

**Negotiating Identity and Masculinity Among Men with
Early Onset Physical Disability**

BY

BRIAN HEYBURN
B.A., Centre College, 2010

THESIS

Submitted as partial fulfillment of the requirements
for the degree of Master of Science in Disability and Human Development
in the Graduate College of the
University of Illinois at Chicago, 2014

Chicago, Illinois

Thesis Committee:

Sarah Parker Harris, Chair
Carrie Sandahl
Carol Gill

ACKNOWLEDGEMENTS

I'd like to first thank my advisor, Dr. Sarah Parker Harris, who took me on as her advisee, without any prior interaction with me, and has proven to be a consummate advisor. This project is a result of your faithful guidance.

I'd also like to thank my committee members, Dr. Carol Gill and Dr. Carrie Sandahl, who have provided me with invaluable feedback that has pushed me to think more critically, articulate myself more effectively, and ultimately, made me a better researcher. I am grateful for all of the ways in which you have counseled me throughout this process.

I'd also like to thank Lieke van Heumen for mentoring me through the process of developing this project from a class paper and into a conference presentation that would eventually pave the way to develop into my thesis. I am grateful for all of the times you met with me to work on this independent project of mine, at the time.

This study would not be possible without my participants. I want to thank them for their willingness to share their lives and perspectives with me. Indeed, they are the essential components to this research.

Finally, I would not have had this opportunity to pursue this research and this degree, were it not for the immense support and sacrifice on the part of my family. Their unyielding love and encouragement, are the very reasons I am able to do this work, and be involved with work that has great meaning for me.

BH

TABLE OF CONTENTS

<u>CHAPTER</u>	<u>PAGE</u>
I. INTRODUCTION	1
II. LITERATURE REVIEW	4
A. Conceptual Framework	6
B. Gender and Disability	13
C. Hegemonic Masculinity and Disability	16
D. Disability Identity	22
E. Gender Identity Formation During Adolescence	26
F. Theorizing the Impacts of Early Onset Physical Disability on Masculine Identity Formation	31
G. Responses to Hegemonic Masculinity	35
H. Neutralizing Stigma	49
I. Direction for Research	41
III. METHOD	44
A. Research Aims	44
B. Research Questions	45
C. Research Design	45
D. Sampling and Recruitment	48
E. Data Collection	50
F. Data Analysis	52
G. Confidentiality	56
H. Researcher Role	57
IV. RESULTS AND DISCUSSION	59
A. Traditional Stereotypes of Masculinity	60
1. Perceptions of American masculinity	60
B. Responses to Masculinity	61
1. Individual characteristics and efforts	62
a. Neutral impact of disability	63
b. Developmental adherence to traditional standards	64
c. Perceived improved social position of disabled men	65
2. External influences	66
a. Early feelings of difference	67
b. Barriers	70
c. Reformulations of masculine embodiment	75
C. Limitations	83
V. CONCLUSION	86

TABLE OF CONTENTS (continued)

<u>CHAPTER</u>	<u>PAGE</u>
APPENDICES.....	92
Appendix A.....	93
Appendix B.....	96
Appendix C.....	99
Appendix D.....	100
Appendix E.....	101
CITED LITERATURE.....	102
VITA.....	106

LIST OF TABLES

<u>TABLE</u>		<u>PAGE</u>
I.	THEMES AND SUBTHEMES	55

SUMMARY

Current research on masculinity and disability focuses on the ways in which disability interacts with masculinity, but there is a lack of research on the ways in which masculinity interacts with specific impairment types. This study seeks to give attention to men with early onset physical disabilities and their development of masculinity and disability, as previous research has suggested that the early onset of a physical disability may shelter these men from expectations of masculinity. This research is designed to explore the experiences of this population, guided by four research questions: 1) the ways in which men with early onset physical disabilities perceive or define traditional American standards for masculinity; 2) how these men compare their own senses of masculinity with traditional standards; 3) whether they have redefined masculinity for themselves or adopted non-traditional standards, and 4) how they compare their own developmental paths with those of other men. This study was exploratory in nature, and was conducted with open-ended surveys. There was a diversity of responses among this population. Some men focused on individual characteristics and efforts as means to accessing traditional standards of masculinity, while others gave increased attention to the ways in which external influences and barriers impact their access, offering critiques and reformulations of these standards. The results of this study reflect, in part, the findings of existing research, while also offering unique insights into some possibly significant differences among this demographic warranting further research.

I. INTRODUCTION

Masculinity, in America, has come to be associated with warrior values and frantic able-bodiedness, typically represented through aggressive sports and risk-taking activities, career-orientation, activeness, athleticism, sexual desirability and virility, independence, and self-reliance (Connell & Messerschmidt, 2005; Coston & Kimmel, 2012). The reverence of these values throughout United States culture can pose challenges to the masculinity and identity development of men who do not fit these hegemonic norms and ideals, including men with disabilities. In particular, men with early onset physical disabilities have remained an understudied population within existing literature on masculinity and disability. Resulting from a qualitative study done with disabled men and their experiences with disability and masculinity, Gerschick and Miller (1997) proposed a claim that the early onset of a disability may provide a sheltering effect on men with disabilities, such that men who experience the onset of a disability early in life may not be expected to meet the ideals of hegemonic masculinity. However, the researcher of the present study argues that hegemonic masculinity exerts a normalizing force throughout society, from which men with early onset physical disabilities are not immune. This argument is informed by Shuttleworth, Wedgewood, and Wilson (2012), who, in an article that provides a critical evaluation of existing research on disabled men and masculinity, suggest that men with early onset physical disabilities must contend with a more radical transgression of normative embodiment from an early age.

