantly has to tell his friends that he can no longer participate in activities they used to do together, such as going to play basketball. Conversely another woman found her friends to be accommodating after her impairment, however to the point of being demeaning. She expressed here how her relationship with them has changed since becoming impaired.

> "Well we do have friends that come over and I mean I'll come out and sit in the living room or in the dining room, you know, with them and we be joking around and it's entertaining but other than that I really don't do anything… I sort of feel like I don't fit in. You know, to what they're doing… I can't do some of the things that I used to do and feel comfortable." (Phyllis, a black woman in her 60s)

She goes on to discuss how her friends' excessively accommodating behavior can make her feel "helpless" and like "an invalid." Finally, some respondents found it difficult to form new relationships following their impairment, particularly intimate relationships.

In addition to strained interactions with friends and family members following their impairment, respondents also discussed experiencing stigmatization from strangers that limited their participation in social activities in general. In particular, several respondents discussed being stared at by able bodied others when out in public. This behavior made some respondents so uncomfortable that they avoided these situations altogether. For example, one respondent gave up going to the gym, an activity that she once enjoyed, because she could not handle the staring.

> "I used to love going to the gym and swim. I don't do that anymore. I did it once and got- I was just stared at horrendously the whole time that I was there. I could never subject myself to that again." (Beth, a white woman in her 30s)

Medical model: Respondents' experiences of impairment

Impairment itself was significant factor in these respondents' lives, and respondents often attributed difficulty they had moving around and socializing with others to their impairment, rather than to environmental and social barriers.

First, some respondents attributed the difficulty they had moving around in their home to their impairment, rather than to the structural features of their home. For example, when asked about any difficulties she had accessing her kitchen, instead of attributing these difficulties to the structural design of the kitchen one respondent attributed it to her own mobility limitations.

> "I have a little trouble at times, just reaching, you know, certain cabinets, and bending over. It's nothing wrong with how the kitchen's set up. It's just more me, bending over and having to reach and how my back may be aching and maybe my legs giving me a hard time." (Kate, a multi-racial woman in her 30s)

On a similar note, while some respondents had made modifications to their home, these did not always fully alleviate the difficulty they experienced when moving around their home. For example, one respondent who had the most extensive modifications made to her bathroom out of all of the respondents interviewed, continued to have difficulty bathing. She discussed how no amount of modifications was going to alleviate the level of difficulty that she experienced when bathing as this difficulty is stemming from her physical ability to bathe herself, not to accessing the bathtub (Gayle, a black woman in her 50s).

Similarly, some respondents attributed the difficulty they experienced moving around outside of their home to their impairment itself, and not to environmental

barriers. For example, when asked about difficulty she had when getting around outside her home, one respondent discussed the following:

> "Walking is a big difficulty. I can't walk for long periods of time… So that limits my leaving – that just limits my leaving the house period. As I said I've been where I am for almost two years now and because I don't go anywhere because of the inability to walk and get around… It just makes getting around difficulty at a certain point, when you have a disability, going out is not something you really want to do, you know? I actually don't leave the house unless I absolutely positively have to." (Nicole, a black woman in her 40s)

Furthermore, some respondents noted that the difficulty they experience when moving around outside the home depended on the degree of pain they were experiencing on a particular day. Some days they can access a lot of places if their pain is managed, on other days they may not be able to leave the house at all. As one respondent put it,

> "It depends on the degree of pain I'm experiencing. Some days are better than others. Rainy weather particularly brings pain." (Marcus, a black man in his 40s)

Finally, some respondents attributed the difficulty they had in accessing public transportation to their impairment itself. For example, one respondent attributed the difficulty that he has accessing the bus to his impairment alone. He notes that the bus has modifications to make accessing it easier for people with mobility problems; however because of the weakness in his body and the balance issues he experiences, gaining access to the bus can still be a challenge.

> "Yes I have difficulty like getting on the bus. Even though they have a hydraulic lift, it's just me because of my balance and stuff. Yeah I do have problems sometimes. It's not because of the vehicle itself. It's because of me. I just be weak at times." (Lou, a black man in his 50s)

Respondents had very real experiences with impairment that also prevented them from fully participating in social activities, aside from environmental and social barriers they experienced, such as the inability to walk, stand, or sit for extended periods of time and the pain and fatigue they experienced as a result. For some respondents pain meant that they had to cut their activities short.

> "I'd like to be able to go out and eat and be able to sit and have a nice lunch or brunch or whatever the case may be without being in pain. Be comfortable. Be relaxed and don't have to rush back home. Just relax. You know? I don't like having to get McDonalds all the time and then run home because I can't sit at a restaurant and eat. Sitting too long, that's when it bothers me." (Kate, a multi-racial woman in her 30s)

Pain also meant that respondents had to change the type of activities they participate in, giving up activities that they once enjoyed.

> "I used to go to movies a lot more and dinner, stuff like that, all those social events that are going on downtown or at RFK stadium, just different things like that I used to go to I don't do. Because it seems like it can be kind of painful for me to get around and I used to do all that stuff" (Otis, a black man in his 50s)

For others pain meant that they had to limit the amount of activities they could do in a day.

> "Because of the pain in my knees and my back it kind of prevents me from doing- well I get tired easily now. I come home and I would like to keep going. I really would." (Olivia, a black woman in her 50s)

Conversely, for others, it meant that they might be confined to their homes for days at a time.

> "Some days my hip give and my back gives out. So I might be stuck inside two days, three days." (Ben, a black man in his 50s)

Experiences of pain and immobility also stopped some respondents from participating in athletic activities, such as playing sports, walking, running, and dancing. For example, several respondents reported not being able to dance since

becoming impaired, because they no longer have the strength, balance, and stamina to do so.

> "I can't dance anymore... That was my favorite activity. I can't go out dancing. All I can do it sit down and watch other people dance." (Ben, a black man in his 50s)

Claiming a Disabled Identity: The Relationship between Experiences of Environmental Barriers, Social Barriers, and Impairment

Next, I examined how common these experiences were across the three identity groups. In terms of environmental barriers, very few differences were found among the three groups; however respondents who identified as disabled were slightly more likely to experience social barriers in transportation, the workplace, and when socializing that those who do not identify as disabled, and respondents who were still negotiating this identity were less likely to experience social barriers in transportation than those who identified as disabled but were similar on other measures of social barriers (see Table 4.3). The degree to which respondents were impaired was examined using respondents' self-reported difficulty with particular movements, including walking a quarter of a mile, walking up 10 steps, reaching out and lifting weight. In addition, I examined whether or not respondents used assistive devices. Respondents who identified as disabled had slightly more mobility limitations than those who disidentified as disabled and those who were still negotiating this identity. Respondents who identified as disabled or were still negotiating this identity were more likely to use assistive devices and were more likely to have a diagnosis that led to their impairments than were respondents who disidentified with this identity.

[Insert Table 4.3 about here]

In addition to examining the prevalence of environmental and social barriers and impairment among the three identity groups, I also examined how meaningful these experiences were in shaping respondents' identity claims. Despite numerous experiences of environmental barriers in their everyday lives, respondents did not discuss these factors when describing their identification process. Indeed only five respondents out of 30 did so. Respondents did, however, consider social barriers even if they did not experience them frequently. In fact, stigmatization and social exclusion (i.e., decreased socializing, losing friends, difficulty dating, being refused employment etc.) played an important role in some respondents' rejection of or resistance to identifying as disabled.

An important distinction in how social barriers mattered for respondents' identification was found between respondents who identified as disabled and those who disidentified or were still negotiating this identity. Respondents who identified as disabled experienced more instances of social barriers than respondents in the other two identity groups, however, they were also more accepting of their impairment. These respondents often discussed the process by which they came to accept their physical limitations and what this meant for their everyday lived experiences. When it came to social barriers and stigma, experiencing these things made this group of respondents feel bad about their selves, and like other identity groups they sought to avoid these experiences when possible. However, because of their experiences with greater impairment, their acceptance of the limitations, and other factors such as the interactional contexts, experiencing social barriers did not lead them to want to

change their identity claims. Conversely, for respondents who did not identify as disabled or who were still negotiating this identity, experience of social barriers, and even the thought of potentially experiencing social barriers was a critical factor in shaping their disidentification with this identity. This finding is explored more in the next chapter.

Finally, as in the quantitative analyses, impairment itself was very influential in shaping respondents' identity claims. All respondents conceptualized disability from a medical model standpoint. That is, when referring to either their own identity claims as disabled, or their disidentification from a disabled identity, respondents referred to things such as physical limitations, reliance on others to perform everyday tasks, and the use of mobility aids as reasons for why they identified (or disidentified) as disabled. Respondents' reliance on medical model definitions of disablement is elaborated on more in the following chapter.

Summary of Findings

In sum, findings from a nationally representative sample of mobility impaired persons showed that 52 percent did not identify as disabled. Similarly, in the qualitative analyses, three distinct identity groups emerged – individuals who identify as disabled, individuals who disidentified as disabled, and individuals who are still negotiating a disabled identity.

Although respondents from both the quantitative and qualitative samples reported experiences of environmental and social barriers, it was the experiences of social barriers and impairment that were most meaningful in their identity claims. Respondents in qualitative interviews discussed their experiences with social barriers,

particularly with stigma, and their bodily experiences of impairment when discussing their identity claims.

Although in the quantitative analyses experiences of impairment were more significantly related to claiming an identity as disabled than experiences of social barriers, in the qualitative analyses both social barriers and impairment were meaningful in shaping respondents' identity claims. In fact, a complex relationship between these two indicators of disablement was found to be a critical component in shaping identity claims. Respondents who identified as disabled were more likely to be impaired than those in the other identity groups and experiences of impairment were very meaningful for their identity claims. Although these respondents also experienced more social barriers than those who disidentified or were still negotiating this identity, they were more likely to have accepted their limitations and therefore, experiences of social barriers did not cause them to want to disidentify as disabled, and in some cases caused them to identify as disabled. Among respondents who disidentified as disabled and those who were still negotiating this identity, they were less impaired and less likely to experience some forms of social barriers than those who identified as disabled but experiences of social barriers, and the fear of experiencing social barriers was influential in their desire to avoid this identity. This complex relationship is explored more in the following chapter.

These findings provide some support for both the social and medical models of disability. Although environmental barriers were less relevant to impaired individuals identity claims as disabled, social barriers were very influential in shaping one's identity. Additionally, experiences of impairment had very real implications

for impaired individuals' identity claims in both the quantitative and qualitative analyses, above and beyond their experiences with environmental and social barriers. These findings provide support for a more encompassing model of disablement. However, as demonstrated above, the impact of experiences of socially constructed barriers and impairment on identification as disabled is complex. Meaning we cannot assume if one experiences some amount of social barriers and some amount of impairment, they will identify as disabled.

In order to understand how factors such as, environmental and social barriers and impairment come to shape an identity as disabled, it is necessary to explore how information regarding the self gained through these experiences is processed and integrated into the self. In the following chapter I examine how impaired individuals use three self processes (social comparisons, self presentations and reflected appraisals) to gain information regarding their self from their experiences in both larger social contexts and their immediate social contexts to shape their identity claims.

Chapter 5: Claiming a Disabled Identity: The Centrality of the Self

In this chapter, I examine the second research question: How do self processes (i.e., social comparisons, self-presentation, and reflected appraisals) inform the embracement or rejection of a disabled identity? Findings from both the quantitative and qualitative analyses are used to answer this question.

Quantitative Findings

In the quantitative analyses, I was only able to examine the role of reflected appraisals in shaping respondents' identity claims. Respondents' identities were fairly consistent with their reflected appraisals as disabled; however, the reflected appraisals of respondents who did not identify as disabled were slightly less consistent with their own self-appraisals (see Table 5.1). Among the respondents who identified as disabled, 90.9 percent perceived others to view them as disabled and 9.1 percent perceived others to view them as not disabled, whereas 81.7 percent of respondents who did not identify as disabled perceived others to view them as not disabled and 18.3 percent perceived others to view them as disabled.

[Insert Table 5.1 about here]

In order to assess how self processes affect the claiming of an identity as disabled, I regressed claiming an identity as disabled on environmental barriers, social engagement, impairment, and reflected appraisals as disabled (see Table 5.2). The first three models in this table are the same regression models presented in Table 4.2. In Model 4 of Table 5.2 we see that respondents who perceived others to view

them as disabled were significantly more likely to identify as disabled (OR=31.71, p<.001). With the introduction of reflected appraisals, the relationship between environmental barriers outside the home and social activity level and claiming an identity as disabled were no longer significant, while the relationship between employment (OR=.55, p<.001) and claiming a disabled identity increased slightly. Finally, the relationship between severity of movement difficulty and claiming a disabled identity remained strong (OR=1.27, p<.001) and the relationship between difficulty with IADLs (OR=1.19, p<.05) and identifying as disabled decreased in significance.

[Insert Table 5.2 about here]

Sobel tests (MacKinnon and Dwyer 1993; Preacher and Hayes 2004) were used to test if the indirect effects of environmental and social barriers and impairment on claiming an identity as disabled through reflected appraisals are significant. These Sobel tests for mediation were calculated for all significant relationships found in Model 3 of Table 5.2 using the logistic regression coefficients and standard errors. These tests revealed that reflected appraisals mediated the relationship between environmental barriers outside the home (Sobel = 12.848, p<.001), social activity level (Sobel =-9.016, p<.001), employment (Sobel = -13.309, p<.001), severity of movement difficulty (Sobel = 14.891, p<.001), IADLs (Sobel = 13.336, p<001), gender (Sobel = -8.454, p<.001), education (Sobel = -4.723, p<.001), income (Sobel = -9.868, p<.001), and identifying as disabled.

These findings indicate that although both environmental and social barriers and impairment have direct effects on claiming an identity as disabled, reflected

appraisals mediate the relationship between these indicators and claiming an identity as disabled. In other words, a portion of the effect of social and medical model indicators on identity occurs indirectly through reflected appraisals. This indicates that impaired individuals' experiences of socially constructed barriers and impairment influences how they perceive others to view them (as disabled/not disabled) and this in turn affects their own identification with a disabled identity. These findings were further supported in the data from the qualitative interviews.

Qualitative Findings

In the qualitative sample, about two thirds (N=19) of respondents identified as disabled, seven respondents disidentified with a disabled identity, and four were still negotiating this identity.[16] In the qualitative interviews I was able to explore the reflected appraisal process in more depth, as well as two other self-processes that shaped respondents' identities. For example, in the qualitative interviews it was revealed that social comparisons and self-presentations played as important of a role in constructing respondents' identities as did reflected appraisals. Additionally, I was able to examine the fluidity of respondents' identities across contexts and time.

As mentioned in the previous chapter, respondents did not discuss environmental barriers when describing the identification process. Rather respondents focused on social barriers and impairment as contributing factors to their identity

[16] In the interviews, respondents used the terms "disabled" and "have a disability" interchangeably when discussing how they identified. There was some concern that respondents who discussed having a disability, did not necessarily identify as disability. This was not found to be the case. Additionally, the majority of respondent who were probed to see if they believed there was a difference between stating that they were "disabled" and they "have a disability," saw no difference in these terms. Two respondents did see a difference between these terms. Both respondents equated the term "disabled" with being completely helpless, and having a disability is having impairment and limitations. Despite the ability to make this distinction both respondents used the terms "disabled" and "have a disability" interchangeably when discussing their identity.

claims. Experiences of stigmatization and social exclusion (i.e., decreased socializing, losing friends, difficulty dating, being refused employment etc.) played an important role in some respondents' rejection of or resistance to identifying as disabled. Additionally, as in the quantitative analyses, impairment itself was very influential in shaping respondents' identity claims. All respondents defined disability using medical model definitions. That is, when referring to either their own identity claims as disabled, or their disidentification from a disabled identity, respondents referred things such as mobility restrictions, physical limitations, reliance on others to perform everyday tasks, and the use of mobility aids as reasons why they identified (or disidentified) as disabled.

Respondents reported receiving information regarding their selves through a number of mechanisms, which they then used to construct their identities. First, respondents relied on information they received through their social comparisons between themselves and others to not only understand their placement in the social structure, but to verify their own identity claims. In addition, respondents gained information regarding their self through the reflected appraisal process. This included both actual and reflected appraisals from both significant others and the generalized other. Finally, respondents were also agentic in the construction of their own identities, by actively engaging in self-presentations. These findings are described in more detail below.

Respondents' identity claims varied based on a complex interaction between their level of impairment, their awareness of and resistance to stigmatization, and the type and consistency of messages received from others and society as a whole

regarding their disablement. Respondents who identified as disabled had more mobility limitations than the other identity groups, and received consistent messages indicating that they were "disabled" through both social comparisons and reflected appraisals. Additionally, these respondents reported that they presented themselves to others as disabled and felt others accepted these presentations. Respondents who disidentified as disabled had fewer mobility limitations than respondents who identified as disabled, and they received consistent messages indicating they were not disabled through both social comparisons and reflected appraisals. However, persons who disidentified as disabled also played a very active role in interpreting social comparisons, and reflected appraisals and presenting themselves as not disabled in order to resist experiences of stigmatization, and this was influential in affecting others appraisals of them. Finally, respondents who were still negotiating this identity, also had fewer mobility limitations than those who identified as disabled, however, they received mixed messages regarding their disability status through their interactions. Like respondents who disidentified from this identity, they received messages through their social comparisons that indicated that they were not disabled, and they played in active role in trying to present themselves as not disabled in order to avoid stigmatization. However, as with respondents who identified as disabled they received consistent messages through reflected appraisals indicating that they were disabled. In the following section, I will discuss in more detail how these three self processes (social comparisons, reflected appraisals and self-presentations) influenced the constructions of each identity group.

The Identifiers: "I can't imagine somebody calling me -- an amputee -- not disabled"

Respondents who identified as disabled recognized the fact that they possessed characteristics that placed them in the social identity group "disabled" and these characteristics were largely indicators of disablement from a medical model standpoint. When asked why they identified as disabled, these respondents often discussed the condition, disease, or injury that led to their disablement, their impairment itself, and their functional limitations. For example, when asked why she identified as disabled one woman stated,

> "(I) had the stroke and not being able to move around without some kind of assistance and something I can use, like a walker." (Diane, a black woman in her 50s)

In claiming an identity as disabled, respondents also considered the information regarding their self that was gained through self processes. First, respondents who identified as disabled consistently made upward social comparisons between themselves and others who were able bodied, which verified their identities as disabled. Respondents also gained information from others' actual and reflected appraisals of them as disabled. These appraisals were consistent with respondents' own views of their self almost all of the time (See Table 5.3). Additionally, respondents' own self-presentations and their perceptions of others' acceptance of these presentations served to verify their identity claims. These self processes are described in more detail below.

[Insert Table 5.3 about here]

Social comparisons among the "disabled"

As in previous research, respondents made social comparisons between themselves and *able-bodied others* when forming their identity as disabled (Watson 2002; Priestley 1999). These respondents often noted how their physical difference marked them as "disabled." For example, when asked why he considered himself to be disabled one respondent stated,

> "Because I'm unable to do what a person that's standing up could be able to do." (Shawn, a black man in his 40s)

Similarly another respondent stated,

> "I can't move around like the average person. I have to have things accessible for me." (Latisha, a black woman in her 30s)

Because these respondents had become impaired later in life (i.e. they were not born impaired), they also made comparisons between their current selves and their previously able-bodied self. In fact, for one woman, the realization that she could no longer do the things she was once able to do as an able-bodied person indicated to her that she was disabled:

> "I could do things that others did but after really having the surgery and everything I went into a little state of depression because I was used to… I coached basketball, I had cheerleaders, I taught- I was an educational aid for Head Start up to the 6th grade and it began to bother when I couldn't go up and down steps. I couldn't jump rope and had problems with the shoulders." (Gayle, a black woman in her 50s)

In addition to making social comparisons between themselves and able bodied others, including past selves, respondents also relied on the information they received regarding their self from significant others in their lives, as well as the generalized other. This information was consistent with, and perhaps influenced by, the information these respondents gained through their social comparisons.

Actual and reflected appraisals among the "disabled"

Respondents reported receiving *actual appraisals* regarding their "disability" from a number of sources. A couple of respondents who received actual appraisals from others reported receiving these appraisals from "legitimizing" sources, including medical professionals and the state/federal government who informed them that they met the criteria for claiming disability benefits. Other respondents discussed how family members, friends, and neighbors had directly told them that they viewed them as disabled, or conversely, did not view them as disabled (discussed below). As one respondent put it,

> "They tell me all the time… Everyone I know does [thinks I'm disabled] because they keep asking me the same question 'I can't believe they don't give you disability [benefits].' Even people that get disability tell me, 'I can't believe they won't give it to you.' …even people I don't know walk up to me and ask 'oh you should get that.' Neighbors that I don't even know but they see me all the time." (Ben, a black man in his 50s)

As with their self-appraisals, respondents based their *reflected appraisals* on their own recognition that they possess attributes that placed them in the social category "disabled" and their belief that significant others (i.e., family, friends, coworkers, neighbors, and government officials) and/or the generalized other would also recognize this. For example, when asked why they believed others viewed them as disabled, some respondents discussed their functional limitations, stating things like,

"Because I don't have use of my legs." (Diane, a black woman in her 50s)

Often respondents commented that their "disability" was *visible* to others and this is why they perceived others to view them as disabled. For example one woman stated,

> "They can look at me and see that I have a disability." (Nicole, a black woman in her 40s)

In fact, respondents considered a number of "markers" of disability that were visible to others, including the way they walked, their use of assistive devices, and the pain they experience when moving around as indicators of their disablement and reasoning for why they perceived others to view them as disabled.

Respondents also believed that their reliance on others for help with everyday tasks indicated to those others that they were disabled. For example, one respondent believed significant others (i.e., family members and a home health aide) viewed her as disabled because she needs their assistance with ADLs and IADLs.