This study responds to the lack of existing literature on the experiences and development of men with early onset physical disabilities, as well as to the claim that

men with early onset physical disabilities are sheltered from the expectations exerted by hegemonic masculinity throughout society. In order to better understand the experiences of this population, this research draws upon existing literature that explores the areas of gender, masculinity, disability, identity, adolescent development, and stigma. It is important to note that this study uses a Disability Studies framework in its understanding of disability, which conceptualizes disability as separate from impairment, such that disability is caused by social, political and economic inaccessibility to those living with impairments. Similarly, this study is informed by existing literature (Butler, 1990; Connell, 2005b) that argues for a non-essentialist, performative understanding of gender, or understanding gender as constructed through performance. Gender identity is constituted by the performance of expressions that are mistakenly assumed to be its results, or a gendered being is a result of its actions. Gender, then, plays itself out on the surface of the body, and gendered bodies are regulated through diffuse channels of power that are present throughout all areas of society. Thus, in this way, the ways in which men are regulated to adhere to hegemonic understandings of masculinity can be seen, as well as the ways in which hegemonic masculinity can be viewed as a regulatory agent over other gendered beings, as a result of its revered and privileged position within a patriarchy.

Conducting research into the ways in which men with early onset disabilities create meaning in their lives throughout their developmental years can give narrative to these experiences. Further, this may open up the possibility for future generations of men with physical disabilities to begin to establish more positive identities for themselves at an earlier age. Through the recording of the narratives of men with early

onset disabilities, we can begin to understand how these men contend with hegemonic masculinity and start to understand the process of alternative masculine identity formation. This study may include the struggles of contending with the hegemony of masculinity as well as the nonstandard ways these men create meaning within their lives. The aim in studying the narratives of this population also includes contributing to efforts of deconstructing the oppression that hegemonic masculinity exerts over women as well as other subjugated masculinities. In so doing, an effort can then be made to restructure social institutions, policies and attitudes to include a wider range of masculinities, of which men with disabilities can be a part. As such, the members of these populations in future generations will hopefully have greater chances to resist the oppression that hegemonic masculinity exerts and allow for a wider variety of masculinities to be recognized as legitimate. This thesis will provide research to help explore this area of study.

Chapter I will review the existing literature on the relevant topics surrounding this research, including gender and disability, hegemonic masculinity and disability, gender identity formation during adolescence, responses to hegemonic masculinity, and neutralizing stigma. Chapter II will discuss the methodology employed for this research, including the research aims, research design, sampling, recruitment, data collection, data analysis, confidentiality, researcher role and bias, and limitations. Chapter III will discuss the results and discussion of the research, including an analysis of the themes and sub-themes identified within the data. Finally, the conclusion will discuss the significance and implications of the research findings.

II. LITERATURE REVIEW

Disability has traditionally been conceived in strictly medical terms, and defined as a medical deficit located specifically within the individual for which the person must seek medical assistance and rehabilitative efforts in the aim of a 'cure', or elimination of disability. However, with the evolution of a growing body of scholarship on the ways in which society responds to and interacts with a person with a disability, this static definition has transformed to incorporate new ways of thinking about disability as a creation of social injustice. Tobin Siebers (2008), in a section on disability identity within his larger work on disability theory, states that "unlike the medical approach, the emerging field of disability studies defines disability not as an individual defect, but as the product of social injustice, one that requires not the cure or elimination of the defective person, but significant changes in the social and built environments" (p. 3). A new definition of disability that focuses on the social interplay of people with disabilities and society challenges the notion that there is a certain set of prescribed physical or mental attributes that afford one the status of 'full human being'. Through the study of the oppression exerted upon people with disabilities by various social, economic, political, and attitudinal systems, it is revealed that disability is not simply an individual 'problem', but is a concept that is rife with the complexities of an individual with impairment(s) living in an inaccessible society.

The presence of a disability in one's life carries the potential to pose complications in the development of one's identity, as it can negatively influence the way in which an individual relates, or is able to relate, to prevailing gender norms. In particular, this can present challenges for men with physical disabilities who find

themselves living in a culture which emphasizes ideals such as individualism, autonomy and independence as imperatives, when having a disability is often thought to contravene these values, when it is culturally associated with dependence and helplessness (Shuttleworth, Wedgewood, & Wilson, 2012). This process of struggling to identify with the prevailing ideas about masculinity may prove more difficult in men with early onset disabilities, who endure the subjugation that accompanies living with a disability throughout their developmental years. It can be hypothesized that it is more difficult for men with early onset to disabilities to establish integrated identities for themselves when they feel at odds with prevalent notions of masculinity throughout their adolescence, a time that is widely accepted as a critical time for identity formation. This may differ from men who acquire a disability later in life or after adolescence, who may have been able to identify themselves more closely with hegemonic norms of being a man throughout their formative years.

This chapter will explore literature on the intersections of gender and disability, as well as the intersection of hegemonic masculinity and disability, while also covering literature on disability identity, gender identity formation during adolescence, responses to hegemonic masculinity, and neutralizing stigma. The exploration of this literature will be used to argue that the early onset of a physical disability may present unique circumstances under which to develop one's identity and masculinity, which may differ from that of men with acquired disabilities. It will turn now to the conceptual framework of the research.

A. Conceptual Framework

Disability studies, as a discipline, is grounded in an understanding of disability as a social construction and makes a distinction between 'impairment' and 'disability'. The field refers to 'impairment' as a mental or physical condition with which a person lives, and refers to 'disability' as the social, political and economic barriers that people with impairments face throughout society. The current study seeks to examine the concepts of gender, masculinity and identity as manifested in the lives of men with early onset physical disabilities through a disability studies lens. Analyzing data related to these three concepts from a disability studies standpoint will add perspectives of disabled men to each of these areas, thereby helping to create a more robust cultural understanding of each and making them more accessible to a wider population while alleviating the oppression that hegemonic masculinity exerts on all people, including people with disabilities.

Harriet Bradley (1996) describes gender in the following way: "Gender refers to the varied and complex arrangements between men and women, encompassing the organization of reproduction, the sexual divisions of labor and the cultural definitions of femininity and masculinity" (p. 205). Bradley (2013) expands upon this understanding of gender by making three claims. First, she proposes that gender is a social construct; that it is a category by which humans divide up and make sense of the world. It is a historical concept that is not fixed, but varies depending upon time, place and culture. Second, gender as a construct is deployed politically and is continually bound up in discourses of power relations between men and women. Third and finally, it must be seen as a lived experience. Gender is both a material and cultural phenomenon; it

refers both to the lived experiences of men and women as well as to the ideas that are developed to help make meaning of the relations between men and women, as well as to frame them (Bradley, 2013). Raewyn Connell's (2005a) work on masculinities, which serves as a critical survey of Northern thought around the subjects of masculinity, elaborates on the social construction of gender, and claims that "gender is a way in which social practice is ordered" (p. 71). Further, Connell argues that gender is not a set of biological determinants; rather it is a historical process that involves the body in a social practice that constantly refers to bodies and what they do. This provides a critical understanding of the ways in which gender is socially constructed and influenced by the individual's context, rather than understanding it simply as biologically determined, which can have implications for the ways in which we approach an understanding of the masculinity of men with early onset physical disabilities.

Gender, in this study, is understood not as a set of essential attributes inherent to a respective sex. Instead, as Butler (1990), whose work serves as a critical response to essentialist understandings of gender, suggests gender is produced through performance and is regulated through practices of gender coherence. Butler's argument is expanded by her explanation that there is no gender identity behind the expressions of gender. Gender identity is constituted in the performance of expressions that are mistakenly assumed to be its results. In short, a gendered being does not exist prior to its deeds; however, the gendered being is a result of its actions. There is no ontological status separate from the acts, gestures, and enactments that constitute its reality. Instead, gender is the fabrication of an interior essence that plays itself out in performance on the surface of the body. Thus, it is the public's desire to maintain the

regulation of sexuality within a heterosexual binary that creates the illusion of an interior and gender core respective to two separate sexes. However, Butler argues that the construction of the gender labeled 'woman' will not manifest itself solely in the bodies of females, and similarly, the construction of 'man' will not manifest itself solely in the bodies of males. Understood this way, gender is then seen as fluid, and that assumed biological determinants of gender encourage an oversimplified understanding of gender as a binary.

Philosopher and gender theorist, Judith Butler (1993) argues that the materiality of the body, or biological sex, then, constitutes a normative category, or relates to the Foucaultian idea that it is a regulatory force that produces the bodies that fall under its governance. This productive power implies its "power to produce-demarcate, circulate, differentiate-the bodies it controls" (Butler, 1993, p. xii). Butler contends that 'sex' is not a static condition of a body, but is a process in which the materialization of "sex" is achieved through the reiteration of regulatory norms. The body will then be thought of in tandem with the materialization of these regulatory norms; sex will become one of the norms by which a person becomes viable, or "qualified for life within the domain of cultural intelligibility." (Butler, 1993, p. xii). Therefore, through this lens, the ways in which bodies are insidiously regulated by normative categories of sex and gender, and the oppression exerted upon those who fall outside of their parameters can be seen.