> "I need a lot of assistance. I used to do my hair. I have problems shampooing, curling and rolling my hair. I need assistance when I go to the grocery store, especially lifting up on the shelf like… problems with, you know, showering and using the toilet." (Gayle, a black woman in her 50s)

For some, it was not just the experience of receiving help that made them believe others viewed them as disabled, but the fact that reliance on help from others was a divergence from their personalities as independent persons. For example, one woman who described herself as always being very independent, now struggled with the idea that she must be reliant on her friends and family in accomplishing everyday tasks, like grocery shopping. A fact that she thinks has ultimately changed how significant others view her. Here she discusses who she perceives to view her as disabled and why:

> "Just my family that's always around me, especially my mom. And when I have to call people and ask them for help or to take me to certain places… because I'm an independent person so I never really had to ask anyone to do anything. It's just since my knee has been like this I've been asking for help." (Keisha, a black woman in her 20s)

Others' behaviors toward these respondents during social interaction also informed their reflected appraisals. As in previous studies, these respondents reported receiving unsolicited help from others (both significant others and the generalized other) which led them to believe that those others perceived them as disabled (Connors an Stalker 2007; Toombs 1995; Kaufman-Scarbourough 2001; Morris 1991; Cahill and Eggleston 1995). For example, one respondent described experiences of receiving unsolicited help from both significant others and strangers when moving around,

> "Bus drivers are more patient with me, and more helpful it seems. Just more polite even… walking up stairs, (friends) grab me by the arm, just to steady… because the last thing they want to see me do is fall again." (Marcus, a black man in his 40s)

Respondents also picked up on other non-verbal cues during social interactions that led them to perceive others view them as disabled. For example, a couple of respondents discussed how the "gazes" of strangers (Goffman 1963) when out in public made them aware of their differentness and led them to believe that they were perceived as disabled. As one woman put it,

> "Well they really haven't said it but it's the way they look at me. Especially the way I walk. My feet wobbles and it goes out and goes in. It gets real shaky and my legs and stuff and people look at me funny… when I'm going places it's like 'what's wrong with her?' …it's like 'There's something wrong with her. Why is she walking like that? Almost like retarded.'" (Olivia, a black woman in her 50s)

Additionally, some respondents based their reflected appraisals on their own self-presentations. That is, they believed their presentations of self as disabled were accepted by others and therefore they perceived others to view them as disabled.

Self presentations among the "disabled"

For both the generalized other and significant others, some respondents believed that their self-presentations informed these others of their disablement and that is why they perceived others to view them as disabled. For example, some respondents commented that they had discussed their impairment with significant others, and although their significant others had never outright told them that they believed they were disabled, these respondents believed that they accepted their identity claims.

Variability in appraisals among the "disabled"

As shown in Table 5.3, there was very little variability in the appraisals (both actual and perceived) respondents received from others, however it did occur in a couple instances. Among the three disabled identified respondents who reported that some people view them as disabled and others do not, three distinct answers were provided. First, one woman believed that the generalized other would view her as disabled because of the fact that she walks with a cane and she has physical limitations, however, she commented that she has received actual appraisals from both significant others in her life (i.e., family, friends, and her doctor) which deny that she is disabled. Conversely, another woman perceives her family to view her as disabled because she has talked at length with them about the problems she is experiencing, however she does not believe anyone else would view her as disabled because she does not have any documentation to prove that she is in fact disabled (i.e. Supplemental Security Income benefits). Finally, another woman reported that she perceives her social worker to view her as disabled based on her social workers'

actual appraisals regarding her physical limitations; however she does not feel that her children view her as disabled because they are so dependent on her.

The one respondent who did not perceive others to view her as disabled reported that she actively presents herself as not disabled in order to avoid stigmatization. For this respondent, the stigmatization, particularly images of disabled persons as unattractive and undesirable that are ascribed to disabilities is too much for her to cope with. As she put it,

> "I'm too pretty, too cute to have a disa- ailment." (Dina, a black woman in her 40s)

Although she recognizes that her impairment and functional limitations make her "disabled," she chooses to present herself to others in a way defies stereotypes regarding disabled people, and in doing so she hopes to shift the image of what it means to be disabled.

> "Because there's always somebody that feels as though it's the worst thing in the world. Until they see somebody like me, who says 'She's pretty! She looks nice and her attitude is good' and they say 'hey it's not that bad after all' once they meet me… because you can be cute and disabled."

However, in an attempt to present a different way of being disabled, this respondent perceives most others actually do not perceive her as disabled.

Interestingly although two disabled identified respondents discussed having their disability challenged by able bodied others, as their impairment is not always visible if they are wearing pants, reported that they still believed others (generalized and significant) viewed them as disabled because their impairment unquestionably made them disabled. For example, one woman who walks with a prosthetic leg often has her disability questioned when wearing pants, however she still viewed

significant others and the generalized other to view her as disabled once her impairment became visible,

> "I can't imagine somebody calling an amputee not disabled. That would just be stupid." (Beth, a white woman in her 30s)

Adding that although these others questioned her identity, they immediately recognized the fact that she was disabled when she displayed her prosthetic:

> "You can see the recognition on their faces, 'oh, she's a person with a disability."

Most respondents who identified as disabled discussed experiences of stigmatization, and how this in turn affected the way they viewed their self.

Managing stigma among the "disabled"

Because all of the respondents I interviewed became impaired in adulthood, they themselves were aware of stigmatizing beliefs regarding disablement when they were able-bodied and in some cases held stereotypical beliefs themselves regarding disabled people. For example, these respondents, themselves, characterized disabled persons as being unable to live independently or contribute to society, as unsuitable partners and unattractive, and so on. After becoming impaired they had to learn to cope with the stigmatization they themselves now experienced.

For some respondents, experiences of stigma were so great that they attempted to hide their impairments in order to mediate strained interactions with able bodied others, despite the fact they themselves still identified as disabled. For example, a couple of respondents reported that they will not wear clothing that exposes their mobility aids (i.e., prosthetics and leg braces).

> "I don't wear miniskirts or shorts in public. But that's not to alter people's perceptions of me, it's a question of self-consciousness. It's

> all about the staring… it makes me feel very ugly honestly. And deformed is actually a word I use a lot with my shrink. I feel deformed." (Beth, a white woman in her 30s)

Although this respondent identified as disabled, she still sought to avoid stigmatization and the negative self-evaluations that occurred as a result.

Similarly, other respondents did not use mobility aids due to the stigma attached to them. For example, one woman is resistant to using a wheelchair even though she can no longer participate in many activities because of her inability to walk for extended periods of time. When asked why she would not use a wheelchair she stated,

> "That's too much… I don't want to get too comfortable with something like that. I still want to walk and be active and I think if I did that, it's gonna make me lazy and that's not healthy." (Latisha, a black woman in her 40s)

Another woman, who uses a cane everyday in order to get around, describes herself as lazy for doing so. Although she recognizes that she is more stable on her feet when using the cane, when asked how she feels when she uses it she said,

> "Lazy, like it's saying I really need it." (Jackie, a black woman in her 40s)

While all respondents live in a society that stigmatizes those with disabilities, not all internalize this stigmatization. For some respondents the social support they received from others, not only provided them with the assistance they needed but also helped to keep them socially engaged, and moreover helped them understand that despite having impairments they could still participate fully in society. As one woman put it,

> "I figured I could get around just as well. It just took me a little while longer to get there… I accept my limitations. I don't stress myself out about the things that I know I cannot do… I kind of think about my

> family and my friends and how some people go out of their way to make sure that I don't feel like they don't let me feel like I'm just one of the people. …they try to make sure I don't feel excluded." (Diane, a black woman in her 50s)

Others changed their activities and have adjusted to the fact that they cannot do the things they once did.

> "Because I can't do things I used to do. Like now instead of going out on the basketball court or running or bicycling I get me a game. Play the Playstation III or the X-Box. Or play board games, like Monopoly, Trouble, that type of stuff, cards." (Shawn, a black man in his 40s)

Transitioning to a new identity: Giving up old identities and claiming disabled

Impairment (and a disabling society) led to the loss of old identities for many respondents, due to the loss of activities, friendships, and jobs. Respondents often discussed how the process by which they came to identify as disabled involved coping with the loss of their old self, adjusting to their physical limitations and the implications for the self, as well as accepting a new stigmatized identity. While some respondents' impairments increased slowly over time, others became impaired in an instant as a result of injuries. Respondents whose impairment was instantaneous had a particularly difficult time adjusting to their impairment, and a subsequent shift in their identities. For example, one respondent who became paralyzed from the waist down as a result of a gunshot wound described the difficulty he experienced transitioning from an active young adult to no longer having the use of his legs.

> "[I was] very athletic. Ran. Swam. Played football, basketball got plenty of bicycle… It took me a long time. I mean at least five years… I was- if you had known me when I first got shot you wouldn't, I doubt you'd want to interview me or talk to me. I was mad at the world. I wouldn't have said a lot to you. I was just mad at everybody. I was 24 years old and very active and just you know (snaps his fingers) had to deal with slow pace everything." (Shawn, a black man in his 40s)

Similarly another respondent discussed going into a state of depression following a car accident which led to the amputation of one of her legs.

> "I had such a hard time identifying as somebody with a disability because I hadn't been for 29 years and I didn't get any warning that I was going to be. Now I always understood the legal part of it. Like legally I don't have a foot therefore I am disabled according to the law and must be, you know, must receive these special protections or whatever legally. But socially it was a much more difficult process." (Beth, a white woman in her 30s)

For both these respondents, and others like them, the transition to identifying as disabled took a number of years. Not only was it difficult for respondents to let go of activities that once defined their selves, but they also had to contend with now possessing a stigmatizing characteristic, which was not only difficult for them to negotiate, but also those around them.

Fluidity of identity among the "disabled"

In spite of the fact that these respondents all identified in the interviews as disabled, this identity claim was somewhat fluid. For example, respondents discussed how their identity as disabled could shift depending on how they physically felt on a given day. Some respondents noted that when they are at home and can get off their feet, and are experiencing minimal to no pain they do not feel like they are disabled, even if these moments are fleeting. For example, one respondent stated that he does not feel disabled when he is at home watching TV.

> "When I be laying down, watching TV, and you know, I got my legs thrown up on the table or something. I feel good. I feel comfortable… But then I start to get up and I feel like I need something to really lift me up off the sofa or something. Knees start popping…" (Bernard, a black man in his 50s)

Others similarly reported that they have "good days" when they have minimal pain, and less functional limitations and they leave the house and participate in everyday activities.

> "When I feel good. I mean real good. And I can accomplish A LOT of things. Yes. And it plays tricks with your mind. Because I have my real, real good days and I could do a lot of things but then when the pain kicks in it kind of throws you off… You feeling on top of the world and you back down again." (Olivia, a black woman in her 50s)

In terms of the fluidity of these respondents' disabled identity, experiences of feeling "not disabled" were temporary and limited. These respondents only felt "not disabled" during periods of time when their pain or functionality difficulties were minimized. However, their impairment symptoms always quickly returned and the majority of their experiences were shaped by their pain and mobility restrictions.

The Disidentifiers: "It's just a bump in the road."

About one quarter of respondents (N=7) in the qualitative sample rejected an identity as disabled. Respondents who did not identify as disabled recognized that they had impairments; however, they largely focused on their abilities as reasoning for why they were not disabled. Central to their rejection of a disabled identity was the awareness of the stigma attached to that identity and the desire to avoid stigmatization. In rejecting an identity as disabled, respondents relied heavily on downward social comparisons between themselves and those whom they considered to be "disabled." The actual and reflected appraisals of others for the most part supported these respondents' identity claims. Furthermore, respondents' own self-presentations played an important role in maintaining consistency between their self appraisals and reflected appraisals.

Stigma and ability claims among the disidentified

Like respondents who identified as disabled, respondents who disidentified with this identity also held beliefs regarding what it meant to be disabled that were based in a medical model context, and often these beliefs were stigmatizing. When asked to define "disabled," respondents described people who cannot get around on their own, people who cannot take care of themselves or must rely on the help of others to do everyday tasks, people who are completely paralyzed, "wheelchair bound" or reliant on other mobility aids, and people who are unable to work, and who have no worth in society. And respondents wanted to resist this stigmatization for themselves.

> "I just don't want to write myself off with a disability. I like to feel like I can still have some kind of use. You know, until I just can't-can't be done no more." (Sam, a black man in his 40s)

Later this same respondent reported that identifying as disabled would make him feel like he had less self-worth.

> "I would feel less than what I am. I really would. I would feel bad."

Despite experiencing mobility restrictions, albeit fewer than those who identified as disabled, these respondents were acutely aware of the stigma associated with disability, and wanted to avoid this, even if it meant ignoring limitations they were experiencing. Although many of these respondents who disidentified with this identity experienced what they described as characteristics of disability, they did not themselves identify as disabled. For example, one respondent, when asked to define a disability discussed the following:

> "Not being able to do daily tasks or to get around… Not being able to partially or completely take care of yourself… someone who has

> trouble walking, someone who has trouble, difficulty getting in and out of buildings and out of cars, someone that can't maybe cook for themselves, like bathe, you know, hygiene kind of stuff like that." (Otis, a black man in his 50s)

When the interviewer pointed out that he himself met some of his own criteria for defining a disability, he stated,

> "Yeah it's difficult sometimes doing them. I look at someone disabled and they can't do at all. 'cause there's nothing I can't do, you know? It's just that, it just sometimes hurt doing it. And in my opinion someone that's disabled can't do those things."

Similarly, despite having significant mobility restrictions, including being very weak, having difficulty walking short distances, and reliance on a walker, another respondent did not identify as disabled.

> "There are certain things that limit me from doing, but others like yourself can do. But I like to say no (I'm not disabled), simply because I'm strong minded and physically I got strength enough and I'll try once and if I can't do it, then I can't do it. But I never want to say, no, I may be physically challenged but I won't say I'm disabled… I just don't want people to never look at me and say 'you can't do this.' Don't put me in that box! …don't cast me out." (Lou, a black man in his 50s)

Social comparisons among the disidentified

As with respondents who identified as disabled, respondents who disidentified with a disabled identity made social comparisons between their physical abilities and others, however this group of respondents tended to make downward social comparisons between themselves and more impaired others, who they considered "disabled". For example, when asked why he did not identify as disabled one respondent stated:

> "Because I'm able to get up and go. I don't need 24-hour people, you know, taking care of me, helping me do this. When I need the help I ask for the help, like when I'm getting out of the bed or I'm reaching

> up to the cabinets or I need help out of the tub…" (Laurie, a black woman in her 40s)

This respondent goes on to define someone who is disabled as needing assistance all the time, adding that they may be in a wheelchair or reliant on crutches to get around. Because she is able to live, for the most part, independently, she doesn't consider herself disabled. In other words, despite her mobility restrictions, need for help some of the time, and reliance on the use of a cane, she does not identify as disabled.

When making comparisons to disabled others, these respondents often perceive their own impairments as less serious than others' impairments. For example, one man who is awaiting knee replacement surgery and currently walks with a cane and has limited mobility feels that his restrictions are far less severe than other impaired persons. When asked if he considered himself to be disabled he stated the following:

> "Not in light of what I see others people have. I mean I got something I have to deal with, that's all. I feel fortunate that I can deal with it. I see people who can't necessarily deal with their problems, wheelchair- or I feel bad when people, you know, when you compare me to those people. It's not fair… I look around to people who have trouble- that can't walk, can't stand, can't- I can basically figure out what to do… what took me three minutes is going to take me seven minutes now and that's all." (Frank, a white man in his 50s)

However, this respondent also recognized that his disidentification is also influenced by his desire to avoid stigmatization.

> "I guess it's partially you don't want to think of yourself as a disability, and partially it's true there are people in a lot worse shape than me."

This is not to say that these respondents who disidentify with a disabled identity all have less severe mobility impairments than those who identify as disabled.

One respondent who has an amputated leg and walks with a prosthetic also does not perceive himself as disabled. Like the previous respondent, he compares himself with other persons with more severe impairments than himself.

> "Well from the time I was in the rehab home for two months on up I've met a lot of people with disabilities that I wouldn't even consider for a minute trading places. Mainly head injuries. People that don't even know that they're sick. People who don't, you know, I have to introduce myself every day. And I really believe that there's a lot of times that I forget that I don't have a leg. And it's just a little inconvenience that's all" (Jim, a white man in his 50s)

Like other respondents, he also described going through an adjustment period when he first became impaired. Although he was first very depressed after losing his leg, once in his rehabilitation center he began to compare himself to others and subsequently began to feel better about his situation.

> "I looked around and saw that I wasn't as bad of shape as some people and my mind started adjusting."

He now describes his amputation as "just a bump in the road."

As with respondents who identified as disabled, these respondents also discussed receiving actual and reflected appraisals from significant others, as well as reflected appraisals of how the generalized other viewed them. Of the seven respondents who did not identify as disabled, two believed others viewed them as disabled and five believed others did not view them as disabled (see Table 5.3).

Actual and reflected appraisals among the disidentified

Only one respondent discussed receiving actual appraisals from others regarding her disability status. This woman discussed how a male friend did not view her as disabled; rather he felt that the pain and mobility limitation she was experiencing was the result of her recent weight gain.

> "My friend, he always say to me 'the leg still hurting 'cause you gained all that weight.' And I say 'nooo, it ain't got nothing to do with it. Should be my feet hurting.' That's what I say to him." (Laurie, a black woman in her 40s)

Although she recognizes that she is in pain and has limited mobility she herself does not think her impairment is a disability, in light of what others who are "disabled" experience. She also perceives other significant others to view her in this same way. Her friends recognize that she is in pain and has difficulty moving, and they will provide accommodations for her, however she doesn't believe they see her as disabled.

Among the respondents who did not believe others viewed them as disabled, their own self presentations played a very important role in affecting how others viewed them, or at least how they perceived others to view them. These respondents believed that despite their impairments, they could *present themselves* to others in ways that supported their identity claims. For example, when considering how others view him, one respondent discussed how he has made it known to his friends that he does not want to be identified as disabled.

> "Because they know how I am. I'm always going to give it a try… My friends all know how I feel. And they know I prefer to say that I'm physically challenged (as opposed to saying he's disabled)." (Lou, a black man in his 50s)

When asked how he thinks people who don't know him perceive him he stated,

> "I wouldn't know what the mind of others would be, their thought process. I wouldn't know… But I never let what a person say, do or think phase me. It don't stop me. That's another worry that a person would not need."

Similarly, another respondent discussed how he does not perceive others to view him as disabled because he does not outwardly claim he is disabled.

> "The reason why I say that is because I don't really show it or say…now when I'm at work I do, you know, say something like 'oh my leg is killing me today' or I'm talking to someone and I might be rubbing it, you know, or something like that. But I'm always able to do whatever it is that we're doing at work. And other than that, my job, nobody would really know that my leg hurts."

This same respondent later stated,

> "They don't really know, you know, some of the things I go through physically. I don't go up to people and you know always say 'oh my leg's killing me' or 'I can't do this, can't do that.' So and as a matter of fact on the contrary I try to hide it, you know, when it's hurting. So in their eyes don't think that they would think that I was handicapped or disabled." (Otis, a black man in his 50s)

Finally, respondents avoided using much needed mobility aids, or receiving proper treatment as a mechanism to avoid being recognized as disabled. As one woman put it,

> "Nobody would believe I have no disability. No way… I'm not walking with a cane and I'm not in a wheelchair." (Caryn, a black woman in her 50s)

Similarly, another respondent never received the appropriate care for his initial injury. In order for him to attend rehabilitation, this respondent would have had to transport himself there via public transportation, while using a wheelchair. The thought of being seen by others in a wheelchair alone was so stigmatizing that he would not leave the house in it, and went without treatment completely. Three years later he still will not go back to the doctor to seek care for his continued impairment because he does not want the impression that he is disabled.

Variability in appraisals among the disidentified

As with respondents who identified as disabled, among the respondents who rejected this identity there was some variability in their reflected appraisals. As

shown in Table 5.3, two respondents perceived others to view them as disabled. These respondents discussed both the views of significant others and the generalized other. For one of these respondents, the strained interactions he experienced when interacting with able bodied others indicated to him that these others viewed him as disabled. He discussed both the gazes he received from strangers when out in public and the difficulty he experiences in dating as indicators of his differentness. The other respondent, perceived his children to view him as disabled because he could no longer physically keep up with them. Additionally, because he uses a cane (which marks him as disabled) and because he often receives unsolicited help from strangers when out in public, he perceives the generalized other to also view him as disabled. However, both of these respondents actively work to use self-presentations to bring their reflected appraisals back in line with their own self-appraisals.

Fluidity of identity among the disidentified

Interestingly, respondents who did not identify as disabled did not discuss having fluidity in their identity, meaning they never experienced times when they felt like they were disabled. When confronted with others' who viewed them as disabled during social interactions, these respondents were quick to discredit these others' actions and beliefs and assert their own identity claims through their self-presentations.

The Negotiators: "I can do everything…I'm just weak on the left side"

Of the respondents I interviewed, 12 percent (N=4) were still negotiating this identity. These respondents received contradictory information regarding their self from their various self-processes, and this was reflected in the contradictory nature of

their identity claims. As with the other respondents, this group of respondents recognized that there are particular characteristics that mark individuals as disabled, and these characteristics included indicators from a medical model standpoint. However, like the respondents who disidentified as disabled, these respondents were also acutely aware of the fact that disability is a stigmatized status, and sought to avoid this. Like respondents who rejected the identity disabled, these respondents recognized the fact that they were impaired; however they also recognized their abilities. These respondents' downward social comparisons between themselves and others with more severe mobility restrictions reinforced their view of self as not disabled. Although, these respondents experienced fewer mobility limitations than did respondents who self-identified as disabled, they did recognize that their mobility limitations that they did experience marked them as disabled. The actual and reflected appraisals of others also consistently indicated to these respondents that they were perceived as disabled (with the exception of one respondent who reported that some others viewed her as disabled and some others did not (see Table 5.3). However, when respondents' reflected appraisals were not in line with how they perceived themselves, some respondents engaged in self-presentations in an attempt to shift others' views of them. Finally, unlike respondents who reject this identity, these respondents do experience fluidity in their identity, where at times they feel disabled and other times they do not.