In order to understand how gender categories and norms are not only regulated, but also created through diffuse systems of power throughout society, Butler's invokes Foucault's claim that juridical systems produce the subjects they subsequently come to represent. These juridical systems of power regulate political life and the subjects who

live within them, and through this regulation, subjects become formed, defined, and reproduced according to the requirements of the structures. Thus, the political system in which these gendered beings are created have an interest in maintaining a heterosexual norm, even though it is the same system that is supposed to operate to facilitate its emancipation. Foucault (1977, 1978) contends that power flows through multiple channels within our society, and that reinforcement of norms are propagated through the functioning of a number of social institutions. He challenges the idea that power is a monolithic, tyrannical entity, but rather that it is diffuse and discreet, producing reality through the structures of everyday life. In Foucault's (1977) *Discipline and Punish*, he claims that "power produces; power produces reality; it produces domains of objects and rituals of truth" (p. 207). He argues that power is not simply a force for repression, but it is a force that produces pleasure, forms of knowledge, and discourse. This productive force, he notes, runs throughout the whole of the social body, and starting with monarchies in the eighteenth century, new economies of power were developed, in which power ran continuous, uninterrupted, adapted and "individualized" throughout the whole of the social body (Foucault, 1977, p. 206). This brings us to an important understanding of the ways in which all bodies are subject to regulation through diffuse systems of power present throughout society, and that gender is similarly bound up in these systems of control, and thus the invisible coercion to conform to these ideals is made more visible.

Insights into creation and regulation of gender within these systems of power gives a more nuanced comprehension of hegemonic masculinity's position within these systems, both as equally subject to these systems of regulation, but also as a privileged

status serving as enforcement mechanism over other gender expressions. Masculinity can be seen not as “a natural character type, a behavioral average, a norm... [but] simultaneously a place in gender relations, the practices through which men and women engage that place in gender and the effects of these practices in bodily experience, personality and culture” (Connell, 2005a, p. 71). Further, in Connell and Messerschmidt’s (2005) evaluation of current conceptualizations of hegemonic masculinity, they report that, initial studies of *hegemonic* masculinity came to understand the concept as “the pattern of practice (i.e., things done, not just a set or role expectations or an identity) that allowed men’s dominance over women to continue. [...] It embodied the currently most honored way of being a man, it required all other men to position themselves in relation to it” (p. 832). Connell (2005a) defines hegemonic masculinity as the configuration of gender practice which embodies the currently accepted answer to the problem of the legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women” (p. 77). Additionally, hegemonic masculinity is not intended to be a category by which to describe all men. Instead, it is a way of grasping a certain dynamic within a social process. It is not a static concept, rather, it is one that is fluid, accomplished through social action and thus differs depending upon the gender relations within a particular setting (Connell & Messerschmidt, 2005). Connell (2005b) reifies this concept by describing hegemonic masculinity as the masculinity that occupies a hegemonic position in a given pattern of gender relations and is not a fixed character type that is always the same. Therefore, understanding hegemonic masculinity in this way, illuminates masculinity exists in a privileged position and exerts

a dominating force over women and other men who possess non-hegemonic masculinities.

The ideal of hegemonic masculinity is one by which men define themselves through their relative position to it. Thus, one's alignment with this model of masculinity in comparison to other men begins to shape one's identity. Jeffrey Weeks (1990), British sociologist whose work largely focuses on the history of sexuality, writes, in his chapter on the value of difference and identity, that "identity is about belonging, about what you have in common with some people and what differentiates you from others. At its most basic it gives you a sense of personal location, the stable core to your individuality" (88). Weeks elaborates that identities, or the desire to express ourselves, our beliefs and desires, are not neutral, and often create conflicts within different communities as well as within individuals themselves. This is a particularly illuminating point for people with disabilities who are ascribed an identity primarily characterized by medical deficit or tragic loss. Indeed, this is a difficult identity to shed for a person with a disability, who continually encounters cultural narratives of disability that are primarily focused on a medical deficit understanding of disability in the majority of their interactions.

In order to explore the ways in which gender becomes stigmatized, and how that stigmatization plays out in the gendered lives of men with early onset physical disabilities, it is prudent to explore sociologist Erving Goffman's (1963) work on stigma, which explores the experiences of individuals who either do not or are unable to conform to society's standards of normality. Goffman (1963) notes that American men are measured against the understood 'complete' male, who is "young, married, white, urban, northern, heterosexual, Protestant, father, of college education, fully employed,

of good complexion, weight and height and a recent record in sports” (p. 139). He contends that any man who fails to meet any of these standards is likely to view himself as “unworthy, incomplete, and inferior”, which may have the tendency to render him apologetic for the traits that he perceives as undesirable (Goffman, 1963, p.139). Explorations of stigma describe, in more detail, the processes through which a marginalized individual can be put, and the attention given to Goffman is particularly useful in the context of masculinity, as he describes hegemonic norms against which men are compared.