Self appraisals among the negotiators

First, when these respondents discussed their own self-appraisals, they were often contradictory. For example, one woman initially answered yes when asked if

she considered herself to have a disability and then went on to describe her impairment.

> "Because I have problems. I have carpal tunnel and I suffer with arthritis and especially with my knees and legs. They are- they give me a fit. Some days I can't work. And especially my carpal tunnel, some day I just- it's unbearable. At night I can hardly rest." (Patty, a black woman in her 50s)

However, the more she talked about her impairment, the less she felt that she has a disability. At one point in the interview she states,

> "I don't consider myself totally disabled…. I really don't (consider myself disabled)"

Her discussion than began to focus on her abilities, as reasoning for why she does not at times identify as disabled.

> "I feel like I could do anything. Even with the carpal tunnel, with the problems with my hands, with my knees, with my walking, whatever. You know all I ask is give me a chance."

Similarly, when asked if he considers himself disabled, another respondent changed his response during his discussion. Initially this respondent stated,

> "I don't, others do." (Michael, a black man in his 40s)

However, this respondent then claimed that he would identify as disabled and when asked why he discussed others' actual appraisals of him. In this discussion he discloses how others' appraisals of him might be accurate; however he is resistant to accepting an identity as disabled.

> "Because it's not going to get any better. It's going to get worse before it gets better. You know sometimes you don't see things and it can be right there in front of you. And I have a couple family members that tell me 'You can't walk.' 'Yes, I can.' 'You can't do this.' 'Yes I can.' You know, being a man, the male ego whatever, the male ego telling me yes I can. 'Cause I still think I can and I can. To me it's mind over matter."

The two other respondents who were still negotiating this identity also recognized that they had impairments that may be considered by some as a disability, and although they themselves also feel that they may be disabled, they are resistant to fully accepting this stigmatized identity. As one respondent put it,

> "I do have a disability but I don't want to deal with it. I make myself go as far as I can. I don't like putting it out there." (Clair, a black woman in her 60s)

She doesn't want to be reliant on others, wants to maintain her independence. Instead these respondents focus on their abilities.

> "I can do everything… I'm just weak on the left side. I cannot run but I can walk. I can't walk a long way but I can walk." (Desmond, a black man in his 50s)

Managing stigma among the negotiators

Like respondents who reject a disabled identity, these respondents all held stereotypical beliefs regarding disablement. These respondents defined "disabled" in the following ways: having impairments that are progressive and permanent, not being able to get around by oneself, not being able to take care of oneself, being reliant on others' help, being "wheelchair bound," and being old. The internalization of the stigma attached to a disabled identity was central to these respondents' desire to reject this identity. For example, when asked why he did not want to identify as disabled, one respondent stated,

> "That stigma that you can't do anything, which is not true. You know, that's the thing that from the top of my head. They think that you can't do anything and they can do everything. Disabled people can do everything…" (Frank, a white man in his 50s)

Although he recognizes that these stereotypes regarding disablement are not true, he still does not want others to have these perceptions of him. These respondents relied on social comparisons between themselves and others with more severe mobility restrictions as evidence for why they may not be able to claim a disabled identity.

Social comparisons among the negotiators

In terms of social comparisons, these respondents made downward social comparisons between themselves and others who were more impaired. For example, one woman described herself as "not totally disabled" and made comparisons between herself and a friend, who she considered to be "disabled." Here she describes this friend:

> "I got a friend. She's got- what is it? Lupus. It's hard for her to cook for her family, to bathe, to even get out of the bed. Sometimes, now it's hard for me sometimes to get out of the bed but I mean I feel like I can get up in the morning and it might take me a little longer to do it, but I can take a bath. I can bathe myself. I can brush my teeth, comb my hair. When I have bad days, even I can still do it. It will just hurt more. But she has to depend on people 24-7 to help her. Now I consider that a disability." (Patty, a black woman in her 50s)

Another respondent also compared himself to others with more severe impairments. This respondent suffered a stroke and now has limited mobility on his left side and impaired speech and must rely on a motorized wheelchair to move around. However, he compares himself with others who have more severe mobility restrictions. When asked to define someone who is disabled he stated,

> "Like total messed up people, people who could not move at all. So paralyzed people. I can do everything. I'm just weak on the left side. I can't do things like I used to. I cannot run, but I can walk. I can't walk a long way, but I can walk. I saw people who are paralyzed from the neck down, now they're- that's disabled." (Desmond, a black man in his 50s)

Whereas the information respondents gained regarding their selves through social comparisons supported a rejection of a disabled identity, the actual and reflected appraisals these respondents received supported the claiming of a disabled identity. And unlike their own self-appraisals, respondents received fairly consistent messages regarding their "disablement" from both significant others and the generalized other. Thus it was difficult for them to fully reject a disabled identity when so many others perceived them as such.

Actual and reflected appraisals among the negotiators

Respondents who were negotiating an identity as disabled all perceived others to view them as disabled. These others included significant others, such as family, friends, and more "legitimizing" others, such as doctors and state and federal government officials, as well as the generalized other. Sometimes these perceptions were based on others' *actual appraisals* of the respondent. For example, when asked about his identification with the status "disabled" one respondent replied "I don't, others do." When asked about these others, he discussed how his family and friends often tell him that he is disabled, and because of this he should apply for disability benefits. He has also been told by government officials that he could qualify for disability benefits; however he has not yet applied for these benefits. Similarly, another respondent discussed how her friends make comments indicating that they believed she had a disability.

> "Like I have a couple of friends they feel like '[name] you are disabled. You can't use your hands every day. You have problems using your hands. You have problems walking.'" (Patty, a black woman in her 50s)

Respondents also based their *reflected appraisals* on non-verbal cues from able bodied other during social interactions, such as being offered unsolicited help. For example, one respondent, a black woman in her forties, recounted how family members are constantly trying to help her without asking. She also reported receiving a lot of unsolicited help from able bodied others when out in public. Conversely, some respondents also believed that the non-verbal cues they presented to others indicated to these others that they were disabled. For example, one respondent discussed the pain he experiences, and how his facial expressions might indicate to others that he is disabled:

> "I have family members and other friends who have seen me, seen my facial expressions sometimes when I get up and put pressure… some of them was with me when I came home from the hospital…"
> (Michael, a black man in his 40s)

When some respondents experienced reflected appraisals that were not in line with how they perceived themselves they would engage in self-presentations in an attempt to shift others' views of them.

Self presentations among the negotiators

For one woman who was actively negotiating the identity "disabled," the stigmatization she received from others was enough to make her want to reject this identity, despite the fact that she experienced many mobility restrictions that at times prevented her from performing everyday tasks. When others made claims that she was disabled, or during interactions when she perceived others to view her as disabled, she would attempt to present herself as not disabled. Here she described one experience where others' assertions made her feel so "belligerent" that she felt compelled to discredit their identity assignment.

> "I get angry. I truly get angry. I do not have a disability…. My girlfriend, she'll tell you, 'please don't tell her that,' because I get belligerent. Because you know, like it's a little guy. I remember one day he was getting ready to get on a bus, I'll never forget it, and that girl said 'Oh, let her go first. She's got a disability.' Because I had a cane. I turned around and looked at her and [name removed] like 'Shoot lady, don't-' and I said- I won't tell you what I said- 'I don't have a disability!' And there's this little boy and he's on crutches, you know he's paralyzed. What do they call that? His legs are going together and he has to use- put his arms in both braces. I said 'now he has a disability.' You know? That's a disability." (Patty, a black woman in her 50s)

Fluidity of identity among the negotiators

Like other respondents who identified as disabled, these respondents also reported experiencing fluidity in their identity. These respondents reported that their identities as disabled could change depending on how they physically felt on a particular day (i.e., pain and degree of mobility restrictions). For example, one respondent discussed feeling like she was disabled when her pain is debilitating.

> "Sometimes I do because sometimes it's unbearable and sometimes I can't do anything for myself. I have to get someone else to do it. But not all the time… then I feel like I have a disability." (Patty, a black woman in her 50s)

However, the lack of permanence of the pain she experiences causes her to not identify as disabled. Because no matter how severe the pain is she is experiencing, she knows it will eventually pass. Similarly, for another respondent, there are days when she doesn't want to get out of bed and doesn't want to leave the house because of the pains she is in, but she doesn't always feel like she has a disability. Although, when she can't leave the house is when she feels disabled.

> "It's holding me back. It's like my brain says yes but my body says no." (Clair, a black woman in her 60s)

However, when she's able to get up early and can get out of the house and stay out all day, this is when she doesn't feel like she has a disability. Another respondent also commented that he feels disabled when he considers his mobility limitations:

> "I cannot walk without a cane. When I cannot run." (Desmond, a black man in his 50s)

He doesn't feel disabled when he considers his abilities.

> "I can do everything except walk."

However, unlike other respondents, the group I call the "negotiators" did not report an overall experience of feeling disabled or not disabled the majority of the time.

In sum, a number of factors influenced these respondents' identity claims as disabled, not disabled, and still negotiating. Interestingly these respondents did not include experiences with environmental barriers, such as stairs, heavy and narrow doorways, uneven surfaces, etc., in their discussion of identity, despite citing numerous experiences with environmental barriers. Instead they largely focused on their impairments and their abilities, and their experiences of stigmatization as reasons for why they claim and/or reject an identity as disabled. As argued in the social identity literature, all respondents had a clear conceptualization of what constituted being disabled. This conceptualization was largely based on a medical model standpoint. Although all respondents experienced some degree of pain, fatigue, and mobility restrictions, these experiences did not automatically translate into them identifying as disabled. Respondents were also acutely aware of the stigmatization associated with being disabled, and some had already experienced this firsthand. Whether they experienced it or not, the fear of this stigmatization was enough to make some respondents want to reject an identity as disabled. However, respondents

diverged in the type of messages they received regarding their selves through social comparisons and actual and reflected appraisals, as well as their own ability to make successful self-presentations. The consistency of information regarding the self gained through self processes coupled with how impaired respondents were and the visibility of their impairments appeared to influence whether or not respondents felt their group boundaries were permeable and whether or not they could successfully claim or reject a disabled identity.

Respondents who identified as disabled recognized that they possessed characteristics that placed them in the social identity group disabled, and the information gleaned from social comparisons, reflected appraisals, and others' acceptance of their self-presentations all served to verify their identity claim (see Table 5.4). While these respondents experienced stigmatization, they were also accepting of their limitations and did not perceive their social group as permeable. Therefore, they identified as disabled.

[Insert Table 5.4 about here]

In contrast, respondents who disidentified as disabled possess fewer mobility limitations, had fewer visible markers of impairment, were resistant to stigmatization, and received consistent messages through social interactions that indicated they were not viewed as disabled. This combination of factors likely contributed to respondents' perceptions of their social group as permeable and their efforts to distance themselves from a disabled identity. These respondents verified their identity claims by making social comparisons between themselves and those with greater mobility restrictions, and by actively presenting their selves as not disabled.

Finally, respondents who were still negotiating this identity felt both disabled and not disabled. Although they had fewer mobility restrictions than those who identified as disabled, these respondents did recognize that their impairments could mark them as disabled. Like respondents who disidentified with this identity, these respondents desired to avoid stigmatization and would actively present themselves as not disabled. These respondents' downward comparisons between themselves and those with more severe mobility restrictions serve to verify that they were not disabled. However, the information they received regarding their self through the reflected appraisal process served to verify that they were disabled. Therefore these respondents have been unsuccessful in maintaining any identity claims, and thus report that they feel at times disabled, and other times not disabled.

Summary of Findings

The findings from the quantitative and qualitative data demonstrate that indicators of disability from both the social and medical models, as well as self processes all play an important role in claiming an identity as disabled. Although respondents from both samples experienced numerous environmental and social barriers, it was their experiences of social barriers and impairment that had strong effects on their identity claims. In addition, experiences of socially constructed barriers and impairment were mediated through self processes in shaping respondents' identity claims. Finally, the consistency of messages received regarding their self helped shape their identity claims.

Respondents were agentic in their identity claims. Respondents were selective in regards to which others they chose to compare themselves, which in turn verified

the identity claim. Some respondents also engaged in effective self presentations which served to confirm their identity claims. In taking these actions, respondents may have brought others appraisals in line with their own. However, for respondents who were still negotiating this identity, their self-presentations were not always accepted as valid. Despite actively presenting themselves as not disabled, others continued to view these respondents as disabled. This self process was an effective tool in verifying identities among respondents who identified as disabled and those who did not, but not for those who were still negotiating this identity.

Albeit somewhat dependent on the degree to which these individuals were impaired or experienced socially constructed barriers, impaired individuals are agentic in terms of what appraisals were meaningful, with whom they compared themselves, and how they presented themselves to others. These findings demonstration that it is not just the experiences of socially constructed barriers and impairment that matter for identification of self as disabled, but rather how impaired individuals integrate these experiences into their self - a process that is better understood using self-theories as elucidated in this chapter.

Chapter 6: Social Status and Disabled Identity Construction

In this chapter, I examine the final research question: How is the process of an identity formation as disabled influenced by social statuses, such as gender, race, social class, and age? In part one of this chapter, I discuss the main effects of these statuses on identity, with quantitative data. In part two, using data from the qualitative interviews, I expand on how a key social status – gender - is relevant to the disabled identity process. Finally, in the third part of this chapter, I examine interaction effects, and show how the social and medical models influences identity, but more so for those with high status.

Effects of Gender, Race, Social Class, and Age: Findings from the Quantitative Data

In the preceding analyses (see Table 5.2, Model 4), gender, education and income were found to have strong and persistent effects on the claiming of a disabled identity, independent of socially constructed barriers and impairment. Females had lower odds of identifying as disabled compared to males (OR= .46, p<.001). As a respondent increased in age, the odds that they would identify as disabled also increased (OR=1.03, p<.001). Finally, higher family income decreased the odds that a respondent would identify as disabled (OR= .94, p<.001). No race or education differences were found.

The introduction of environmental barriers and social engagement into the model had no effect on the relationship between gender (OR=.43, p<.001) and income (OR=.96, p<.001) on claiming an identity as disabled. However, the effect of

age on claiming an identity as disabled decreased in significance (OR=1.01, p<.05), and education level became positively and significantly related to claiming an identity as disabled (OR=1.12, p<.01).

The introduction of medical model indicators into the analysis slightly decreased the odds of being female and claiming a disabled identity even more (OR=.37, p<.001). No change in the relationship between income (OR=.96, p<.001), nor education (OR=1.14, p<.01) and claiming an identity as disabled occurred. The effect of age, however, did diminish to non-significance.

Finally, with the introduction of reflected appraisals, the odds of females identifying as disabled increased slightly (OR= .51, p<.001), and the relationship between income (OR= .97, p<.01) and education (OR = 1.18, p<.01) and identifying as disabled remained the same as in Model 3.

In sum, strong and persistent effects of gender, education and income on claiming a disabled identity were found. Interestingly, higher status individuals (i.e., men and more highly educated individuals) were more likely to identify as disabled once all of the variables were included in the model. The relationship between gender and education, and claiming a disabled identity increased in magnitude in the final and full model. That is, even after controlling for social and medical model indicators of disability, men and higher educated individuals had higher odds of claiming a disabled identity than did women and individuals with less education.[17] A negative persistent relationship is found between individuals' income levels and claiming a disabled identity. Respondents with less income are more likely to claim a disabled

[17] Two way interactions between gender and race, and gender and education, were not significantly associated with claiming a disabled identity (analyses not shown).

identity, independent of the environmental and social barriers they experienced, as well as their degree of impairment. This finding is not surprising given that respondents who are low income may be seeking out government resources, and therefore must claim an identity as disabled. In the next set of analyses, I examined further the relationship between gender and claiming an identity as disabled using data from the qualitative interviews. However, because of the nature of the qualitative sample, I was not able to examine the relationship between socioeconomic status and claiming a disabled identity.

Gender Inequalities in Claiming a Disabled Identity and Gender Enactments: Findings from the Qualitative Data

Gender was found to influence the process of claiming a disabled identity in a number of ways. First, several women discussed how their experiences of impairment were invalidated by others and consequently they were not viewed as disabled by these others. These experiences had an impact on these women's everyday lived experiences, and in some cases, on their own identity claims. Women's experiences of impairment were not validated in two ways that I detail below. First, a few women who were mothers reported that because they were the primary caregiver in their family, other family members did not perceive them as disabled. Second, some women reported that significant others did not recognize them as disabled, but rather perceived them to be simply overweight. No men reported such experiences. Disability was also found to influence the enactment of gender in terms of masculinity and femininity. First, several women (and one man) discussed feeling unattractive and undesirable as a partner because of their impairment. Finally, many

men that I interviewed also discussed the loss of athleticism as an important disabling experience that resulted from their impairment. However, this pattern was also found among some women. These findings are discussed in more detail below.

Questioning Women's Disablement - "Mom shouldn't get sick"

Earlier research on gender inequalities in disability pointed to the fact that disability is more detrimental for women, as they are stereotyped as lacking resources necessary to be a suitable partner and mother and to achieve ideal beauty standards (Sheldon 2004; Gill 1996; Oliver 1990; Vernon 1999; Zitzelsberger 2005; Thomas 1997; Asch and Fine 1992; Hanna and Rogovsky 1991). This section will elucidate how being female may affect the actual claiming of an identity as disabled, regardless of actual impairment.

As mentioned above, a few mothers discussed how their role as the primary caregiver in their family served to undermine their identity claims as disabled. These women felt that because their children were dependent upon them, they did not perceive them as disabled. For example, one mother, who self-identifies as disabled, believes her adult children (who also have health issues of their own) do not perceive her as disabled. Here she describes how her children respond to her limitations,

> "The children, they say there's nothing wrong with me. They would like to work me to death. So they say 'there's nothing wrong with you mom.' And that's sometimes, you know, they work me even more." (Olivia, a black woman in her 50s)

When asked how this makes her feel when her children do not validate her identity claims, she stated,

> "It makes you feel bad because they're not really considering that, you know, mom doesn't- mom shouldn't get sick. I guess it's because I've

> been doing so much stuff for them for so long that they still like, 'well there's nothing wrong. Nothing can ever happen.'"

This mother also acknowledged how her own behavior contributes to her children's perceptions of her. Here she describes her daily activities and how she often has no time left to care for herself.

> "Washing dishes, washing clothes, going to the doctor's office (with her kids), going grocery shopping… A lot of times I put myself on the backburner and that can be difficult."

Similarly, another mother, who did not identify as disabled, also discussed how as a single mother she is so burdened with caregiving and home maintenance that she doesn't have time to deal with her impairment.

> "I have to do everything. I take the kids to all the doctor's appointments. I have to do it all… I don't even have time even to get to a doctor (for herself)…. Have to go grocery shopping and washing and do this, do that, schoolwork….everything falls on me." (Caryn, a black woman in her 50s)

This respondent went on to discuss how she does not think her children view her as disabled because they are so reliant on her and she cites this as one of the reasons why she does not perceive herself as disabled. This respondent felt that if she had to rely on others, the way her children rely on her, then she would be disabled. This is an interesting point as it suggests, as other previous research also has, that caregiver and disabled are contradictory roles (Sheldon 2004; Gill 1996; Oliver 1990; Vernon 1999; Zitzelsberger 2005; Thomas 1997; Asch and Fine 1992; Hanna and Rogovsky 1991). As these women demonstrate, acting as caregiver can contradict, in some cases, individuals' identity claims as disabled. This is further supported by mothers who felt that the relinquishment of their role as caregiver, as a result of their impairment, served to verify their identity claims as disabled.

For example, another mother, who was still negotiating her identity as disabled, also felt that her children did not view her as disabled because her children are very dependent on her. Like the mother above who identifies as disabled, this respondent describes her children's dependency on her in the same way: "They work me to death." However, for this respondent, her ability to fulfill her caretaking role as a mother, which she greatly values, is directly tied to her negotiation of an identity as disabled. Here she describes how she does not feel disabled when she can care for others.

> "I'm tired but I like doing something, doing things for whoever needs them. This makes me feel like I'm not disabled even though I walk like I am." (Clair, a black woman in her 60s)

Conversely, she feels disabled on days when she can't leave the house due to pain and fatigue, and therefore cannot help other family members with their own everyday needs.

Other mothers also discussed how their inability to physically keep up with their children at times, and provide for them, indicated to them their disablement, and subsequently affected their identification as disabled. For example, one mother discussed how she both identified as disabled and perceived her children and grandchildren to view her in this way because her impairment often kept her from caring for them.

> "They can look at me and see that I have a disability. They know that, especially my kids. They know that there are days when grandma is hurting too bad and she doesn't want to get up and she doesn't want to go. She doesn't want to do, you know? Even though I don't leave the house, I'm still the primary cook. I'm still the primary clothes washer, and, you know, I'm still the primary house- I still primarily take care of the house. Of course they know there are days when momma just don't want to do." (Nicole, a black woman in her 40s)

Similarly, another mother also identified as disabled and perceived her children and other family members to view her in this way. For this mother, the inability to keep up with her active young children due to a recent impairment makes her feel disabled.

> "My children, they like to go to different places and do different things. And they're just not used to being in the house on the weekends and… they want to be, on nice days, outside and stuff. So you want to go out and do things but you can't." (Keisha, a black woman in her 20s)

A couple of men also discussed their children's perceptions of them and how these perceptions influenced their own self-perceptions. However, these respondents' observations had less to do with their roles as caretakers, and more to do with their loss of physical abilities. For example, one male respondent did not perceive himself to be disabled; however, he did feel that his adult children, in particular, viewed him as disabled. When asked why he felt his children viewed him as disabled he discussed how he could no longer physically keep up with his children.

> "I'm slowed down, and you know, I take my time. You know, you asked about doors, they're not a problem because I take my time and I get through them. But they're (his children) running ahead and they're going wherever they got to get to. They don't mind parking six blocks from- which I used to do. Now I like to get dropped off, so…" (Frank, a white man in his 50s)

Another father, who is disabled as a result of mobility and visual impairments, discussed his daughters' reactions to him losing his eye due to injury. This respondent identifies as disabled and perceives his children to view him as disabled.

> "Like they say 'daddy got one eye.' So you know, let's keep it real. And then, you know, that make me feel kind of uncomfortable because I didn't have it (a disability) and now I got it. But that makes me feel I'm disabled." (Jamal, a black man in his 40s)

Although these men did discuss their children, and in particular their children's perceptions of them, when discussing their own identity claims, their discussions revolved more around their children's views of their abilities and not their caregiving and its complexities on claiming a disable identity.

These findings build from previous research in which able-bodied others view disabled women as incapable of caretaking and are discouraged from mothering (Sheldon 2004; Gill 1996; Oliver 1990; Vernon 1999; Zitzelsberger 2005; Thomas 1997; Asch and Fine 1992; Hanna and Rogovsky 1991). This study differs from previous research as it examines women who became mothers prior to becoming impaired. For some of these women, instead of being denied the role of mother, they are being denied (by their children) the role of being disabled. However, as noted, mothering is a role that is very meaningful for these women, and the inability to effectively fulfill this role influences their identity claims as disabled.

Questioning Women's Disablement – "The leg still hurting 'cause you gained all that weight."

Another way others questioned women's disability identity claims was by attributing their physical limitations to reasons others than impairment. For example, during the interviews a couple of women discussed how others attributed their physical limitations to recent weight gains, rather than to a disability. Here one woman describes how significant others do not view her as disabled, but rather as overweight.

> "My friend, he always say to me 'the leg still hurting 'cause you gained all that weight.'" (Laurie, a black woman in her 40s)

Although this respondent did report gaining 25 pounds since her injury occurred, she herself does not feel as though the weight is contributing to the residual pain she still feels from that injury.

> "I say 'nooo, it ain't got nothing to do with it. Should be my feet hurting.' That's what I say to him."

While she doesn't attribute her residual pain to weight gain, but rather to the prior injury, she also does not perceive herself to be disabled and she does not perceive others to view her as disabled, as result of their direct appraisals.

Similarly, another woman mentioned that she perceives herself to be disabled and while she generally perceives others to view her as disabled, she doesn't perceive specific significant others to view her as disabled. Like the respondent above, this respondent's significant others also attribute her physical limitations to her weight, rather than an underlying condition, and therefore they do not view her as "disabled." Despite being diagnosed with severe arthritis, she receives direct appraisals from significant others, in which they tell her that the pain and physical limitations she experiences would be alleviated if she got more exercise and lost weight.

This is not to say that weight gain is an unlikely contributing factor to these women's impairment. In fact, other women in the study did acknowledge how weight gain in combination with underlying conditions led to their impairment. For example, one woman stated that her knee injury and the resulting pain and movement difficulty that followed were the source of her impairment. However, her doctor had told her that her weight is also putting additional strain on her knee, preventing it from fully healing.

> "(The doctor) said by me being a little overweight that puts another strain on the knee." (Keisha, a black woman in her 20s)

Correspondingly, another woman described how she gained almost 150 pounds since the onset of her impairment, and she believes that this weight gain further limits her mobility. However, both of these women identified as disabled, and also considered others to view them as disabled, independent of their weight gain.

What is most interesting about this finding, however, is that no men mentioned this issue of weight when discussing their identity claims despite the fact that several male respondents were overweight. Although, given the prevalence of gendered stereotypes regarding disability in the general population, these findings are not surprising. For example, one study found able bodied others tended to attribute males' impairment to masculine, external activities, such as injuries from war, sporting accidents, or on the job accidents, whereas females' impairments were more likely to be attributed to internal or personal causes such as disease or illness or accidents that could be associated with carelessness, such as, falling down the stairs (Hanna and Rogovsky 1991). Attributing women's experiences of pain, fatigue and physical limitations to factors other than impairment delegitimizes their experiences and denies their identity claims.

Gender and Femininity/Masculinity: Becoming Unattractive and Undesirable

Women were also more likely than men to discuss the internalization of stereotypes which labeled disabled persons as unattractive and undesirable partners. Feeling unattractive as a result of one's impairment was a common theme among the women interviewed, particularly among respondents who were looking to partner. As

mentioned in the previous chapter, some women made upward social comparisons between themselves and other able bodied women, including their own formerly able-bodied self. These social comparisons led them to perceive themselves as unattractive and undesirable to others. For example, one woman stated,

> "It's just that, you know, you got a disability and you look at the other women. It make me have low self-esteem. Because then I feel damn they don't have this, they got one over me…. I just compare myself, like when I go out. And it's not just about a person, but I compare myself to this person or this, or I think my friend messing with somebody and I say 'oh and she,' in my mind, 'this person don't have this handicap,' stuff like that." (Jackie, a black woman in her 40s)

Similarly, another woman discussed how her impairment makes her feel unattractive and less desirable to men.

> "It (the amputation) makes me feel ugly honestly. And deformed is actually a word I use a lot… I feel deformed…. It's a pretty drastic change to go from being 29 and pretty and having me sort of fawning over you, blah, blah, blah, having no problems getting dates, whatever, and then now I'm full of scars and very self conscious about that and exposing the prosthesis in a public setting makes me feel unattractive." (Beth, a white woman in her 30s)

Although all of these women identified as disabled, they would actively try to conceal their disablement when out in public. In fact, as mentioned in the previous chapter, these women were often so good at concealing their impairments that others would often not recognize them as disabled, and at times challenge their disabled identity when they sought to claim it.

One man did discuss during the interviews feeling self-conscious of his impairment when dating,

> "I've never had a woman come out and tell me this. It's just something I sense. Sometimes I sense that women don't want to get involved with a guy that's got a prosthetic leg… I don't think anyone in their right mind is going to come out and say anything. It's just a feeling. You

> know, women that I've pursued, you know, just, you know… or maybe I'm just a donkey and they don't want to get involved with me. I don't know…. I guess I really believe that there's women that just don't want to get involved with a guy that's different from the norm." (Jim, a white man in his 50s)

However, unlike the women above this man does not perceive himself to be disabled and he makes no effort to conceal the fact that he is impaired.

This finding is not surprising, given previous research which suggests that impaired women are denied traditional female roles, as they are stereotyped as lacking resources necessary to be a suitable partner, mother and to achieve female beauty ideals (Sheldon 2004; Gill 1996; Oliver 1990; Vernon 1999; Zitzelsberger 2005; Thomas 1997; Asch and Fine 1992; Hanna and Rogovsky 1991).

Loss of Athleticism: "I used to be an athlete. Now I just watch guys."

While issues of mothering, attractiveness/weight, and dating often came up during women's discussions of their identity claims, for men, many of the discussions of how they came to identify as disabled centered on the loss of their athletic abilities. Again, this finding is not surprising given that previous research which has examined the interaction of gender and disablement has found that disability runs counter to hegemonic masculinity. However, in the current study I found that because impairment or disability at times prevents men from enacting male gendered roles, this serves to make them feel disabled. Several men mentioned how as a result of their impairment they could no longer participate in athletic activities. As one man put it,

> "I used to be an athlete. Now I just watch guys." (Bernard, a black man in his 50s)

The inability to engage in athletic activities was a theme that came up throughout my interviews with men, without solicitation on my part. All of these men cited loss of these activities as reasons for why they identified as disabled, however one of these men was still negotiating this identity. For example, when asked why he identified as disabled, one man discussed how the inability to play sports was an indication to him that he was disabled.

> "I can't shoot baskets and stuff like that anymore. Can't play racquetball, can't play handball. I'm definitely not riding a horse. Things that I used to do… not playing Frisbee, not throwing a Frisbee around. Football is out of the picture… I'm disabled because I can't do what I used to do. I basically physically can't do it." (Ben, a black man in his 50s)

Similarly, when asked why he considers himself to be disabled another man stated this was due to the loss of his athleticism.

> "To me a disability is something that hinders you from normal activity and that is definitely my case. There are things I cannot do, like play soccer or run or get the proper exercise that I need." (Marcus, a black man in his 40s)

It should be noted however that some women also discussed how their loss of athleticism was disabling for them. For these women, the loss of ability to perform athletic activities that had also once been part of their normal routines felt disabling to them. For example, one woman described the loss of her ability to do physical activities as when she first realized that she was disabled.

> "I used to do a lot of walking. I was a person who was very, very active… swimming. I can't do my swimming like I used to, and the walking I used to do, and I used to run." (Dina, a black woman in her 40s)

In sum, there is strong indication from the quantitative data that indicates women at the same level of impairment as men are less likely to identify as disabled.

The qualitative data also shows that gender shapes the disablement process. Women's experiences of impairment are not always taken seriously. First, because of some women's roles as mothers, their experiences of fatigue, pain, and movement difficulty are denied and subsequently they are not viewed as a disabled. This is consistent with prior research which finds that disability and motherhood are often perceived as contradictory roles (Sheldon 2004; Gill 1996; Oliver 1990; Vernon 1999; Zitzelsberger 2005; Thomas 1997; Asch and Fine 1992; Hanna and Rogovsky 1991). Women's identity claims are also rejected in other ways, and their experiences of pain, fatigue and mobility limitations are attributed to things other than impairment, such as weight gain. Furthermore, women who are impaired encountered more difficulty when it came to dating and forming intimate relationships. In other words, being "disabled" made it difficult for these women to enact a feminine gender role. Part of the reason for this is disability runs counter to feminine standards of beauty, a stereotype that the women I interviewed were well aware of and had at times internalized. These findings may help explain why women are less likely to make identity claims as disabled – that is, they are not supported when they do, and they may have little incentive to do so due to greater costs.

Social Statuses and Identity: Status Differences in the Impact of Social and Medical Model Indicators on Claiming a Disabled Identity

In the final set of analyses I examined how the relationship between socially constructed barriers and impairment and claiming an identity as disabled differed by social statuses. Using data from the quantitative analyses, two way interactions were created by interacting indicators of disability from the social and medical models of

disability with gender, race, class, and age.[18] These interactions were added to the regression models to determine if environmental barriers, social barriers and impairment have differential effects on claiming a disabled identity depending on one's position in the social structure.

Overall 10 significant interactions were found, however, here I focus on interactions between gender, race, social class, and age and the three of the main independent variables that continued to be significant in the full regression model (see Model 4 of Table 5.2): employment status; severity of movement difficulty, and instrumental activities of daily living (IADLs). First, race and age both affected how employment status influences the claiming of an identity as disabled. Additionally, education level affects how severity of movement difficulty influences the claiming an identity as disabled. Finally, gender, race, poverty level and education level all affect how IADLs influence the claiming of an identity as disabled. These findings are discussed in more detail below.

The Social Model: Employment Status

The relationship between employment status and claiming a disabled identity differed by race (OR=2.21, $p<.05$) (See Table 6.1). In analyses not shown here, I performed separate regression analyses for blacks and whites to further understand the effects of this significant interaction between race and employment status on claiming a disabled identity. Among blacks, no significant relationship was found between employment and claiming a disabled identity (OR=1.46, p=ns), however,

[18] A dichotomous indicator of poverty was used in lieu of income or education as a measure of class, and dichotomous indicators of age and education groups (i.e., young versus old, high school education or less versus some college or more) in lieu of the continuous age and education variables.

among whites, those who were employed had significantly lower odds of claiming a disabled identity (OR=.48, p<.001) (analyses not shown).

[Insert Table 6.1 about here]

The relationship between employment status and claiming a disabled identity differed, as well, by age (OR=1.99, p<.01) (see Table 6.2). In analyses not shown here, I performed separate regression analyses for younger adults and older adults to further understand the effects of this significant interaction between age and employment status on claiming a disabled identity. Among respondents who were young (18-44) (OR=.35, p<.001) and old (45-64) (OR=.69, p<.05) being employed decreased the odds that they would claim a disabled identity; however this relationship was smaller among older respondents (analyses not shown).[19]

[Insert Table 6.2 about here]

The Medical Model: Severity of Movement Difficulty

The only social status that was found to interact with severity of movement difficulty in predicting the claiming of a disabled identity was education (OR=1.31, p<.05) (see Table 6.3). In analyses not shown here, I performed separate regression analyses for respondents in the low education group (i.e., completion of high school or less) and those in the high education group (i.e. some college or more) to further understand the effects of this significant interaction between education level and severity of movement difficulty on claiming a disabled identity. For respondents in

[19] The interactions education*severity of movement difficulty, race*IADLs, poverty*IADLs, gender*IADLs, education*IADLs, race*work, age*work were added to the full regression model (Model 4 of Table 5.2). Only four of these interactions remained significantly associated with claiming a disabled identity. Education by severity of movement difficulty (OR=1.23, p<.05), education by IADLs (OR=.70, p<.01), race by employment status interaction (OR=2.22, p<.05) and age by employment status (OR=1.94, p<.01) continued to be significantly associated with claiming a disabled identity (analyses not shown).

the low education group, severity of impairment had no effect on claiming a disabled identity (OR=1.15, p=ns), however, for respondents who were in the high education group the severity of their movement difficulty increased the odds that they would claim an identity as disabled (OR=1.48, p<.001) (analyses not shown).

[Insert Table 6.3 about here]

Medical Model: IADLs

As described earlier, IADLs are difficulties performing household management tasks, including preparing one's meals, shopping for groceries, managing money, using the telephone, doing heavy and light yard work. The relationship between IADLs and claiming an identity as disabled differed by gender (OR=.68, p<.05) (see Table 6.4). In analyses not shown here, I performed separate regression analyses for women and men to further understand the effects of this significant interaction between gender and IADLs on claiming a disabled identity. For women, having difficulty performing IADLs was not significantly associated with claiming a disabled identity (OR=1.12, p=ns), however for men, the more difficulty experienced with these activities the higher the odds that they would claim an identity as disabled (OR=1.50, p<.05) (analyses not shown).

[Insert Table 6.4 about here]

Additionally, the relationship between IADLs and claiming an identity as disabled differed by race (OR=.74, p<.05) (see Table 6.1). In analyses not shown here, I performed separate regression analyses for blacks and whites to further understand the effects of this significant interaction between race and IADLs on claiming a disabled identity Among blacks, experiencing difficulty with IADLs was

not associated with claiming a disabled identity (OR=.79, p=ns); however, among whites, those who experienced more difficulty with IADLs had higher odds of claiming an identity as disabled (OR=1.27, p<.01) (analyses not shown).

The relationship between IADLs and claiming an identity as disabled also differenced by education level (OR=.78, p<.05) (See Table 6.3). In analyses not shown here, I performed separate regression analyses for respondents in the low education group and those in the high education group to further understand the effects of this significant interaction between education level and IADLs on claiming a disabled identity Among respondents who were in the low education group, the more difficulty experienced with IADLs, the higher the odds of claiming an identity as disabled (OR=1.29, p<.01), however among respondents in the high education group, experiencing difficulty with IADLs was not associated with claiming a disabled identity (OR=1.04, p=ns) (analyses not shown).

Finally, the relationship between IADLs and claiming an identity as disabled differed by income (OR=1.12, p<.05) (see Table 6.5). In analyses not shown here, I performed separate regression analyses for respondents whose income was above the poverty line and those whose income was below the poverty line to further understand the effects of this significant interaction between income and IADLs on claiming a disabled identity. Among respondents whose income was above the poverty line, experiencing difficulty with IADLs significantly increased the likelihood of claiming an identity as disabled (OR=1.29, p<.001); however, among respondents whose income was below the poverty line, having difficulty performing

IADLs had no significant effect on claiming a disabled identity (OR= .95, p=ns) (analyses not shown).

[Insert Table 6.5 about here]

These findings indicate that individuals of higher (or more valued) statuses who were not employed, have more severe movement difficulties, and have more difficulty performing IADLs are more likely to claim an identity as disabled (See Table 6.6). That is, among whites and young adults, not being employed increases the likelihood that they will identify as disabled, whereas for women and blacks employment status has no effect on claiming a disabled identity. Additionally, among the more highly educated, persons with more severe movement difficulties are more likely to claim an identity as disabled. Finally, among men, whites, and persons whose income is above the poverty line experiencing difficulty with IADLs increases the likelihood they will claim a disabled identity. Conversely, for women, blacks, and persons whose income is below the poverty line, experiencing difficulty with IADLs has no effect on claiming a disabled identity. One exception is respondents who are less educated and experience IADLs are more likely to identify as disabled than those who are more educated. The reason why respondents of higher status who experience IADLs are more likely than those of lower status to claim a disabled identity may be rooted in sociocultural differences in these groups when it comes to attachment to the labor force, the severity of movement difficulty, and performing IADL type activities.

[Insert Table 6.6 about here]

In terms of employment status, being employed is a normative activity for adults between the ages of 18-64. However, employment is a more normative activity

for younger adults, as the likelihood of making labor force exits increases with age. Therefore, younger adults, who are not employed, may be seen as non-normative and this may influence their perceptions of their abilities and thus their identification as disabled. However, the finding of a race by employment status interaction effect on claiming a disabled identity appears puzzling at first given the higher prevalence of disability in the black population in comparison to whites, and the higher labor force exit rates of blacks due to disability, in comparison to white workers (Hayward, Friedman, and Chen 1996). However, this effect may be the result of sociocultural factors that shape black individuals' labor force experiences. Because of the lack of employment opportunity, the lesser returns from work, and the nature of the work available to blacks, they may have less attachment to the labor force (Bound, Schoenbaum, and Waidmann 1996), and therefore exiting the labor force for reasons such as impairment, may have less influence on their identity as a disabled person, in comparison to whites.

The measure of work used in this study is somewhat problematic as well, mainly because it is not known why respondents are unemployed. Exits from the labor force may be voluntary or involuntary, and they may be caused by a number of reasons, including one's impairment, discrimination, and economic reasons, such as a lack of opportunities available. For example, blacks may attribute their unemployment to other reasons, such as discrimination or changes in the economy (i.e., the availability of appropriate work).

One reason why experiences of impairment affect identity claims differently for high low and status individuals may be because claiming a disabled identity

validates functional limitations that impede one's ability to claim their other more valued statuses. For example, among men having functional limitations is known to decrease their ability to effectively engage in masculine performances (Gerschick 2000; Morris 1991; Robertson 2004; Valentine 1999). Therefore, claiming a disabled identity may legitimate the loss of activity that marks their masculinity.

Another reason for these findings may be response bias. For example, the validity of IADLs as a measure of disability has been called into question by several studies, which have found difficulty performing IADLs to be a function of gender (Fleishman, Spector, and Altman 2002; Peek and Coward 1999) and socioeconomic status (Kabir et al. 2001). IADLs, including grocery shopping and preparing meals are tasks that are traditionally performed by women. Therefore, these tasks may be particularly difficult to men to perform in comparison to women (Kabir et al 2001; Allen, et al. 1993).

While no research has examined the possibility of response bias in IADL measures by race, it is possible that a cultural effect is occurring here as well. Blacks, in comparison with whites, may be more likely to receive help from significant others due to the structure of black communities. Therefore, black adults who are impaired and having difficulty performing IADLs may receive more help from others, which could make them feel less disabled.

In sum, findings from the quantitative analyses indicate that among whites and younger respondents being unemployed led to higher odds of claiming a disabled identity, in comparison to blacks and older respondents. Additionally, among respondents of higher statues (i.e., whites, men, higher social class) having more

severe movement difficulty and difficulty performing IADLs was significantly related to claiming an identity as disabled. However, these findings should be interpreted with caution, as there are a number of reasons for why these patterns are occurring that could not be explained within the scope of this study.

Summary of Findings

Social statuses, particularly gender and social class have important implications in the construction or rejection an identity as disabled. Those with higher social statuses (men and more highly educated) were more likely to claim (or be able to claim) a disabled identity, all things equal.

Findings from the qualitative interviews also showed how gender shapes the disabled identity process. Women were more likely than men to have their disabled identity claims challenged by others. In particular, mothers were denied this identity by their children who relied on them as the recipients of their caregiving. Conversely, mothers also recognized how their disability and their roles as mothers were contradictory. For some mothers, their inability to perform their caregiving roles made them feel disabled. Women's disability claims were also challenged by significant other who attributed their experiences of pain, fatigue and mobility limitations to things other than impairment, such as weight gain. By denying these women's identity claims as disabled they were also denying them the much needed support and care. These findings are a possible explanation of why women are less likely than men to claim an identity as disabled. Perhaps when they attempt to do so they are denied and when they are allowed to do so, their womanhood is then called into question.

Women also felt the negative experiences of impairment, as disability runs counter to their femininity. These women felt less attractive and desirable and found it hard to make intimate connections with others. Although men did discuss some experiences of being denied masculinity, such as the inability to play sports, as a result of their impairment, some women also discussed similar experiences.

Consistent with this, interactions between social statuses and the medical model were identified. Generally among respondents of higher statues (i.e., whites, men, higher social class) having more severe movement difficulty and difficulty performing IADLs was significantly related to claiming an identity as disabled. Additionally, among whites and younger respondents being unemployed led to higher odds of claiming a disabled identity, in comparison to blacks and older respondents. The claiming of a disabled identity among individuals of higher statuses may serve to validate their inabilities to enact these higher statuses as result of their impairments. For example, men who can no longer play sports may rely on their identity claims as disabled to justify their inability to enact masculinity. In other words, although claiming a disabled identity may be beneficial to all impaired individuals in terms of receiving much needed resources such as government support, for high status individuals, claiming an identity as disabled may provide additional social benefits at the interactional level.