It is widely accepted that adolescence is the primary period during which identity begins to be explored, challenged, and questioned. Thus, this time period can pose particularly unique circumstances for individuals who feel excluded from more socially accepted identity groups, including people with disabilities, and more specifically, men with early onset physical disabilities who become more immediately stigmatized, due to their ability status, from gendered norms of masculinity. Marcia (1980), a developmental psychologist and theorist writing on identity in adolescence, contends that identity is a “self-structure, an internal, self-constructed dynamic organization of drives, abilities, beliefs and individual history” (p. 159). He further explains that as this structure becomes better developed, individuals become more aware of the ways in which they are both unique and similar in relation to others, as well as the ways in which they can use their strengths and weaknesses in navigating the world. Inversely, if this self-structure is less developed, an individual will experience more confusion about their own distinctiveness from others and thus, are forced to rely on external sources to evaluate themselves. Marcia (1980) asserts that adolescence is a critical time during

the project of identity formation as a transition in approach to cognitive tasks takes place. In particular, individuals begin to prioritize their own unique organization of one's history, skills, shortcomings and goals over others' expectations and directives. Thus, studying the ways in which the presence of disability during the adolescence of men with early onset physical disabilities impacts their identity formation is prudent for understanding how disability relates to culturally normative paths of identity development and of the ways in which gender and disability interact throughout this developmental process.

B. Gender and Disability

Rosemarie Garland-Thomson (2002), based on her critical literature review of feminist theory and seeking to integrate disability into this analysis and develop a feminist theory of disability, claims that disability interacts with gender in specific and complex ways, and she proposes an integration of feminist theory into disability studies in order to develop a feminist theory of disability. She contends that, disability, like gender, is a pervasive concept throughout all aspects of culture such that it structures "institutions, social identities, cultural practices, political positions, historical communities, and the shared human experience of embodiment" (Garland-Thomson, 2002, p. 76). The proposal of a feminist theory of disability is intended to foster an understanding of the complexities surrounding the cultural histories of the body. Further, this theory is meant to address feminist concerns, broadly defined, such as the status of the lived body, the privilege of normalcy, multiculturalism, sexuality, the social construction of identity, and the commitment to integration. With this understanding of

the interaction between gender and disability, a framework is given to comprehend the significance of the ways in which gender impacts cultural interpretations of disability.

In light of an understanding of the significance that gender plays in cultural interpretations of disability, Gerschick (2000), whose theorizing work seeks to explore the intersections of gender and disability, expands upon Butler's (1990) proposal that gender is produced through performance, to emphasize the importance of bodily materiality and to contend that performance of gender is dependent upon one's ability to conform the body to the socialized expectations and roles associated with each gender. Further, one's sense of self rests precariously upon the social rejection or validation of one's performance of gender. Bodies are central to achieving recognition as appropriately gendered individuals through gender performance, as they are the instruments through which gender is displayed and physically enacted. Connell (2005a) claims that "Bodies cannot be understood as a neutral medium of social practice. Their materiality matters. They will do certain things and not others. Bodies are *substantively* in play in social practices such as sport, labour and sex" (p. 58). Consequently, individuals with disabilities become more vulnerable to rejection of their gender performance as men or women, and, indeed, the severity of disability influences the level to which the body is socially compromised (Gerschick, 2000). Further, Connell (2005a) asserts that gender is vulnerable when the performance cannot be sustained.

The performance of gender for men accords with values associated with masculinity in the United States, such as warrior values and frantic able-bodiedness represented through aggressive sports and risk-taking activities, career-orientation, activeness, athleticism, sexual desirability and virility, independence, and self-reliance

do not allow a space for men with physical disabilities to establish positive identities based on their own experiences and abilities (Connell & Messerschmidt, 2005; Coston & Kimmel, 2012). However, Coston and Kimmel (2012) maintain that disabled men are often unable to meet the unquestioned and idealized standards of appearance, behaviors and emotions that are expected of men. Gerschick (2002) concludes: "...for men with physical disabilities, masculine gender privilege collide with the stigmatized status of having a disability, thereby causing status inconsistency, as having a disability erodes much, but not all, masculine privilege" (p. 1265). Similar struggles exist for a gay man, whose masculinity becomes associated with effeminacy and therefore experience similar subjugation as women (Coston & Kimmel, 2012). In an effort to elucidate the gendered differences between being a male with a disability and a female with a disability, Asch and Fine (1988), in their collection of essays on the experiences of women with disabilities, report that our culture views being female and disabled as 'redundant' whereas being a male and disabled is viewed as a 'contradiction'. Rosemarie Garland-Thompson (2002) clarifies the distinction between the gendered differences of disability further by arguing that sickness, and therefore, abnormality, is gendered female, suggesting that both women and disabled people are typically imagined as medically abnormal. In short, she asserts that sickness, disability and abnormality are associated with being female. Therefore, it can be inferred that having a disability is culturally seen as complicating disabled men's ability to align themselves with hegemonic standards of masculinity, and serves as an emasculating force.

While the experience of disability impacts each gender differently, such that being a disabled female is viewed as redundant, while being a disabled male is viewed

as a contradiction, having a disability persists as an abnormal position in society. Therefore, it has been subjugated with shared parallels with the ways in which women have experienced oppression and struggles in identity formation. Further, while masculinity remains as the revered norm throughout society, the presence of a disability among men with early onset disabilities may be able pose a challenge to this absolute hegemony that men enjoy through questioning the ways in which we force men to identify themselves, beginning in earnest during adolescence.