Chapter 7: Discussion and Conclusion

In this dissertation, I examined the process by which individuals with physical impairments come to identify as disabled. Using data from a nationally representative sample of adults with mobility limitations, as well as data from 30 qualitative interviews, I assessed how factors such as environmental and social barriers, as well as experiences with impairment affect the claiming or rejection of an identity as disabled. In addition, drawing on theories of the self, I examined how these experiences are mediated through self-processes in forming one's identity. Finally, I examined how these processes are influenced by one's gender, race, social class and age.

Despite being physically impaired, many individuals in the current study did not identify as disabled. This finding was consistent with previous research on disability identity construction (Priestley 1999; Watson 2002; Taub, McLorg and Fanflik 2004; Watson 1998; LoBianco and Sheppard-Jones 2007; Iezzoni et al 2000). However, data from the qualitative interviews uncovered a third identity group that was not readily apparent in the quantitative data – individuals who are in the process of negotiating a disabled identity. These respondents had not formed stable identities as either disabled or not disabled. Although they sought to disidentify from a disabled identity, they received many messages that indicated others viewed them as disabled.

The first research question asked: How do environmental and social barriers versus physical impairments affect the claiming of a disabled identity among adults with physical impairments? Experiences of environmental and social barriers had important implications for respondents' identity claims. In both the quantitative and

qualitative data, the more environmental and social barriers respondents experienced, the more likely they were to identify as disabled. However, experiences of impairment also had strong implications for identifying as disabled. Respondents who experienced more physical limitations and used assistive devices were more likely to claim an identity as disabled. During the interviews, respondents discussed social barriers and impairment, but not environmental barriers, as important factors that influenced their identity claims.

The second research question asked: How do self processes (i.e. reflected appraisals, social comparisons, and self-presentation) inform the embracement or rejection of a disabled identity? Self processes were fundamental in helping respondents understand their positioning in society and verify their identity claims. First, reflected appraisals were instrumental in providing respondents with feedback regarding how significant others and the generalized other viewed them in terms of being disabled, in both the quantitative and qualitative analyses. Individuals who perceived others to view them as disabled were significantly more likely to claim an identity as disabled. Moreover, reflected appraisals were found to mediate the effects of environmental barriers, social barriers and impairment on claiming a disabled identity. This indicates that impaired individuals' experiences of socially constructed barriers and impairment influenced how they perceived others to view them (as disabled/not disabled) and this in turn affected their own identification with a disabled identity.

In the qualitative analyses, I was able to explore two other self processes: social comparisons and self presentations. Both of these self processes played a

critical role in respondents' identity claims. Respondents relied on social comparisons between themselves and others to understand their place in the social structure (i.e., whether or not they are disabled). To do so, respondents first defined what it meant to be disabled. This definition contained criteria often used in medical model definitions of disability. That is, they recognized disability as stemming from mobility limitations, reliance on assistive devices and the help of others, and impairments. Respondents then used to this information as criteria with which to compare themselves against others. However, respondents differed in the types of social comparisons they made. Respondents who identified as disabled typically did not view their identity group as permeable and therefore made upward social comparisons between themselves and able bodied others to verify their identity claims. Conversely, respondents, who did not identify as disabled, did view their social group as permeable and therefore made downward social comparisons between themselves and others who were more impaired, and who they considered disabled. Permeability of group boundaries or the ease at which individuals were able to move from one social group to another, depended on the degree to which respondents were impaired, the visibility of their impairments and the consistency of messages they received regarding how others perceived them. This is discussed further below.

Self-presentations played an important role in allowing some respondents to verify their identity claims. Respondents who identified as disabled and those who did not identify as disabled had effective self-presentations, meaning they felt others accepted the presentations they put forth as valid. However, for respondents who were still negotiating this identity, their self-presentations were not always accepted

by others. Despite actively presenting themselves as not disabled, others continued to view these respondents as disabled.

In sum, self processes mediated the relationship between respondents' experiences with social barriers and impairment and their identity claims. Respondents' identity claims were ultimately determined by the consistency of information learned about their self through these self processes. For example, respondents who identified as disabled received consistent actual and reflected appraisals that they were in fact disabled, and these messages were consistent with respondents' own self-appraisals. Additionally, these respondents made upward social comparisons with those who were able bodied, which served to validate their differentness from able bodied others. Although these respondents experienced stigmatization and as a result would not disclose their disability in particular contexts, these respondents were also more accepting of their impairments and their "disability" than respondents who did not identify as disabled and those who were still negotiating this identity. A finding that is consistent with other literature that claims individuals who have accepted their disability are more apt to claim it as an identity and will see it as a positive aspect of their self (Mpofu and Harely 2006).

Respondents who did not identify as disabled did not simply possess a negative identity, but rather a disidentification (Killian and Johnson 2006; McCall 2003). Respondents who disidentified were acutely aware of the stigmatization of a disabled identity and sought to avoid it. For these respondents, because they were less impaired, had fewer markers of disablement (use of an assistive device), and received consistent messages from others indicating that they were not viewed as disabled,

they were able to view their own identity boundaries as permeable and therefore effectively disidentified. Through their social comparisons and self presentations they verified their disidentification from a disabled identity. These findings are similar to those of Killian and Johnson (2006) and Waters (1990) who found individuals who were resistant to a stigmatized identity (in this cases an immigrant identity, and black American identity respectively) engaged in identity work by asserting their disidentification with a stigmatized, ascribed identity, and through self presentations.

Last but not least, among respondents who were still negotiating this identity, the information they received through self-processes was inconsistent. Although these respondents experienced fewer physical limitations than those who identified as disabled, they also recognized that they possessed characteristics that could mark them as disabled. Additionally, these respondents perceived others to view them as disabled, for these same reasons. However, like respondents who disidentified from this identity, these respondents sought to avoid stigmatization and made downward social comparisons between themselves and others who were more impaired than themselves. This strategy, as well as their own self-presentations, contradicted the information received through reflected appraisals. Yet because of the varying messages they received these respondents were unable to make a claim as disabled or not disabled. In other words, despite their efforts to reject a disabled identity, others did not accept their identity claims, and therefore these respondents remained in the process of negotiating this identity.

Finally, the last research question asked: How is this process influenced by social statuses, such as gender, race, social class and age? Social statuses (i.e., gender,

race, class and age) were also influential in this process. First, significant effects of gender and social class were found in the quantitative analyses. Even after controlling for social and medical model indicators of disability, those with higher social statuses (men and more highly educated) were more likely to claim a disabled identity. Additionally, a negative persistent relationship was found between individuals' income levels and claiming a disabled identity. Respondents with less income are more likely to claim a disabled identity, independent of the environmental and social barriers they experienced, as well as their degree of impairment, perhaps reflecting efforts to obtain government benefits.

Findings from the qualitative analyses indicated that women were more likely than men to have their identity claims challenged, particularly those who were mothers. Additionally, women's experiences of disablement also limited their ability to fulfill traditional female roles. These findings are not surprising as disabled women have long been stereotyped as lacking resources necessary to be a suitable partner, mother and to achieve female beauty ideals (Sheldon 2004; Gill 1996; Oliver 1990; Vernon 1999; Zitzelsberger 2005; Thomas 1997; Asch and Fine 1992; Hanna and Rogovsky 1991). Women's inability to verify their disabled identity claims may also explain why men, in particular, are more likely to claim a disabled identity. As demonstrated in the analyses of self-processes verification of identify claims through reflected appraisals has important implications for identity maintenance.

Finally, significant interactions were also found between some social statuses, and employment status, severity of movement difficulty, and IADLs in predicting identity claims as disabled or not disabled. Among higher status individuals (i.e.,

whites and younger adults), being unemployed was significantly related to claiming an identity as disabled. Additionally, among the more educated, those with more severe movement difficulty were more likely to identify as disabled. Finally, among individuals of higher status (i.e., whites, men, and those not in poverty) having difficulty performing IADLs was significantly related to claiming an identity as disabled.

These findings indicate that social statuses play an important role in the identification process as disabled. More specifically, these findings indicate that social inequalities exist within the disablement process. Impaired individuals of high status are more likely than those who are of low status to claim a disabled identity, and in the case of gender, men's claims of a disabled identity are more likely to be accepted by others than are women's claims.

One reason for why individuals of higher status are more likely to identify as disabled compared to individuals of low status may be that high status individuals gain more benefits in the interactional context than those of low status. High status individuals who experience loss of physical abilities and stigmatization may find it harder to maintain their other high status identities. For example, men who are physically impaired may find it difficult to maintain a masculine identity. However, by claiming a disabled identity, men may account for the loss in ability to effectively present a masculine identity. In doing, so they may be able to alleviate negative emotions they experience as a result of being unable to verify other salient identities.

As noted earlier, claiming a disabled identity may be less beneficial for women than men. In previous research, impaired women are more likely to be

socially isolated (Hanna and Rogovsky 1991; Bureau of Labor Statistics 2009) and more economically disadvantaged than are impaired men (Hanna and Rogovsky 1991; Fine and Asch 1992). In the current study impaired women were also more likely than impaired men to experience to internalize negative stereotypes regarding disabled persons as unattractive and undesirable partners. Status differences in identity claims as disabled, and the differential benefits gained from disabled identity claims among various status groups, point to social inequalities in the disablement process. Systematic differences in the ability to claim a disabled identity and benefit from doing so, has important implications for the everyday lived experiences of impaired persons, from accessing economic resources to having the self validated.

Limitations

There are several limitations to this study which should be addressed. First, this study is limited in that it only examines the experiences of young to middle aged adults. While the sample was limited to mobility impaired individuals between the ages of 18-64 years for methodological reasons, it limits our understanding of how these processes affect impaired individuals outside of the sample. The construction of a disabled identity and the extent to which the factors examined in this study affect this process may vary depending on where one is in the life course. For example, the process of identifying as disabled may be different for individuals who are born with impairments versus those who become impaired later in life. One reason for this may be that individuals who are born with impairments are not likely to experience the loss of other identities in the same way as those who become impaired later in life, and therefore they may be more willing to accept an identity as disabled. Conversely,

individuals who become impaired in very late life may view their impairment as normative, and therefore may be less likely to identify as disabled. However, it is not always easy to determine the onset of impairment, particularly in the case of impairments that progress gradually over time. In the qualitative interviews, the majority of respondents had difficulty determining the exact onset of their impairment, particularly if they became impaired over time. In the quantitative data, when respondents were asked about the difficulty they experienced when performing certain activities, such as walking a quarter mile, walking up ten steps, standing, etc., they were also asked when they first began to have difficulty with each of these activities. However, because these activities were used to construct a measure of disablement, there was no appropriate way to determine onset, as respondents could have varying level of difficulty with these different activities that first occurred t different time points. Additionally, the onset of other indicators of impairment (i.e., use of mobility aids, ADLs, IADLs) could also have occurred at different time points, making it difficult to accurately assess the onset of the respondents' impairments. Therefore, I did not examine onset of impairment in this analysis.

Additionally, this study only examines one type of impairment – physical impairments. This process of disablement may differ for other types of impairment (e.g., sensory or intellectual impairments), as factors such as physical and social barriers, and impairment may have differential effects on identity construction depending on one's type of impairment. For example, experiences with physical barriers may not influence identity claims in the same way for persons with intellectual impairments, as it does for persons with mobility impairments.

Additionally, some research suggests that social barriers may vary depending on the nature and visibility of one's impairment (Goldstein and Blackman 1975; Cesare, Tannebaum, and Dalessio 1990). Future research should expand this model to include other types of impairments, such as sensory impairments and other age groups, such as children, adolescents, and older adults.

Another limitation of this study is that it does not examine the role of multiple identities in the claiming of a disabled identity. It is possible that ability to claim an identity as disabled is influenced by the other identities individuals claim and the salience and commitment they have for those other identities (Burke 2004). If these identities are in conflict with one another, as may be the case of gender and disabled identities, individuals may not be able to assert these two identities at the same time and have them both verified (Burke 2004). Although it was not within the scope of this study to examine the salience of and commitment to impaired individuals' other competing identities, future research should examine this, as it may have important implications for particular groups' disability identity claims.

The quantitative data used in this study was collected in 1994 and 1995, only a short time following the implementation of the Americans with Disabilities Act. Encounters with environmental and social barriers may have changed over the last fifteen years and these changes cannot be accounted for using this data. Although the data from the qualitative interviews provides a snapshot of the types of barriers impaired individuals continue to experience today, it does not give us a representative picture of the experiences of impaired persons in the present day, and moreover the sample is predominately African American. However, given the fact that the

qualitative sample is similar to nationally representative sample from the quantities analyses in terms of education, income, and age, and the fact that there were no race differences in identity claims found in the quantitative data, the qualitative data may be close to representative of the experiences of physically impaired adults.

Another limitation of this study is that the data is not longitudinal. This limitation applies particularly to the qualitative data. In the qualitative data a third identity group was revealed – the negotiators. However, because the data is only cross sectional I cannot determine if those who were placed into this identity group, later identify as either disabled or not disabled. Identity theory predicts that individuals who cannot verify their identity claims – as in the case of the negotiators – will ultimately abandon their identity claims in favor of other identities that can be verified. In the case of the respondents who were negotiating this identity at the time of the interviews, I would also predict that they would eventually identify as either disabled or not disabled. However, without longitudinal data this cannot be determined.

Finally, because none of the interviewers on this project were impaired, there is potential bias in the data. Validity of interview data can vary depending on the social similarities/differences between interviewers and the respondents they are interviewing (Tourangeau, Rips, and Rasinski 2000). However, respondents for the most part appeared comfortable during the interviews and shared a great deal of detail regarding their daily experiences and feelings.

Implications

This study makes several important contributions to both the scholarly literature and social policy. First this research has important implications for the self-concept literature. This research effectively connects two bodies of literature on identity – self theories and Social Identity Theory. As cited earlier, social identities, such as disabled, develop through "categorical representational meaning systems shared by large segments of society that can provide expected characteristics for those who belong to that category" (Deaux and Martin 2003: 105). Although social identity theory focuses on the cognitive aspects of in-group and out-group comparisons, it does not acknowledge the role of the interactional context in shaping identity (Deaux and Martin 2003). One strength of this study is that it demonstrates how the types of messages impaired individuals receive from others regarding their self during social interactions, as well as the messages they receive through social discourse regarding impairment, and other aspects of their environment (i.e., environmental barriers, social exclusion) impact their identity claims as disabled.

Furthermore, this research adds to other literature which examines how individuals can reject seemingly impermeable social identities (Killian and Johnson 2006; Pyke and Johnson 2003; McCall 2003). Although social identities are often objectively ascribed to those who possess particular characteristics, using self theories this study demonstrates not only how individuals can be agentic in accepting or rejecting these others' placement of them in social identity groups, but also who can be agentic and under what conditions.

This research also answers the call for the integration of stratification into identity theories (Hunt 2003). This is the first study, to the author's knowledge, that

shows that inequalities exist in the construction of an identity as disabled, and that women in particular are less likely to be able to claim a disabled identity. At first the findings from the current study appear somewhat contradictory to other studies which show high status individuals are more likely to disidentify from a stigmatized identity (Killian and Johnson 2006; Waters 1990). One reason for the inconsistency of these findings may be due to the nature of the relationship between disability and other statuses. In the case of disability, claiming this stigmatized identity may alleviate negative emotions experienced by not being able to claim other identity claims. In other words, high status individuals may have more to gain from claiming a disabled identity and because of the power granted to them because of their higher statuses, it may be easier for high status individuals to claim a disabled identity

In terms of the disability literature, the findings from this study provide some support for both the social and medical models. Environmental and social barriers both had important influence on impaired individuals' identification with disability. However, it is important to note that environmental barriers were not recognized in the qualitative interviews as meaningful factors in respondents' identification process. Also, despite the more recent scholarship that recognizes disability as a social construction, bodily experiences of impairment itself, including having mobility restrictions, functional limitations, pain and fatigue, had very real, and strong implications for impaired individuals' identification as disabled.

Moreover, this study provides support for the need of a more expansive model of disablement, which includes both experiences of socially constructed barriers and impairment, as well as other factors such as self processes and social statuses. Simply

combining the medical and social models of disability may not be a fruitful endeavor, as they are conceptually distinctive models. Medical models of disablement, view disability as stemming from impairment, and thus are concerned with the eradication and/or prevention of bodily imperfections that limit individuals' abilities to participate in their social worlds. Conversely, the social model of disablement views disability as a social oppression stemming from environmental and social barriers in society that prevent impaired individuals from fully participating in society, and thus are concerned with social change (Shakespeare and Watson 2001). These conceptualizations of disablement have important implications at both the societal level and at the personal level. First, the implications of conceptualizing disability as an individual outcome, and subsequently using medical model measures of disablement lead to social policy which affects the availability of rehabilitative services. Whereas, the implications of conceptualization of disability from a social model perspective, and using social model measures of disablement lead to outcomes such as social policy to reduce discrimination. At the personal level, conceptualizing disablement from a medical model standpoint, involves an understanding of disablement as a limitation that stems from the self. Whereas, conceptualizing disablement from a social model standpoint, empowers impaired individuals to demand equal citizenship (Shakespeare 2001). However, as found in this study, aspects from each model are experienced daily by those with physical impairments, and when medicated through self-process come to shape how they view their self.

Although, some "medical models" of disablement (i.e., the ICIDH-2 model, the Nagi model and the IOM-2 model) have incorporated aspects of the social milieu

into their modeling of disablement, they continue to recognize disability as stemming from impairment, and do not recognize disability as a social oppression emerging from barriers in society. Conversely, the social model of disablement does not recognize bodily experiences as disabling. However, findings from the current study recognize both such experiences --socially constructed barriers and impairment-- as disabling. Additionally, these experiences do not just happen upon the person but are experienced through the person. That is, experiences of socially constructed barriers and physical impairments are processed through the self. Impaired individuals' experiences of socially constructed barriers, impairment and social statuses were mediated through self processes in shaping respondents identifications as disabled. Although there may be other factors that also contribute to impaired individuals identity claims that are not captured in this study, these findings provide a strong base for future research to build upon.

Finally, there are some important implications for disability policy and disabled persons' rights. Although it has been 20 years since the passing of the 1990s American with Disabilities Act, stigmatization of disabled persons continues to be a real and significant problem. Impaired individuals who resist an identity as disabled are also likely to resist receiving the proper care and benefits and protections they are entitled to. Because of fear of social exclusion, numerous individuals that I interviewed reported forgoing the use of mobility aids, rehabilitation treatment, and applying for disability benefits. Instead they are willing to endure more pain, fatigue, and immobility. Although much has been done to decrease environmental barriers in

society, social barriers are still quite pervasive and have powerful effects on impaired persons' self identification.

Conclusion

In conclusion, not all individuals who experience impairment identify as disabled. However, claiming a disabled identity has important implications for attaining economic resources (Reeve 2002; Wendell 1996), advocating for one's needs in both the built and social environment (Taub, McLorg, and Fanflik 2004) and forming a collective identity through which political action can take place (Wendell 1996). Experiences of environmental and social barriers and impairment all have important implications for constructing an identity as disabled. Moreover, self-processes, such as reflected appraisals, social comparisons, and self-presentations perform an important role in helping impaired individuals' understand their positioning in society and verify their identity claims. The degree to which individuals are impaired, their desire to avoid stigmatization, and the consistency of the messages they receive from both the larger social structure and significant others, determine their identity claims. Finally, social statuses, particularly gender, social class and age have important implications in the construction (or rejection of) an identity as disabled.