C. **Hegemonic Masculinity and Disability**

Examining more intently the masculine standards with which men contend, Connell (2005a) asserts that hegemonic masculinity materializes the currently accepted answer to the problem of patriarchal legitimacy that seeks to guarantee the dominant position of men and the subordination of women. Discursive practices, such as speech that reinforces understandings and informs practice of hegemonic masculinity, allow men to adopt expressions of their masculinity when it meets their interactional needs in securing their position of dominance over women. These actions can depend upon a man's location, and thus vary widely (Wetherell & Edley, 1999). In a study of a sample of men from a range of ages and occupational backgrounds, Wetherell and Edley found that while hegemonic masculinity regulates men's conduct through consensual shared forms of sense-making, a multiplicity of hegemonic sense-making is relevant to the construction of masculine identities. For example, one man may emphasize his ability to consume alcohol in his definition of his own masculinity, whereas another man may highlight his physical prowess and aptitude for sports.

Further, it is also important to note that there exists oppression of certain masculinities such that the oppressed masculinities have no bearing on the formation of hegemonic masculinity. In a critique of Connell's concept of hegemonic masculinity, Demetriou (2001) argues that hegemonic masculinity creates external hegemonies, such as oppression of women as well as internal hegemonies, such as the oppression of gay men. These oppressed masculinities exist in tension with, but never penetrate, the hegemony. Thus, it is also contended that any effort to maintain hegemonic masculinity, will implicitly incorporate the dehumanization of other groups. Judith Butler (1993), in an extension of her work on theories of gender, gives illustrates this idea by suggesting that the construction of the gendered subject simultaneously requires the production of abject beings, or those who are considered to be outside of the constituted subject. These abject beings are designated as those who live in 'unlivable' or 'uninhabitable' areas of social life and who do not enjoy the designation of 'subject', but whose existence circumscribes the subject and defines the limit between the subject and the abject. Masculinities, despite its many forms, demonstrate men's fantasies and desires, but do not necessarily reflect the reality of their lives (Connell & Messerschmidt, 2005). Thus, masculinity is not defined by one fixed set of traits or characteristics, but can vary depending upon the man, such that it reinforces his dominance within a particular setting.

Additionally, much of what has informed these idealized ways of being a man include the conceptions about the ability to work within an industrial capitalist society. Winter and Robert (1980), in a paper on male dominance in late capitalism, argue that men acquired the privilege of access to industrial work and increased participation in the

growing world of production and exchange in advanced capitalist societies. Masculinity, according to these authors, is defined as the internalization of the technical reasoning, or the reasoning that serves the corporate economy and its interests. Connell (2005) elucidates the characteristics that define masculinity in an industrial capitalist system, those of strength, endurance, a degree of insensitivity and toughness, and group solidarity. Further, Connell (2005a) recounts an interview that he conducted with a research subject, who noted that “working men’s bodily capacities *are* their economic asset” (p. 55). In his chapter on capitalism and disabled identity, Robert McRuer (2006) discusses the ways in which the domestic sphere reinforces able-bodied, heterosexual, and gender norms in a manner that propagates capitalist imperatives. This domestic space also bolsters heterosexual norms and gendered divisions of labor. In this way, it can be seen that the domestic space has been constructed in tandem with the maintenance of a capitalist system, and the exclusivity of this constructed domestic sphere is not only critical to the survival of our current economic system, but creates an oppressive environment for anyone who does not meet capitalist or gendered standards.

Connell (2005a) emphasizes a material understanding of hegemonic masculinity in current globalized, neoliberal economies, such that the focus remains on the privilege that businessmen and CEOs have in defining hegemonic masculinity. However, other research, such as Elias and Beasley (2009), whose article centers around hegemonic masculinity and globalization, adds nuance to this argument so as to clarify the fact that within current globalized neoliberal economies, it is insufficient to study hegemonic masculinity solely through the material, top-down power structures that exist within

today's economies. This study must be balanced with an examination of the ways in which everyday, discursive practices also help to define hegemonic masculinity and legitimates the workings of global capitalism. Connell and Messerschmidt (2005) clarify this concept by explaining that masculinity should be analyzed at three different levels: local, regional, and global. The local level is constructed in the arenas of face-to-face interactions of families, organizations, and immediate communities. Regional masculinity is constructed at the level of culture or the nation state. Global masculinity is constructed in such arenas such as world politics, and transnational business and media. Analysis of hegemonic masculinity should recognize that there are often linkages between the levels. However, these connections between levels are not necessarily unidirectional. For example, hegemonic masculinity at a regional level can provide a cultural framework that becomes materialized through local, daily practices and interactions. Therefore, while the precise ways in which hegemonic masculinity is defined within an economic context may have changed, the contention remains that masculinity is reified through economic practices. Understanding this nuance within current economic contexts can help us to better understand the impacts of globalized neoliberal economies on materializations of gender.

Further, Connell (2005a) asserts that "the physical sense of maleness and femaleness is central to the cultural interpretation of gender" (p. 52). Included in this cultural interpretation of masculine gender are certain muscular shapes, postures and ways of moving, as well as particular sexual possibilities. In recent historical eras, prowess in sport has become a defining characteristic of masculinity in United States mass culture. Male bodies are monitored through rules of the sport, and in so doing,

these bodies are brought into competition with each other in order to assert superiority over the other. Masculine embodiment in sport involves the coordinating of the whole body in stylized movements, rather than simply the use of one organ. Thus, the skillful integration and use of the entire body in a range of difficult physical feats in the context of sport is what becomes admirable among male competitors, and begin to establish a hierarchy among men as well as male dominance of women.

Illuminating Connell's (2005a) assertion that gender is vulnerable when the performance of each gender cannot be sustained, Gerschick and Miller (1997) claim that the construction of masculinity around the imperatives of bodily performance becomes vulnerable when these bodily performances cannot be executed, such as in the case of physical disability. Physical disability among men can be argued to block their access to dominant conceptions of masculine identity, as their physical state is perceived by society to undermine the typical role of the male body in United States' culture. Disabled men often report feeling as if their condition is at odds with beliefs commonly held about men, presenting them with difficulty in conforming to the prevailing understandings about men and their behavior, or hegemonic masculinity (Shuttleworth et al., 2012).

In order to understand the ways in which able-bodiedness affords men privilege over their disabled counterparts, it would be helpful to understand the ways in which Robert McRuer (2002) applies the concept of compulsory heterosexuality to a disability context to help reveal how able-bodiedness is able to maintain its hegemonic position. The oppression that dominant characteristics such as heterosexuality and able-bodiedness exert is hidden by false claims that 'alternative' ways of being remain viable

and positive identities. He claims that compulsion mystifies a system in which there is actually no choice about alternative ways of being. Thus, able-bodiedness remains the preferred identity, regardless of arguments to the contrary, and this preference affords able-bodied people a privilege withheld from disabled people. McRuer cites an example of Michael Bérubé and his son Jaime, who has Down's syndrome. Bérubé writes about the ways in which people assume that he must be disappointed in his son's condition, and that he feels burden to prove the contrary to others. Thus, people preemptively conclude that it would simply be better if his son were 'normal' because our culture assumes that these hegemonic identities and perspectives are universally preferable. This theory helps to illustrate that the possession of a disability does, in fact, result in a spoiled identity.

Hegemonic masculinity reinforces its oppressive position in a similar manner over both femininity as well as other subjugated masculinities, such that hegemonic masculinity remains the idealized way of being a man. Therefore, hegemonic masculinity, like able-bodiedness and heterosexuality, remain desired norms despite the claims that our culture makes that non-hegemonic ways of being, such as homosexuality and living with a disability, are legitimate alternatives. This illusory sense of freedom to embody an alternative way of being cloaks a hidden compulsion to strive towards a hegemonic norm. Thus, as Connell (2005a) concludes, bodies are inescapable in the construction of, and compulsion to, heterosexuality, masculinity, able-bodiedness. The positions of prominence in which each of these categories find themselves, and the bodies they represent, become the objects of history and politics, including identity politics. Thus, elucidating the concepts of hegemonic masculinity in

this way helps to give attention to the pervasive expectations that this concept exerts in the lives of all men, and clarifies the barriers presented to men with early onset physical disabilities, with which they must contend throughout their development. The prolonged and persistent confrontation of these hegemonic standards throughout one's development can be seen to pose challenges to the development of identity and masculinity of this population, particularly when experienced throughout the primary years of development.

D. **Disability Identity**

Similar to the ways in which bodies are central to the construction of heterosexuality, masculinity, able-bodiedness, and the accompanying identities, Davis (2006) discusses the development of a system in which bodies are marked by their degree of deviation from a 'norm' and therefore marked and identified as such. Within this system, the person enters into a relationship with the body such that the body forms the identity, becoming the person's fixed position on the 'normal curve'. In this model, in which fingerprinting was used to measure and mark physically different bodies, these physical differences become equated with the identity of the person. These markers not only impacted the identity of the individual, but also impacted the perceptions of these bodies, particularly that they were perfectible (Davis, 2006).

In contrast to this strictly medicalized understanding of disability, in which pathology determines perceptions and identity of an individual, evolving research of disability, primarily in the field of disability studies, has begun to alter the way in which disability is conceived in our society. Rather than conceiving of disability as a physical or mental defect, Tobin Siebers (2008) claims that disability is a cultural and minority

identity. The recognition of disability as an identity rather than a biological or natural property is to acknowledge it as an elastic social category both subject to social control as well as capable of affecting social change. Sociologist, Tom Shakespeare (1996), in his work on disability, identity, and difference, writes that disabled people's project of establishing a positive identity is indeed a complicated one. He further describes disability identity as an interconnected concept among personal, social, and political arenas. Many theorists have written on the topic of identity and specifically, disability identity, and its complex nature. Further, it is recognized that issues of identity in the context of disability are not only associated with personal acceptance and affirmation, but are associated with a broader disability culture and civil rights movements as well.