Tables

Table 3.1: Descriptive Statistics from the Quantitative Sample (N=3,358)

	Range	Mean	SE
Self Processes			
Disabled identity	(0-1)	0.48	0.01
Reflected appraisals as disabled	(0-1)	0.43	0.01
Social Statuses			
Black	(0-1)	0.13	0.01
Female	(0-1)	0.68	0.01
Education	(1-5)	2.37	0.02
Income	(0-26)	17.27	0.15
Age	(18-64)	46.38	0.23
Social Model Indicators: Environmental Barriers			
Barriers in the home	(0-4)	0.37	0.02
Barriers outside the home	(0-1)	0.22	0.01
Transportation barriers	(0-1)	0.08	0.01
Paratransit	(0-1)	0.55	0.01
Social Model Indicators: Social Engagement			
Social activity level	(0-7)	4.51	0.03
Socializing enough	(0-1)	0.47	0.01
Socializing too much	(0-1)	0.06	0.00
Socializing too little	(0-1)	0.47	0.01
Married	(0-1)	0.49	0.01
Employed	(0-1)	0.46	0.01
Medical Model Indicators			
Severity of movement difficulty	(0-5)	2.59	0.03
ADLs	(0-5)	0.74	0.03
IADLs	(0-6)	1.00	0.03
Use assistive devices	(0-1)	0.24	0.01

Table 3.2: Demographics of Qualitative Interview Respondents (N=30)

	Total	%
Gender		
Male	14	47%
Female	16	53%
Race		
Black	25	83%
White	3	10%
Multi-Racial	2	7%
Education		
Less than HS	2	7%
High school degree	13	43%
Some college	11	37%
College degree	3	10%
Professional degree	1	3%
Income		
$0-$20,000	25	83%
$20,001-$30,000	3	10%
$30,000+	2	7%
Age		
18-44	8	27%
45-67	22	73%
Marital Status		
Never married	16	53%
Married	2	7%
Widowed	4	13%
Separated/Divorced	7	23%
Don't know	1	3%
Employment Status		
Employed	9	30%
Not employed	21	70%

Table 4.1: Descriptives of Impaired Individuals who Self-Identified as Disabled and Not Disabled

		Disabled (N=1,618)	Not Disabled (N=1,740)			
	Range	**Mean**	**Mean**	**Difference**	**SE**	
Social Model Indicators: Environmental Barriers						
Barriers in the home	(0-4)	0.57	0.19	0.38	(0.03)	***
Barriers outside the home	(0-1)	0.34	0.11	0.23	(0.02)	***
Transportation barriers	(0-1)	0.12	0.04	0.08	(0.01)	***
Paratransit	(0-1)	0.56	0.54	0.02	(0.02)	
Social Model Indicators: Social Engagement						
Social activity level	(0-7)	4.20	4.80	-0.60	(0.07)	***
Socializing enough	(0-1)	0.44	0.51	-0.07	(0.02)	**
Socializing too much	(0-1)	0.05	0.07	-0.02	(0.01)	
Socializing too little	(0-1)	0.51	0.44	0.07	(0.02)	***
Married	(0-1)	0.47	0.52	-0.05	(0.02)	**
Employed	(0-1)	0.30	0.60	-0.30	(0.02)	***
Medical Model Indicators						
Severity of movement difficulty	(0-5)	3.14	2.09	1.05	(0.05)	***
ADLs	(0-5)	1.13	0.37	0.76	(0.06)	***
IADLs	(0-6)	1.43	0.61	0.82	(0.05)	***
Use assistive devices	(0-1)	0.32	0.16	0.16	(0.02)	***
Social Statuses						
Black	(0-1)	0.15	0.11	0.04	(0.01)	**
Female	(0-1)	0.59	0.76	-0.17	(0.02)	***
Education	(1-5)	2.26	2.46	-0.20	(.04)	***
Income	(0-26)	15.57	18.84	-3.27	(0.28)	***
Age	(18-64)	47.93	44.96	2.97	(0.45)	***
Self Processes						
Reflected appraisals as disabled	(0-1)	0.88	0.09	0.79	(0.01)	***

Table 4.2: Identifying as Disabled Regressed on Environmental and Social Barriers, and Impairment (N=3,358)

	Model 1		Model 2		Model 3	
	OR	**CI**	**OR**	**CI**	**OR**	**CI**
Social Statuses						
Female	0.46***	(0.38-0.55)	0.43***	(0.36-0.52)	0.37***	(0.31-0.45)
Black	1.08	(0.88-1.33)	1.02	(0.81-1.29)	1.00	(0.78-1.28)
Education	1.01	(0.94-1.08)	1.12**	(1.04-1.21)	1.14**	(1.05-1.23)
Income	0.94	(0.93-0.95)	0.96***	(0.94-0.97)	0.96***	(0.95-0.97)
Age	1.03***	(1.02-1.03)	1.01*	(1.00-1.02)	1.01	(1.00-1.02)
Social Model Indicators: Environmental Barriers						
Barriers in the home			1.38***	(1.22-1.56)	1.02	(0.89-1.17)
Barriers outside the home			2.42***	(1.91-3.06)	1.51***	(1.16-1.98)
Transportation barriers			1.31	(0.92-1.86)	0.91	(0.63-1.33)
Paratransit			0.98	(0.84-1.16)	0.99	(0.84-1.17)
Social Model Indicators: Social Engagement						
Social activity level			0.91**	(0.86-0.97)	0.94*	(0.88-.99)
Socializing too much			1.05	(0.71-1.57)	1.01	(0.67-1.53)
Socializing too little			0.95	(0.79-1.13)	0.87	(0.73-1.05)
Married			1.05	(0.87-1.27)	1.01	(0.83-1.22)
Employed			0.42***	(0.34-0.50)	0.49***	(0.40-0.60)
Medical Model Indicators						
Severity of movement difficulty					1.42***	(1.30-1.55)
ADLs					1.00	(0.90-1.10)
IADLs					1.24***	(1.11-1.37)
Use assistive devices					1.21	(0.93-1.57)
Wald Statistic			32.52 df=(15, 346)		29.17 df=(19, 342)	

Note: Time between interviews is controlled for in all models.

Table 4.3: Environmental Barriers and Social Barriers, and Impairment Experienced by Respondents from the Qualitative Interviews

	Range	Disabled (N=19)	Not Disabled (N=7)	Negotiating (N=4)
Environmental Barriers				
Barriers in the home	(0-1)	0.89	1.00	1.00
Barriers outside the home	(0-1)	0.72	0.57	0.75
Transportation barriers	(0-1)	0.74	0.57	0.25
Barriers in the workplace	(0-1)	0.47	0.29	0.50
Barriers to socializing	(0-1)	0.26	0.43	0.50
Social Barriers				
Barriers outside the home	(0-1)	0.11	0.14	0.00
Barriers in transportation	(0-1)	0.68	0.14	0.00
Barriers in the workplace	(0-1)	0.37	0.14	0.50
Barriers to socializing	(0-1)	0.42	0.14	0.50
Impairment				
Difficulty walking	(0-3)	2.32	1.71	1.25
Difficulty w/steps	(0-3)	1.89	1.71	0.75
Difficulty reaching	(0-3)	0.89	0.67	0.75
Difficulty lifting	(0-3)	1.63	1.14	0.50
Use assistive devices	(0-1)	0.95	0.57	1.00
Diagnosis	(0-1)	0.95	0.43	1.00

Table 5.1: Claiming an Identity as Disabled by Reflected Appraisals (N= 3,358)

	Identity	
Reflected Appraisals	**Disabled**	**Not Disabled**
Disabled	1581	296
	(47.1%)	(8.8%)
Not Disabled	159	1322
	(4.7%)	(39.4%)

Table 5.2: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, and Reflected Appraisals (N=3,358)

	Model 1		Model 2		Model 3		Model 4	
	OR	**CI**	**OR**	**CI**	**OR**	**CI**	**OR**	**CI**
Social Statuses								
Female	0.46***	(0.38-0.55)	0.43***	(0.36-0.52)	0.37***	(0.31-0.45)	0.51***	(0.40-0.66)
Black	1.08	(0.88-1.33)	1.02	(0.81-1.29)	1.00	(0.78-1.28)	1.11	(0.81-1.51)
Education	1.01	(0.94-1.08)	1.12**	(1.04-1.21)	1.14**	(1.05-1.23)	1.18**	(1.06-1.30)
Income	0.94***	(0.93-0.95)	0.96***	(0.94-0.97)	0.96***	(0.95-0.97)	0.97***	(0.95-0.98)
Age	1.03***	(1.02-1.03)	1.01*	(1.00-1.02)	1.01	(1.00-1.02)	1.01	(1.00-1.02)
Social Model Indicators: Environmental Barriers								
Barriers in the home			1.38***	(1.22-1.56)	1.02	(0.89-1.17)	1.01	(0.84-1.21)
Barriers outside the home			2.42***	(1.91-3.06)	1.51**	(1.16-1.98)	1.37	(0.98-1.93)
Transportation barriers			1.31	(0.92-1.86)	0.91	(0.63-1.33)	0.82	(0.51-1.34)
Paratransit			0.98	(0.84-1.16)	0.99	(0.84-1.17)	0.98	(0.79-1.21)
Social Model Indicators: Social Engagement								
Social activity level			0.91**	(0.86-0.97)	0.94*	(0.88-.99)	0.98	(0.91-1.06)
Socializing too much			1.05	(0.71-1.57)	1.01	(0.67-1.53)	1.39	(0.82-2.34)
Socializing too little			0.95	(0.79-1.13)	0.87	(0.73-1.05)	0.84	(0.66-1.09)
Married			1.05	(0.87-1.27)	1.01	(0.83-1.22)	1.09	(0.83-1.42)
Employed			0.42***	(0.34-0.50)	0.49***	(0.40-0.60)	0.55***	(0.42-0.71)
Medical Model Indicators								
Severity of movement difficulty					1.42***	(1.30-1.55)	1.27***	(1.12-1.43)
ADLs					1.00	(0.90-1.10)	0.98	(0.87-1.10)
IADLs					1.24***	(1.11-1.37)	1.19*	(1.04-1.36)
Use assistive devices					1.21	(0.93-1.57)	0.86	(0.63-1.17)
Self Processes								
Reflected appraisals as disabled							31.71***	(25.19-39.94)
Wald Statistic	41.35 df=(6, 355)		32.52 df=(15, 346)		29.17 df=(19, 342)		57.18 df=(20, 341)	

Note: Time between interviews is controlled for in all models

Table 5.3: Claiming an Identity as Disabled by Reflected Appraisals (N=30)

Reflected Appraisals	Identity Disabled (n=19)	 Not Disabled (n=7)	 Negotiating (n=4)
Disabled	1	5	--
Not Disabled	3	--	1
Some do/Some don't	1	5	--

Table 5.4: Self Processes from Qualitative Interviews

	Identifiers	**Disidentifiers**	**Negotiators**
Social Comparisons	Disabled (Upward)	Not Disabled (Downward)	Not Disabled (Downward)
Reflected Appraisals	Disabled	Not Disabled	Disabled
Self Presentations	Disabled	Not Disabled	Not Disabled

Table 6.1: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, Reflected Appraisals, and Race Interactions (N=3,358)

	Model 1		Model 2		Model 3	
	OR	**CI**	**OR**	**CI**	**OR**	**CI**
Social Statuses						
Female	0.51***	(0.40-0.66)	0.50***	(0.39-0.64)	0.50***	(0.39-0.65)
Black	1.11	(0.81-1.51)	1.36	(0.37-5.01)	1.38	(0.75-2.54)
Education	1.18**	(1.06-1.30)	1.18**	(1.07-1.31)	1.18**	(1.07-1.31)
Income	0.97***	(0.95-0.98)	0.96***	(0.95-0.98)	0.97***	(0.95-0.98)
Age	1.01	(1.00-1.02)	1.01	(0.99-1.02)	1.01	(1.00-1.02)
Social Model Indicators: Environmental Barriers						
Barriers in home	1.01	(0.84-1.21)	0.98	(0.81-1.19)	0.99	(0.83-1.18)
Barriers outside home	1.37	(0.98-1.93)	1.43	(0.99-2.06)	1.43*	(1.03-2.00)
Transportation barriers	0.82	(0.51-1.34)	0.81	(0.46-1.42)	0.79	(0.49-1.28)
Paratransit	0.98	(0.79-1.21)	0.94	(0.73-1.20)	0.97	(0.78-1.20)
Social Model Indicators: Social Engagement						
Social activity level	0.98	(0.91-1.06)	1.01	(0.93-1.10)	0.98	(0.90-1.06)
Socializing too much	1.39	(0.82-2.34)	1.28	(0.73-2.24)	1.34	(0.80-2.25)
Socializing too little	0.84	(0.66-1.09)	0.80	(0.60-1.07)	0.83	(0.65-1.08)
Married	1.09	(0.83-1.42)	1.08	(0.81-1.44)	1.09	(0.84-1.43)
Employed	0.55***	(0.42-0.71)	0.50***	(0.38-0.65)	0.54***	(0.42-0.71)
Medical Model Indicators						
Severity of movement difficulty	1.27***	(1.12-1.43)	1.27***	(1.12-1.43)	1.28***	(1.12-1.46)
ADLs	0.98	(0.87-1.10)	0.97	(0.87-1.09)	0.89	(0.79-1.01)
IADLs	1.19*	(1.04-1.36)	1.20**	(1.05-1.37)	1.28**	(1.11-1.47)
Use of assistive devices	0.86	(0.63-1.17)	0.86	(0.63-1.18)	0.81	(0.59-1.11)
Self Processes						
Reflected appraisals as disabled	31.71***	(25.19-39.94)	32.43***	(25.65-40.99)	32.86***	(25.89-41.70)
Interactions						
Black*Barriers in the home			1.11	(0.78-1.58)	--	--
Black*Barriers outside the home			0.80	(0.34-1.90)	--	--
Black*Transportation barriers			1.18	(0.46-3.01)	--	--
Black*Paratransit			1.26	(0.63-2.53)	--	--
Black*Social activity level			0.79	(0.63-1.00)	--	--
Black*Socializing too much			1.54	(0.32-7.44)	--	--
Black*Socializing too little			1.58	(0.79-3.15)	--	--
Black*Married			1.12	(0.53-2.38)	--	--
Black*Employed			2.21*	(1.12-4.35)	--	--
Black*Severity of movement difficulty			--	--	0.86	(0.66-1.13)
Black*ADLs			--	--	1.65**	(1.24-2.20)
Black*IADLs			--	--	0.75*	(0.57-0.97)
Black*Use of assistive devices			--	--	1.52	
Wald Statistic	57.18 df=(20, 341)		40.81 df=(29, 332)		47.53 df=(24, 337)	

Note: Time between interviews is controlled for in all models

Table 6.2: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, Reflected Appraisals, and Age Interactions (N=3,358)

	Model 1		Model 2		Model 3	
	OR	**CI**	**OR**	**CI**	**OR**	**CI**
Social Statuses						
Female	0.51***	(0.40-0.66)	0.50***	(0.39-0.64)	0.51***	(0.39-0.65)
Black	1.11	(0.81-1.51)	1.04	(0.76-1.42)	1.10	(0.82-1.50)
Education	1.18**	(1.06-1.30)	1.17**	(1.05-1.29)	1.18**	(1.06-1.30)
Income	0.97***	(0.95-0.98)	0.97***	(0.95-0.98)	0.97***	(0.95-0.98)
Age	1.01	(1.00-1.02)	--	--	--	--
Older adults	--	--	0.66	(0.28-1.57)	1.18	(0.72-1.93)
Social Model Indicators: Environmental Barriers						
Barriers in the home	1.01	(0.84-1.21)	0.93	(0.75-1.16)	1.00	(0.84-1.21)
Barriers outside the home	1.37	(0.98-1.93)	1.00	(0.62-1.62)	1.37	(0.97-1.93)
Transportation barriers	0.82	(0.51-1.34)	1.06	(0.53-2.10)	0.83	(0.52-1.35)
Paratransit	0.98	(0.79-1.21)	1.15	(0.84-1.59)	0.98	(0.79-1.21)
Social Model Indicators: Social Engagement						
Social activity level	0.98	(0.91-1.06)	0.96	(0.86-1.08)	0.98	(0.91-1.06)
Socializing too much	1.39	(0.82-2.34)	1.34	(0.67-2.67)	1.36	(0.81-2.30)
Socializing too little	0.84	(0.66-1.09)	0.96	(0.66-1.38)	0.83	(0.65-1.07)
Married	1.09	(0.83-1.42)	0.88	(0.58-1.32)	1.09	(0.84-1.42)
Employed	0.55***	(0.42-0.71)	0.37***	(0.26-0.52)	0.53***	(0.41-0.69)
Medical Model Indicators						
Severity of movement difficulty	1.27***	(1.12-1.43)	1.27***	(1.13-1.43)	1.30**	(1.10-1.54)
ADLs	0.98	(0.87-1.10)	0.97	(0.86-1.09)	0.96	(0.79-1.16)
IADLs	1.19*	(1.04-1.36)	1.20**	(1.05-1.38)	1.14	(0.96-1.35)
Use of assistive devices	0.86	(0.63-1.17)	0.88	(0.64-1.19)	1.11	(0.71-1.76)
Self Processes						
Reflected appraisals as disabled	31.71***	(25.19-39.94)	32.94***	(26.21-41.40)	31.79***	(25.23-40.05)
Interactions						
Age*Barriers in home			1.17	(0.87-1.55)	--	--
Age*Barriers outside home			1.68	(0.87-3.25)	--	--
Age*Transportation barriers			0.76	(0.33-1.77)	--	--
Age*Paratransit			0.76	(0.47-1.24)	--	--
Age*Social activity level			1.03	(0.87-1.20)	--	--
Age*Socializing too much			1.21	(0.43-3.36)	--	--
Age*Socializing too little			0.77	(0.48-1.25)	--	--
Age*Married			1.47	(0.90-2.39)	--	--
Age*Employed			1.99**	(1.22-3.22)	--	--
Age*Severity of movement difficulty			--	--	0.97	(0.78-1.20)
Age*ADLs			--	--	1.04	(0.83-1.31)
Age*IADLs			--	--	1.08	(0.834-1.39)
Age*Use of assistive devices			--	--	0.64	(0.37-1.11)
Wald Statistic	57.18 df=(20, 341)		41.11 df=(29, 332)		47.34 df=(24, 337)	

Note: Time between interviews is controlled for in all models

Table 6.3: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, Reflected Appraisals, and Education Interactions (N=3,358)

	Model 1		Model 2		Model 3	
	OR	**CI**	**OR**	**CI**	**OR**	**CI**
Social Statuses						
Female	0.51***	(0.40-0.66)	0.51***	(0.39-0.66)	0.51***	(0.40-0.66)
Black	1.11	(0.81-1.51)	1.08	(0.80-0.66)	1.08	(0.79-1.46)
Education	1.18**	(1.06-1.30)	--	--	--	--
Some College or More	--	--	1.18	(0.47-2.93)	0.85	(0.52-1.39)
Income	0.97***	(0.95-0.98)	0.97**	(0.95-0.99)	0.97***	(0.95-0.99)
Age	1.01	(1.00-1.02)	1.01	(1.00-1.02)	1.01	(1.00-1.02)
Social Model Indicators: Environmental Barriers						
Barriers in the home	1.01	(0.84-1.21)	1.04	(0.81-1.33)	1.00	(0.83-1.20)
Barriers outside the home	1.37	(0.98-1.93)	1.57	(1.07-2.30)	1.38	(0.99-1.93)
Transportation barriers	0.82	(0.51-1.34)	0.86	(0.47-1.58)	0.84	(0.52-1.34)
Paratransit	0.98	(0.79-1.21)	0.93	(0.69-1.26)	0.97	(0.79-1.20)
Social Model Indicators: Social Engagement						
Social activity level	0.98	(0.91-1.06)	0.98	(0.89-1.07)	0.98	(0.91-1.06)
Socializing too much	1.39	(0.82-2.34)	1.13	(0.59-2.18)	1.36	(0.81-2.31)
Socializing too little	0.84	(0.66-1.09)	0.75	(0.55-1.02)	0.84	(0.65-1.08)
Married	1.09	(0.83-1.42)	1.16	(0.83-1.62)	1.05	(0.81-1.38)
Employed	0.55***	(0.42-0.71)	0.62**	(0.45-0.86)	0.56***	(0.44-0.72)
Medical Model Indicators						
Severity of movement difficulty	1.27***	(1.12-1.43)	1.25***	(1.11-1.40)	1.14	(0.98-1.32)
ADLs	0.98	(0.87-1.10)	0.99	(0.88-1.11)	1.07	(0.90-1.26)
IADLs	1.19*	(1.04-1.36)	1.20**	(1.05-1.37)	1.31**	(1.11-1.54)
Use of assistive devices	0.86	(0.63-1.17)	0.89	(0.66-1.20)	0.77	(0.52-1.13)
Self Processes						
Reflected appraisals as disabled	31.71***	(25.19-39.94)	31.70***	(25.25-39.79)	32.43***	(25.68-40.95)
Interactions						
Education*Barriers in the home			0.93	(0.68-1.26)	--	--
Education*Barriers outside the home			0.67	(0.35-1.28)	--	--
Education*Transportation barriers			0.98	(0.36-2.63)	--	--
Education*Paratransit			1.14	(0.69-1.90)	--	--
Education*Social activity level			1.03	(0.88-1.21)	--	--
Education*Socializing too much			1.67	(0.66-4.23)	--	--
Education*Socializing too little			1.32	(0.82-2.11)	--	--
Education*Married			0.81	(0.51-1.29)	--	--
Education*Employed			0.78	(0.47-1.28)	--	--
Education*Severity of movement difficulty			--	--	1.31*	(1.06-1.62)
Education*ADLs			--	--	0.82	(0.64-1.05)
Education*IADLs			--	--	0.78*	(0.62-0.99)
Education*Use of assistive devices			--	--	1.39	(0.77-2.52)
Wald Statistic	57.18 df=(20, 341)		40.58 df(=29, 332)		47.68 df=(24, 337)	

Note: Time between interviews is controlled for in all models

Table 6.4: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, Reflected Appraisals, and Gender Interactions (N=3,358)

	Model 1		Model 2		Model 3	
	OR	**CI**	**OR**	**CI**	**OR**	**CI**
Social Statuses						
Female	0.51***	(0.40-0.66)	0.19**	(0.07-0.52)	0.41**	(0.25-0.68)
Black	1.11	(0.81-1.51)	1.09	(0.81-1.48)	1.10	(0.81-1.48)
Education	1.18**	(1.06-1.30)	1.18**	(1.06-1.30)	1.18**	(1.06-1.30)
Income	0.97***	(0.95-0.98)	0.96***	(0.95-0.98)	0.97***	(0.95-0.98)
Age	1.01	(1.00-1.02)	1.01	(0.99-1.02)	1.01	(1.00-1.02)
Social Model Indicators: Environmental Barriers						
Barriers in home	1.01	(0.84-1.21)	0.88	(0.66-1.17)	1.00	(0.83-1.20)
Barriers outside home	1.37	(0.98-1.93)	1.74*	(1.02-2.98)	1.40	(0.99-1.97)
Transportation barriers	0.82	(0.51-1.34)	0.88	(0.36-2.10)	0.83	(0.51-1.36)
Paratransit	0.98	(0.79-1.21)	1.17	(0.79-1.75)	0.98	(0.79-1.22)
Social Model Indicators: Social Engagement						
Social activity level	0.98	(0.91-1.06)	0.87	(0.75-1.01)	0.98	(0.91-1.06)
Socializing too much	1.39	(0.82-2.34)	0.63	(0.25-1.58)	1.38	(0.82-2.34)
Socializing too little	0.84	(0.66-1.09)	0.72	(0.46-1.12)	0.85	(0.66-1.09)
Married	1.09	(0.83-1.42)	1.08	(0.71-1.64)	1.09	(0.84-1.43)
Employed	0.55***	(0.42-0.71)	0.44***	(0.29-0.65)	0.55***	(0.43-0.72)
Medical Model Indicators						
Severity of movement difficulty	1.27***	(1.12-1.43)	1.27***	(1.12-1.43)	1.10	(0.90-1.34)
ADLs	0.98	(0.87-1.10)	0.97	(0.86-1.10)	0.89	(0.73-1.09)
IADLs	1.19*	(1.04-1.36)	1.20**	(1.05-1.37)	1.58**	(1.18-2.11)
Use of assistive devices	0.86	(0.63-1.17)	0.85	(0.63-1.16)	0.94	(0.55-1.61)
Self Processes						
Reflected appraisals as disabled	31.71***	(25.19-39.94)	33.17***	(26.05-42.24)	32.47***	(25.71-41.01)
Interactions						
Female*Barriers in the home			1.22	(0.89-1.66)	--	--
Female*Barriers outside the home			0.71	(0.37-1.37)	--	--
Female*Transportation barriers			0.95	(0.36-2.52)	--	--
Female*Paratransit			0.77	(0.47-1.27)	--	--
Female*Social activity level			1.19*	(1.00-1.42)	--	--
Female*Socializing too much			2.91	(0.99-8.52)	--	--
Female*Socializing too little			1.25	(0.74-2.11)	--	--
Female*Married			1.02	(0.63-1.67)	--	--
Female*Employed			1.41	(0.84-2.36)	--	--
Female*Severity of movement difficulty			--	--	1.22	(0.96-1.54)
Female*ADLs			--	--	1.15	(0.90-1.46)
Female*IADLs			--	--	0.68*	(0.49-0.95)
Female*Use of assistive devices			--	--	0.85	(0.44-1.65)
Wald Statistic	57.18 df=(20, 341)		39.96 df(=29, 332)		49.70 df=(24, 337)	

Note: Time between interviews is controlled for in all models

Table 6.5: Identifying as Disabled Regressed on Environmental and Social Barriers, Impairment, Reflected Appraisals, and Poverty Interactions (N=3,358)

	Model 1		Model 2		Model 3	
	OR	**CI**	**OR**	**CI**	**OR**	**CI**
Social Statuses						
Female	0.51***	(0.40-0.66)	0.50***	(0.38-0.64)	0.49***	(0.38-0.64)
Black	1.11	(0.81-1.51)	1.05	(0.77-1.44)	1.05	(0.77-1.44)
Education	1.18**	(1.06-1.30)	1.15**	(1.04-1.27)	1.14*	(1.03-1.26)
Some College or More	0.97***	(0.95-0.98)	--	--	--	--
Income	--	--	1.47	(0.62-3.51)	1.60	(0.90-2.84)
Age	1.01	(1.00-1.02)	1.01	(1.00-1.02)	1.01	(1.00-1.02)
Social Model Indicators: Environmental Barriers						
Barriers in the home	1.01	(0.84-1.21)	0.97	(0.79-1.20)	1.00	(0.83-1.21)
Barriers outside the home	1.37	(0.98-1.93)	1.42	(0.95-2.12)	1.39	(0.99-1.95)
Transportation barriers	0.82	(0.51-1.34)	0.88	(0.49-1.57)	0.81	(0.50-1.31)
Paratransit	0.98	(0.79-1.21)	0.96	(0.74-1.24)	0.98	(0.79-1.22)
Social Model Indicators: Social Engagement						
Social activity level	0.98	(0.91-1.06)	0.96	(0.88-1.05)	0.98	(0.91-1.06)
Socializing too much	1.39	(0.82-2.34)	1.91*	(1.06-3.43)	1.42	(0.84-2.40)
Socializing too little	0.84	(0.66-1.09)	0.90	(0.67-1.20)	0.84	(0.65-1.08)
Married	1.09	(0.83-1.42)	0.99	(0.76-1.31)	1.01	(0.80-1.29)
Employed	0.55***	(0.42-0.71)	0.52***	(0.38-0.70)	0.55***	(0.43-0.71)
Medical Model Indicators						
Severity of movement difficulty	1.27***	(1.12-1.43)	1.28***	(1.13-1.44)	1.22**	(1.07-1.40)
ADLs	0.98	(0.87-1.10)	0.98	(0.87-1.10)	0.94	(0.83-1.08)
IADLs	1.19*	(1.04-1.36)	1.20**	(1.05-1.38)	1.30**	(1.12-1.50)
Use of assistive devices	0.86	(0.63-1.17)	0.86	(0.63-1.18)	0.87	(0.62-1.22)
Self Processes						
Reflected appraisals as disabled	31.71***	(25.19-39.94)	33.05***	(26.22-41.66)	32.83***	(26.12-41.25)
Interactions						
Poverty*Barriers in the home			1.11	(0.78-1.57)	--	--
Poverty*Barriers outside the home			0.85	(0.44-1.62)	--	--
Poverty*Transportation barriers			0.74	(0.28-1.98)	--	--
Poverty*Paratransit			1.14	(0.70-1.85)	--	--
Poverty*Social activity level			1.09	(0.94-1.27)	--	--
Poverty*Socializing too much			0.24*	(0.08-0.71)	--	--
Poverty*Socializing too little			0.70	(0.42-1.18)	--	--
Poverty*Married			1.23	(0.68-2.20)	--	--
Poverty*Employed			1.32	(0.72-2.43)	--	--
Poverty*Severity of movement difficulty			--	--	1.17	(0.92-1.47)
Poverty*ADLs			--	--	1.12	(0.85-1.48)
Poverty*IADLs			--	--	0.76*	(0.58-0.99)
Poverty*Use of assistive devices			--	--	0.95	(0.47-1.93)
Wald Statistic	57.18 df=(20, 341)		40.88 df=(29, 332)		48.29 df=(24, 337)	

Note: Time between interviews is controlled for in all models

Table 6.6: Summary of Interactions

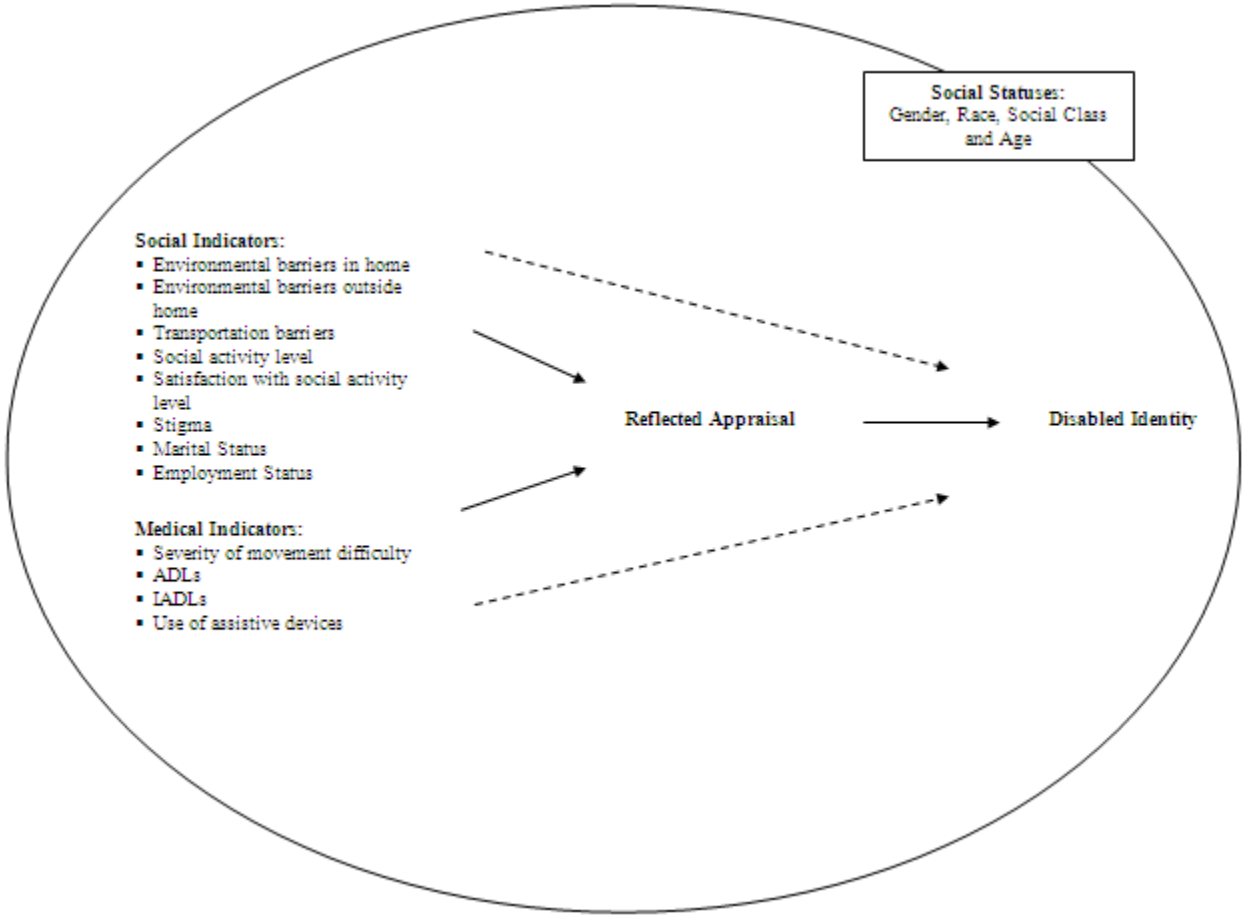
	OR[1]	Effect on Identity[2]	High Status More Likely to Claim
Employment Status			
Race	2.21*	blacks < whites	Yes
Age	1.99**	old < young	Yes
Severity of Movement Difficulty			
Education	1.31*	low educated < highly educated	Yes
IADLS			
Gender	0.68*	women < men	Yes
Race	0.74*	blacks < whites	Yes
Education	0.78*	highly educated < low educated	No
Poverty	1.12*	in poverty < not in poverty	Yes

[1]Odds ratios are from Tables 6.1-6.5

[2]The interactions education*severity of movement difficulty, race*IADLs, poverty*IADLs, gender*IADLs, education*IADLs, race*employed, age*employed were added to the full regression model (Model 4 of Table 7). Only four of these interactions remained significantly associated with claiming a disabled identity. Education by severity of movement difficulty (OR=1.23, $p<.05$), education by IADLs (OR=.70, $p<.01$), race by employment status interaction (OR=2.22, $p<.05$) and age by employment status (OR=1.94, $p<.01$) continued to be significantly associated with claiming a disabled identity (analyses not shown).

Figures

Figure 1: Conceptual Model



Appendices

Appendix A: Criteria for Selection in the NHIS-D Phase 2-Adult Followback

For selection into Phase 2 respondents had to meet the following criteria. Items marked by an asterisk must be combined with at least one other criteria item in order to be considered a positive screen.

* Unable to work - work main activity
* Limited in kind or amount of work - work main activity
* Unable to do housework - housework main activity
* Limited in kind or amount of housework - housework main activity
* Unable to work - housework main activity
* Limited in kind or amount of work - housework main activity
* Any other activity limitation
* Needs help for eating, bathing, dressing (ADLs)
* Needs help for household chores (IADLs)
* Any other activity limit ages <18 & 70+
* Needs help ADLs some ages 5-59 & all ages 60-69
* Needs help IADLs some ages 5-59 and all ages 60-69
* Poor self rated health status
* Medicare coverage
* Medicaid coverage
* Social Security or RR retirement for disability
* Ever applied for social securing benefits

  Receive supplemental security income
* Every applied for SSI
* Receive any other disability pension

  Legally blind

  Difficulty seeing expected to last 12 months

  Trouble hearing expected to last 12 months

  Difficulty communicating outside family onset age <22

  Difficulty communicating outside family, onset age >21 or unknown

  Difficulty communicating so family members understand

  Difficulty communicating basic needs to family

  Difficulty understanding others, onset age <22

  Difficulty understanding others, onset age >21 or unknown

  Difficulty with age appropriate learning

  Cane

  Crutches

  Walker

Medically prescribed shoes
Manual wheelchair
Electric wheelchair
Scooter
Expected to use brace 12+ months
Artificial leg/arm
Dizziness lasting 3+ months
Problem with balance lasting 3+ months
Ringing, roaring, buzzing in ears lasting 3+ months
Learning disability
Cerebral Palsy
Cystic Fibrosis
Down Syndrome
Mental Retardation
Muscular Dystrophy
Spina Bifida
Autism
Hydrocephalus
Bath/shower - get help
Dress - get help
Eat - get help
Get in/out bed/chair - get help
Toilet - get help
Getting around in home - get help

Bathing - a lot of difficulty, expected to last 12+ months
Dressing - a lot of difficulty, expected to last 12+ months
Eating - a lot of difficulty, expected to last 12+ months
Transfer from bed/chair - a lot of difficulty, expected to last 12+ months
Toileting - a lot of difficulty, expected to last 12+ months
Get around inside - a lot of difficulty, expected to last 12+ months
Bath - a lot of difficulty - no help/reminder, expected to last 12 months
Dress - a lot of difficulty - no help/reminder, expected to last 12 months
Eat - a lot of difficulty - no help/reminder, expected to last 12+ months
Transfer bed/chair - a lot of difficulty - no help/reminder, expected to last 12+ months
Toilet - a lot of difficulty - no help/reminder, expected to last 12+ months
Get around inside - a lot of difficulty - no help/reminder, expected to last 12+ months
Prepare meals - get help or supervision

Shopping - get help or supervision
Managing money - get help or supervision
Using telephone - get help or supervision
Heavy housework - get help or supervision
Light housework - get help or supervision
Prepare meals - a lot of difficulty, expected to last 12+ months
Shopping for personal items - a lot of difficulty, expected to last 12+ months
Managing money - a lot of difficulty, expected to last 12+ months
Using phone - a lot of difficulty, expected to last 12+ months
Heavy housework - a lot of difficulty, expected to last 12+ months
Light housework - a lot of difficulty, expected to last 12+ months
Prepare meals - a lot of difficulty - no help or supervision expected to last 12+ months
Shopping - a lot of difficulty - no help or supervision expected to last 12+ months

Using phone - a lot of difficulty - no help or supervision expected to last 12+ months

Lift 10 pounds - unable, expected to last 12+ months
Lift 10 pounds - unable, no/don't know expected to last 12+ months
Walk up 10 steps - unable, expected to last 12+ months
Walk up 10 steps - unable, no/don't know expected to last 12+ months
Walk 1/4 mile - unable, expected to last 12+ months
Bending - unable, No/don't know if expected to last 12+ months
Reach up or out - unable, expected to last 12+ months
Reach up or out - unable, No/don't know if expected to last 12+ months
Use fingers to grasp - unable, expected to last 12+ months
Use fingers to grasp - unable, no/don't know if expected to last 12+ months
Hold pen/pencil - unable, expected to last 12+ months
Use pen/pencil - unable, no/don't know if expected to last 12+ months

Depressed
Trouble with friendships
Trouble in social settings
Trouble concentrating
Stress
Confused
Phobia

Schizophrenia
Paranoid Disorder
Bipolar Disorder
Major Depression
Personality Disorder
Senility
Alcohol Abuse
Drug Abuse
Other serious mental disorder
Medication for ongoing mental disorder
Mental condition interferes with getting/keeping job
Go to sheltered workshop, etc. to develop skills
Go to day activity center during work hours
Get physical therapy for condition expected to last 12+ months
Get occupational therapy for condition expected to last 12+ months
Get vocational rehabilitation services
Have a case manager
Need but did not have case manager
Have a court appointed legal guardian
Regular visits to doctor for condition expected to last 12+ months
* Respondent perceived disability - self or family
* Other perceived disability of anyone in family
Use assistive devices for visual impairment
Trouble hearing with hearing aid, condition expected to last 12+ months
Can't hear loud noises, no aid, condition expected to last 12+ months
Use assistive device for hearing impairment

Composite variable, bathing difficulty, onset age <22
Composite variable, dressing difficulty, onset age <22
Composite variable, eating difficulty, onset age <22
Composite variable, difficulty with getting in/out of bed/chair, onset age <22
Composite variable, difficulty with toileting, onset age <22
Composite variable, difficulty with getting around inside, onset age <22
Composite variable, difficulty with preparing meals, onset age <22
Composite variable, difficulty with shopping, onset age <22
Composite variable, difficulty with money management, onset age <22
Composite variable, difficulty with using phone, onset age <22
Composite variable, difficulty with heavy housework, onset age <22

Composite variable, difficulty with light housework, onset age <22
Composite variable, some difficulty bathing expected to last 12+ months
Composite variable, some difficulty dressing expected to last 12+ months
Composite variable, some difficulty eating expected to last 12+ months

Composite variable, some difficulty toileting expected to last 12+ months
Composite variable, some difficulty getting around expected to last 12+ months
Composite variable, some difficulty preparing meals expected to last 12+ months
Composite variable, some difficulty shopping expected to last 12+ months
Composite variable, some difficulty managing money expected to last 12+ months
Composite variable, some difficulty using phone expected to last 12+ months

Composite variable, some difficulty doing light housework expected to last 12+ months
Composite variable, some difficulty lifting 10 pounds expected to last 12+ months
Composite variable, unable lift 10 pounds, onset <22, expected to last 12+ months
Composite variable, unable walk up steps, onset <22, expected to last 12+ months
Composite variable, unable walk 1/4 mile, onset <22, expected to last 12+ months

Appendix B: Advertisement Flyer

Participants Wanted for Research Study

The National Center for Health Statistics is looking for adults aged 18-60 to answer a variety of health questions. We would like to talk to you if you have difficulty walking or are unable to walk, and use special equipment such as scooter, wheel chair, walker, cane, or crutches to get around. The interview will be no longer than 60 minutes and participants will receive $40.

FOR MORE INFORMATION,

Please call: **301-XXX-XXXX**

Centers for Disease Control and Prevention
National Center for Health Statistics

Appendix C: Qualitative Interviews Telephone Screener

Sample screening script for participant contact by QDRL Laboratory Manager for Testing of Physical & Social Barriers of Mobility-Impaired Persons recruited through local advertisement/flyer

Dial participant's telephone number [hereafter referred to as *P*] as indicated on audiotape recording.

 Note: Speak only to *P*. If the number is answered by an answering machine, call back at another time.

Laboratory Manager: Good morning/afternoon, may I speak to (name)?

 If *P* is not available or not at home, say, "Thank you" and try again at another time.

If the person who answered the phone (NOT P) asks, "Who is calling?" or "What's this about?" say, "I am returning their call to me. I'll try to reach them at another time.

 If *P* has been successfully contacted, continue...

...Hello, my name is [Laboratory Manager's name]. I am calling from the National Center for Health Statistics. You may remember that you responded to the advertisement we placed in the [name of newspaper] on [date] or flyer looking for people who have difficulty walking or are unable to walk and use special equipment such as a scooter, wheel chair, walker, cane, or crutches to get around walking to help us test a variety of health questions.

 Wait for acknowledgment, such as, "Oh, yes, I remember."

...In order to determine if you are eligible for our study, I'll need a few minutes of your time to ask some background questions. Answering these questions is completely voluntary. Your answers will be kept strictly confidential. Is this a good time to ask the questions or should I call back later?

 If not a good time to talk, schedule a time to call back.

 If good time to talk, continue...

1. How old are you? **[If under age 18 or over age 60 go to exit script 1]**

_____

Note to Reviewers: The next two questions will be asked to recruit a range and degree of mobility-impaired persons.

2. Do you use any special equipment such as a scooter, wheel chair, walkers, cane, or crutches to get around? (check all that apply)

- ☐ Scooter
- ☐ Wheel Chair
- ☐ Walker
- ☐ Cane
- ☐ Crutches
- ☐ Other _____

3. By yourself and without using help from another person or without using special equipment, how difficult is it for you to [fill]? Would you say (not at all difficult, somewhat difficult, very difficult, cannot do at all)

** IN order to assess how impaired the individual is ask

- ☐ Walking for a quarter of a mile (that is about 2 or 3 city blocks)?
- ☐ Walking 10 steps without resting?
- ☐ Reaching out (as if to grab a door handle or get something off a shelf)?
- ☐ Lifting or carrying something as heavy as 25 lbs. (such as 2 full bags of groceries)?
- ☐ Lifting or carrying something as heavy as 10 lbs. (such as 1 full bag of groceries)?
- ☐ Doing housework (such as vacuuming, mopping, laundry, etc)?
- ☐ Bathing or showering?
- ☐ Dressing?
- ☐ Preparing meals for yourself or family?

If quota has been met for any of the above [fill conditions], go to exit script 2. Otherwise continue].

4. How many years of education do you have?
   □9 or less □10 □11 □12 □13 □14 □15 □16 □17 □18 □19

5. Are you Spanish, Hispanic or Latino?
   - □ Yes
   - □ No

6. What race or races do you consider yourself to be? You may indicate more than one race.
   - □ White
   - □ Black or African American
   - □ Asian

- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander

7. Please tell me which of the following categories represents your total household income last year:
   - $20,000 or less
   - $20,001 - $40,000
   - $40,001 - $60,000
   - more than $60,000

Entry Script:
...Based on your answers to the questions so far, we would like you to take part in our study. For this study we'd like you to come to the National Center for Health Statistics in Hyattsville, MD/[fill] Community Facility. An interviewer will ask you questions about barriers that you might experience in your home, outside your home, in the workplace, interacting with others, and questions on self perception. Then the interviewer will ask you to explain what you were thinking as you answered the questions. The interviewer will also ask you about your opinions of the questions. Your answers will help us find out if the survey questions will be easy for other people to answer. Everything you say will be kept private. With your permission, we would like to videotape your interview. The tape is a record of what we asked and what you said. Do you give permission to have your interview videotaped? *Yes/No*. **[If no, go to exit script 3. Videotaping is essential for this project].**

Do you have any questions at this point? *Pause to answer questions.* If (not/you have no other questions), then let's get you on the schedule, ok? We will be interviewing (Day, Month/Date) through (Day, Month/Date) from 8 a.m. to 6 p.m. Looking at your schedule, when would you be available to participate? *Schedule.* **[If date/times not available go to exit script 4.]**

A reminder call will be made to you a few days in advance. Should you have any questions or need to change your appointment, please feel free to contact me [name] at [phone number]. Thank you for responding to our ad, and I look forward to seeing you here at (DATE/TIME) *Get respondent to cite date & time if possible.*

Exit script 1: I'm sorry, you have to be between the ages of 18 and 60 to take part in this study and therefore we won't be able to use you at this time. However, I would like to put your name and telephone number you gave me into our database so that I can contact you about other studies coming up in the future. Is that OK? *If yes, record name & telephone number. If no: OK, thank you for your time. Your name and telephone number will not be added to our database.*
Exit script 2: Based upon your answers, it seems that we may already have a number of volunteers with very similar answers to yours. At this point we need to talk with people with some different characteristics. However, if we have cancellations or other slots open up, I may wish to call you back. Would it be okay if I kept your

name, telephone number, and the information you provided in response to the eligibility questions until the end of this study? *If yes*, make notation. *If no,* Would it be okay if I added your name, telephone number, age, educational level, and race to our database so that I can contact you about other studies coming up in the future? If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

Exit script 3: I'm sorry, willingness to be videotaped is required in order to take part in this study and therefore we won't be able to use you at this time. Would it be okay if I added your name, telephone number, age, educational level, and race to our database so that I can contact you about other studies coming up in the future? If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

Exit script 4: I see...ok, we were hoping to complete this particular study between (Month/Date) and (Month/Date), so it looks like we won't be able to schedule you at this time. Would it be okay if I added your name, telephone number, age, educational level, and race to our database so that I can contact you about other studies coming up in the future? If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.

Appendix D: Informed Consent Form

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease
Control and Prevention
National Center for
Health Statistics
3311 Toledo Road
Hyattsville, Maryland
20782

Informed Consent Form for one-on-one interviews

You are being asked to take part in a research study. This consent form tells you about the study and what you will be asked to do. You can choose to take part in the study or not. If you choose to take part, you will need to sign this form.

Purpose of the Research
Surveys are used to collect information on the health and well being of Americans. The surveys help to develop programs to improve the health and health care of people living in the United States.

Before health surveys are conducted, the questions are tested with people like you. It is important that the questions make sense, are easy to answer, and that everyone understands the questions the same way. The National Center for Health Statistics conducts these tests for the surveys it sponsors and for other survey programs. If you agree to take part in this test, we will ask you to answer the survey questions. Then, we will ask you to explain what you were thinking and how you came up with your answers.

The questions that we are working on today are about barriers that you might experience in your home, outside your home, in the workplace, interacting with others, and questions on self perception.

Your interview will show us how to improve these questions. In the future, we may also study your interview along with interviews from other projects. This type of study will teach us about the different kinds of problems people have answering survey questions. The study will help us write better questions in the future.
Procedures
An interviewer will ask you some survey questions. Then, the interviewer will ask you to explain what you were thinking as you answered the questions. The interviewer will ask you if there were any words that were confusing and if you understood what was being asked.

The interview will last no more than 60 minutes, and we will give you $40. In order to receive the $40, you will need to fill out the attached SF-1164 form. You will also be asked to fill out a personal information sheet.

You may find that some of the questions we are testing are sensitive. You may choose not to answer any question for any reason. If you do not want to answer a question, say so, and we will move on to the next one. You may also stop the interview at any time. While the interview is going on, researchers from the National Center for Health Statistics who are working with us on this project may watch the interview.

If you have questions about how the project works, contact XXXX by phone at (XXX) XXX-XXXX, or by mail at NCHS, 3311 Toledo Rd., Hyattsville, MD 20782.

Recordings

We would like to video record your interview. The recording allows us to more carefully study the questions. At the bottom of this form, you will be asked if you are willing to have the interview recorded. If you agree, you may ask to stop the recording at any time, and we will turn off the machine. If you decide to stop taping, we will ask your consent to retain the portion already taped.

If you agree to record the interview, we will keep it in a locked room or in the safe keeping of a staff person from the Questionnaire Design Research Laboratory (QDRL). At a later time, staff from the National Center for Health Statistics who are responsible for developing questions on these topics may watch the interview. However, they must agree to keep your personal data private. Also, they must watch the interview in the QDRL or with QDRL staff present.

At the end of the interview, we may ask you for special permission to play the recording in a more public setting. For example, the interview could be played at a conference or for students who want to learn how to write survey questions. If you do not agree to this special permission, we will not allow anyone other than staff working directly on this project to watch to the recording.

Privacy

We are required by law1 to tell you what we will do with the recording. We must also tell you how we will protect your privacy.

Audio and video recordings are stored in a locked room or secured by a password. All recordings are labeled by a code number, date, time, and project title. The recording is never labeled with your name or other personal facts.

Materials with personal facts (such as names or addresses) are also stored in a locked room. Only QDRL staff have access to this material.

Your name or other personal facts that would identify you will not be used when we discuss or write about this study. People working on this project, however, may recognize you or your voice.

If you have questions about NCHS privacy laws and practices, contact XXXX, Confidentiality Officer at 301-XXX-XXXX.

Benefits and Risks

Other than the $40 you receive, there are no other direct benefits from taking part in this study.

There are no known physical or psychological risks from taking part in this study. We will take all possible steps to protect your privacy. You do not have to give us any information that you do not want to, and you can choose not to answer any question in the interview. You may also stop at any time and still receive the full $40.

If you have any questions about this study, please call the office of the Ethics Review Board at the National Center for Health Statistics, toll-free at 1-800-223-8118. Please leave a brief message with your name and phone number. Say that you are calling about Protocol #2002-03-XX. [Note: The amendment number will be inserted into the form once ERB approval has been received]. Your call will be returned as soon as possible.

Please Read and Sign Below if You Agree

☐ I freely choose to take part in this research study.

I allow NCHS to video record my interview. I also allow NCHS to play my video recording to other people working on this project either in the QDRL or in another location under the direct supervision of QDRL staff.

I do not allow NCHS to record my interview.

_____	_____	_____
Participant Signature	Print name	Date

1The Public Health Service Act provides us with the authority to do this research (42 United States Code 242K) and requires us to hold everything you tell us in strict confidence (42 United States Code 242m(d)). In addition, the provisions of the Privacy Act of 1974 (5 United States Code 552a) and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347) apply, with the latter providing for a felony conviction and/or a fine of up to $250,000 if we violate this promise.

Public reporting burden for this collection of information is estimated to average 75 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a

currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS D-24, Atlanta, GA 30333, ATTN: PRA (0920-0222).

OMB #0920-0222; Expiration Date: 02/28/2010

Appendix E: Demographic Information Form

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease
Control and Prevention
National Center for
Health Statistics
3311 Toledo Road
Hyattsville, Maryland
20782

OMB# 0920-0222; Approval expires 02/28/2010

Participant Data Collection Sheet

For our records we would appreciate it if you would take a minute to fill out this form.

1. How did you hear about us?

Newspaper Ad:		Flyer:	Word of Mouth:
☐ Gazette	☐ Giant		☐ Friend
☐ Sentinel	☐ Safeway		☐ Co-worker
☐ Washington Post/Express	☐ Other		☐ We called you to come back

2. Are you male or female?

☐ Male ☐ Female

3. What is your age?

_____

4. What is your marital status?

☐ Married ☐ Divorced ☐ Widowed ☐ Separated ☐ Never been married

5. Are you Hispanic or Latino?

☐ Yes ☐ No

6. What is your race? Mark one or more races to indicate what you consider yourself to be.

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian or other Pacific Islander
☐ White

7. What is the highest grade of school you have completed?

☐ 9th
☐ 10th

☐ 11th
☐ 12th no diploma
☐ High School Graduate- High School Diploma or the equivalent (for example: GED)
☐ Some college but no degree
☐ Associate Degree in college- Occupational/vocational program
☐ Associate Degree in college- Academic program
☐ Bachelor's degree (For example: BA, AB, BS)
☐ Master's degree (For example: MA, MS, MEng, MEd, MSW, MBA)
☐ Professional or Doctorate (for example: MD, PhD, DVM, JD)

8. Are you currently employed?
☐ Yes ☐ No

9. What is your total household income?
☐ 20K or less ☐ 30K or less ☐ over 30K

Appendix F: Cognitive Interview Protocol

***The following questions are from the 1994-1995 National Health Interview Survey on Disability**
[Physical Barriers]
The first set of questions are about the place you live.

1) Because of a physical impairment, do you have any difficulty –

a) Entering or leaving your home	Yes	No
b) Opening or closing any of the doors in your home	Yes	No
c) Reaching or opening cabinets in your home	Yes	No
d) Using the bathroom in your home?	Yes	No

2) Some residencies have special features to assist persons who have physical impairments or health problems. Whether you use them or not, does your residence have any of these features?

a) Widened doorways or hallways?	Yes	No
b) Ramps or street level entrances?	Yes	No
c) Railings?	Yes	No
d) Automatic or easy to open doors?	Yes	No
e) Accessible parking or drop-off site?	Yes	No
f) Bathroom modifications?	Yes	No
g) Kitchen modifications?	Yes	No
h) Elevator, chair lift, or stair glide?	Yes	No
i) Alerting devices?	Yes	No
j) Any other special features?	Yes	No

If Yes to all items in Q2 skip to Q4. Otherwise ask Q3 for items marked "No" in Q2.

3) Which special features do you NEED to get around your home, but do not have?

a) Widened doorways or hallways?	Yes	No
b) Ramps or street level entrances?	Yes	No
c) Railings?	Yes	No
d) Automatic or easy to open doors?	Yes	No
e) Accessible parking or drop-off site?	Yes	No

f) Bathroom modifications? Yes No

g) Kitchen modifications? Yes No

h) Elevator, chair lift, or stair glide? Yes No

i) Alerting devices? Yes No

j) Any other special features? Yes No

P1) Tell me more about challenges you face when moving around inside your home.

[Transportation]

The next set of questions are about getting around outside your home.

4) Some communities have special bus, cab or van services for people who have difficulty using the regular public transportation service. When using this special service, people can call ahead and ask to be picked up. Is such a service available in your area?

Yes
No (skip to Q7)

5) Have you used this special service in the past 12 months?

Yes (skip to Q7)
No

6) Why haven't you used this service in the past 12 months?

a) Don't know how to use
b) Need help from another person
c) Can't use alone
d) Can't use phone
e) Don't have phone
f) Can't read
g) Illness
h) Can't get reservation for service
i) Hours of service inadequate
j) Pickup unreliable/inconvenient
k) Cost
l) Denied use of service
m) Service not needed/wanted
n) Other reason

7) During the past 12 months, have you used local public transportation, such as a regular bus line, rapid transit, subway or street car?

a) No public system available (Skip to 11)
b) Yes (Skip to Q9)
c) No (Go to Q8)

8) Does an impairment of health problem prevent or limit your use of the public transportation services?

a) No public system available (Skip to Q11)
b) Yes (Go to Q9)
c) No (Skip to Q11)

9) Because of an impairment or health problem, during the past 12 months, did you have any difficulty using the local public transportation service?

Yes
No

10) What types of difficulties did/would you have using the public transportation service?

(DO NOT READ)
a) Cognitive/mental problems (remembering where to go/knowing how to avoid trouble)
b) Fear
c) Vision
d) Hearing
e) Weather
f) Difficulty walking/can't walk
g) Wheelchair/scooter/access problems
h) Problems with other medical/assistive devices
i) Need help from another person
j) Hours inadequate
k) Cost
l) Other
m) DK

P2) What form of transportation do you typically use?
P3) Do you know of special transportation services for impaired persons that are available in your area? Do you use these services?
P4) Do you use public transportation?
P5) Do you experience problems using transportation? What kind of problems – any other than the ones listed here?
P6) Do accessibility problems prohibit you from using these forms of transportation? How often do you encounter such problems?

[General Physical Barriers Outside of the Home]

11) Do you have any (other) problems getting around outside your home due to an impairment or health problem?

Yes
No (Skip to Q13)
DK

12) What (other) problems do you have getting around outside your home?
(DO NOT READ)

a. Cognitive/mental problems (remembering where to go/knowing how to avoid trouble)
b. Fear
c. Vision
d. Hearing
e. Weather
f. Difficulty walking/can't walk
g. Wheelchair/scooter/access problems
h. Problems with other medical/assistive devices
i. Need help from another person
j. Hours inadequate
k. Cost
l. Other
m. DK

Anything else?

P7) What kinds of obstacles to your mobility do you face outside of your home?
P8) Are there other obstacles besides what is asked about here?
P9) How often do you encounter these things?

[Work Barriers]

These next questions are about working for pay or profit.

13) Do you now work at a job or business? Yes No DK

If "Yes" ask Q14-17, If "No" skip to Q18

14) In order to work, do you NEED any of these special features at your worksite, regardless of whether or not you actually have them:

a) Handrails or ramps? Yes No DK

b) Accessible parking or an accessible transportation stop close to the building? Yes No DK

c) An elevator Yes No DK

d) An elevator designed for persons with special needs? Yes No DK

e) A work station specially adapted for your use? Yes No DK

f) A restroom designed for persons with special needs? Yes No DK

g) An automatic door? Yes No DK

Ask for each "yes" response in question 14

15) Do you have (feature) at work?

a) Handrails or ramps? Yes No DK

b) Accessible parking or an accessible transportation stop close to the building? Yes No DK

c) An elevator Yes No DK

d) An elevator designed for persons with special needs? Yes No DK

e) A work station specially adapted for your use? Yes No DK

f) A restroom designed for persons with special needs? Yes No DK

g) An automatic door? Yes No DK

P10) Are you currently working?

P11) Tell me about your ability to move around your work area.

P12) Do you need any of these accommodations in order to effectively do your job?

P13) Thinking about some of these obstacles we just discussed, please tell me how these obstacles make you feel.

[Social Barriers in Employment]

16) IN THE PAST FIVE YEARS, have you been fired from a job, laid off, or told to resign because of an ongoing health problem, impairment, or disability?

Yes
No
Not Sure
DK

17) IN THE PAST FIVE YEARS, because of an ongoing health problem, impairment, or disability, have you been –

a) Refused employment? Yes No DK

b) Refused a promotion Yes No DK

c) Refused a transfer? Yes No DK

d) Refused access to training programs? Yes No DK

Skip to question 19

P14) Have you ever experienced any of these things? Can you tell me more about that?

P15) How did it make you feel?

18) In order to work, would you NEED any of these special features at your worksite?

a) Handrails or ramps? Yes No DK

b) Accessible parking or an accessible transportation stop close to the building? Yes No DK

c) An elevator Yes No DK

d) An elevator designed for persons with special needs? Yes No DK

e) A work station specially adapted for your use? Yes No DK

f) A restroom designed for persons with special needs? Yes No DK

g) An automatic door? Yes No DK

P16) Do you need any of these accommodations in order to effectively do your job? Can you tell me more about this?

P17) What have their work environments been like in the past?

19) IN THE PAST FIVE YEARS, have you been fired from a job, laid off, or told to resign because of an ongoing health problem, impairment, or disability?

Yes
No
Not Sure
DK

20) IN THE PAST FIVE YEARS, because of an ongoing health problem, impairment, or disability, have you been –

e) Refused employment?	Yes	No	DK
f) Refused a promotion	Yes	No	DK
g) Refused a transfer?	Yes	No	DK
h) Refused access to training programs?	Yes	No	DK

P18) Have you ever experienced any of these things? Can you tell me more about that?
P19) What is the worst barrier you have ever experienced? How did it make you feel?

[Social Activities]
The next questions are about various activities you may have participated in.

21) DURING THE PAST 2 WEEKS, did you –

a) Get together socially with friends or neighbors?	Yes	No	DK
b) Talk with friends or neighbors on the telephone?	Yes	No	DK
c) Get together with ANY relatives not including those living with you?	Yes	No	DK
d) Talk with ANY relatives on the telephone not including those living with you?	Yes	No	DK
e) Go to church, temple, or another place or worship for services or other activities?	Yes	No	DK
f) Go to a show or movie, sports event, club meeting, class, or other group event?	Yes	No	DK
g) Go out to eat at a restaurant?	Yes	No	DK

22) Regarding your present social activities, do you feel that you are doing about enough, too much, or would you like to be doing more?
   a) Doing about enough
   b) Doing too much
   c) Would like to be doing more

P20) Can you tell me more about your social activities?
P21) How often do you do any of the above items?
P22) Are you satisfied with your level of social activity?
P23) Are there things that restrict your social activity? How does this make you feel?
P24) Are there other types of barrier/obstacles to social activities that we have not discussed?
P25) What are your experiences like when interacting with non-disabled people? Do you interact with disabled others? How are your experiences interacting with disabled others different from interactions with able-bodied others?

[Identity]

23) Do you consider yourself to have a disability? (Yes/No)

24) Would other people consider you to have a disability? (Yes/No)

P26) What about people in your family? at work? In your neighborhood?

P27) What does it mean to you to consider yourself disabled/not disabled?
P28) Why are you answering the way you do?
P29) Have you ever felt disabled/not disabled?
P30) When did you first feel disabled?
P31) Does your feeling disabled depend on where you are? Who you are with? Explain.

P32) What other identities are meaningful to you? If you had to list these in order of importance, how would you do it?
P33) How would you describe someone who is disabled? Is that person different from you? How? How do you think others see you? Why do/do you know think others consider you to have a disability? Who are the others that you are considering? Do you think this affects how you see yourself?

P34) How do you present yourself to others to make yourself appear less disabled? To make yourself more disabled?

P35) How has your impairment impacted your daily life? What types of things are you not able to do?

P36) How do barriers we discussed affect how you feel about your self/see your self? How do you cope with barriers you experience? Are there places/spaces where you feel more comfortable/are more accessible?

Appendix G: Descriptive Statistics

Table A1: Descriptives of Analytic Sample with Missing Data Retained

	N	Min	Max	Mean	SD	N
Social Statuses						
Female	5165	0	1	0.68	0.47	5165
Black	5165	0	1	0.19	0.39	5165
Education	5143	1	5	2.21	1.12	5143
Income	4520	0	26	16.34	7.81	4520
Age	5165	18	64	47.36	11.26	5165
Social Model Indicators: Environmental Barriers						
Barriers in home	5130	0	4	0.42	0.90	5130
Barriers outside home	5151	0	1	0.24	0.43	5151
Transportation barriers	5108	0	1	0.10	0.30	5108
Paratransit	5164	0	1	0.55	0.50	5164
Social Model Indicators: Social Engagement						
Social activity level	5080	0	7	4.30	1.64	5080
Socializing enough	5078	0	1	0.47	0.50	5078
Socializing too much	5078	0	1	0.06	0.23	5078
Socializing too little	5078	0	1	0.47	0.50	5078
Married	5076	0	1	0.47	0.50	5076
Employed	4871	0	1	0.39	0.49	4871
Medical Model Indicators						
Severity of movement difficulty	4973	0	5	2.78	1.42	4973
ADLs	5134	0	6	0.85	1.48	5134
IADLs	4539	0	6	1.07	1.34	4539
Use of assistive devices	5146	0	1	0.25	0.43	5146
Self Processes						
Reflected appraisals as disabled	4841	0	1	0.48	0.45	4841
Disabled Identity	5096	0	1	0.53	0.50	5096

Table A2: Descriptives of the Final Analytic Sample with Missing Data Removed

	N	Min	Max	Mean	SD	N
Social Statuses						
Female	3358	0	1	0.69	0.46	3358
Black	3358	0	1	0.15	0.36	3358
Education	3358	1	5	2.33	1.13	3358
Income	3358	0	26	17.00	7.52	3358
Age	3358	18	64	46.86	11.25	3358
Social Model Indicators: Environmental Barriers						
Barriers in home	3358	0	4	0.39	0.87	3358
Barriers outside home	3358	0	1	0.22	0.42	3358
Transportation barriers	3358	0	1	0.09	0.28	3358
Paratransit	3358	0	1	0.55	0.50	3358
Social Model Indicators: Social Engagement						
Social activity level	3358	0	7	4.49	1.60	3358
Socializing enough	3358	0	1	0.47	0.50	3358
Socializing too much	3358	0	1	0.06	0.24	3358
Socializing too little	3358	0	1	0.47	0.50	3358
Married	3358	0	1	0.49	0.50	3358
Employed	3358	0	1	0.44	0.50	3358
Medical Model Indicators						
Severity of movement difficulty	3358	0	5	2.63	1.41	3358
ADLs	3358	0	6	0.75	1.41	3358
IADLs	3358	0	6	1.04	1.31	3358
Use of assistive devices	3358	0	1	0.24	0.43	3358
Self Processes						
Reflected appraisals as disabled	3358	0	1	0.44	0.50	3358
Disabled Identity	3358	0	1	0.48	0.50	3358

Appendix H: Glossary of Terms

Impairment: Impairment is defined as "lacking all or part of a limb, or having a defective limb, organism, or mechanism of the body" (Oliver 1996:22).

Disability: Disability is defined as "the disadvantage or restriction of activity caused by a contemporary social organization which takes little to no account for people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (Oliver 1996:22).

Environmental Barriers: Environmental barriers are any barriers to mobility in the built structure. These are often referred to as physical barriers in the social model literature. These can include things such as, steps or stairs, narrow hallways, steep inclines, etc.

Stigma: Drawing on both Goffman's (1963) definition of stigma and modified labeling theory (Link et al. 1989) when I refer to stigma I am referring to discrediting attitudes toward persons with physical impairments.

Social Barriers: When I refer to social barriers I am referring to the outcomes of stigmatization, which can include discrimination, strained interactions, and social exclusion, among others.

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