Identity formation within marginalized populations can also be described as an alienation from one's own experience. Drawing upon Marx's theory that the worker who is alienated under the demands of capitalism, due to the prohibition of activities that constitute selfhood, Sandra Bartky (1990) describes the alienation of women in similar terms. She argues that women suffer from alienation under the dominance of male privilege in our society in ways that are absent from Marx's theory of alienation. Women are excluded from most avenues of cultural expression, such as high culture, popular culture, and language, which are all apparatuses of male supremacy. This argument can be applied to people with disabilities as well, who are so often excluded from cultural production and expression. Bartky's theory can be argued to be relevant to understanding similar developmental processes of men with early onset disabilities, whose experiences, from the beginning of their lives, may also be characterized by alienation, and thus, difficulty in identity formation.

The difficulty of establishing a positive identity in the context of disability has repeatedly been documented in research (Fleischer & Zames, 2001; Gerschick 2000; Gill, 1997; Shuttleworth et al., 2012) such that an individual with a disability may feel conflicted about the best ways in which to integrate disability into one's identity. Illuminating the experiences of men with early onset physical disabilities is critical for the lives of these men because of the vital role that identity can play in developing one's self-esteem. It can be expected that identifying the ways in which members of this population relate to hegemonic masculinity and emphasize aspects of themselves that do not align with the rigid demands of this oppressive concept may help reduce the alienation these men feel from their own experiences. Often, this alienation can be seen as forced upon them through prevailing norms of masculinity. It can also be hypothesized that the reduction of alienation and elevation of self-esteem, through a more integrated sense of self might translate into other health benefits as well. These adjacent health benefits can stem from an elevated sense of self-worth and belonging, leading to higher levels of motivation to care for oneself. Therefore, setting a precedent for positive identity formation among men with physical disabilities and allowing them to integrate their disability with their sense of masculine identity, in their own ways, can have effects that extend to one's general health.

Psychologist and disability studies scholar, Carol Gill (1997) maps out four types of integration in disability identity formation of positive identity for someone with a disability. Initially, Gill reports that people come to feel that they belong, that they direct their desires and actions towards integrating into society. Second, people with disabilities begin integrating into the disability community. Third, people with disabilities

begin to internally integrate their sameness and differentness. Finally, people with disabilities are said to go through a process of 'coming out' in which the individual integrates how one feels with how one presents his or herself. This is the stage in which a person is able to 'be oneself' (Gill, 1997). Shakespeare (1996) further explains the shift that occurs in this fourth type of identity formation by describing the way in which those who reject a medical deficit understanding of disability come to focus on the exclusion and injustice that characterizes disability. Shakespeare also refers to this shift, which reflects changing one's focus on the medical model to the social model of disability, a 'coming out' or a process of positive self-identification.

Each of these steps, as Gill argues, represents an increasing integration of disability into one's own identity with the end result being a positive self-image and identity. She recounts that despite the opportunity for the establishment of a positive self-identity, many individuals with disabilities spend their whole lives attempting to 'pass', whether their disability is visible or not, in an effort to minimize the differences between them and the dominant population. These people, she reports, seem tired and alienated and ultimately lacking a comfortable identity of themselves. "They dare not be themselves in public because they do not yet fully accept their differences and others who are different. They cannot be counted on to critique the values of the dominant culture, so busy are they with meeting the standards" (Gill, 1997, p. 45).

Through a review of literature surrounding disability identity, the numerous ways of identifying a person with a disability can be seen, either through a medical deficit lens, or through a social model lens in which the individual is seen to be disabled by an inaccessible society. While the social model of disability is emerging, there still remain

oppressive conceptualizations of people with disabilities, and accompanying difficulties in establishing positive identities. Therefore, an understanding of the immense difficulties presented to all people with disabilities in establishing positive identities for themselves can contextualize the struggles with which men with early onset physical disabilities contend, in the face of marginalization as non-hegemonic men and disabled individuals. It is important to examine the effects these aspects of marginalization have on this population, when a disability is present throughout their developmental years.

E. Gender Identity Formation During Adolescence

Developmental psychologist and psychoanalyst Erik Erikson's (1968) theoretical model of psychosocial development is divided into eight stages and highlights the importance of adolescence in the identity development process. Erikson writes that adolescents go through processes of development in which they find themselves seeking new ways of connecting the skills and roles they acquired in childhood with the economic imperatives of current society, replacing their original unit of reference, the family, with that of 'society'. During this time, he writes that adolescents become "morbidly, and curiously preoccupied with what they appear to be in the eyes of others as compared with what they feel they are" (Erikson, 1968, p. 128). Adolescents seek to find where they will be able to uniquely contribute their talents and abilities without being forced into work that they find unfulfilling. Thus, the primary project of adolescence, according to Erikson, is finding where one's talents and abilities can align with the current state of society. In so doing, it is hoped that the individual will be able to derive their identity from the ability to use their talents to contribute to current needs of the society. The inability to find a place in which an adolescent can contribute their talents

leads that individual into ideological projects, and may find him or herself inspired by the ideological potential of a society, or the vision of a society that welcomes a broader range of talents in which they can be included. This project of identifying the ways in which an adolescent can connect their talents with the needs of the current society may be a significantly more challenging task for people with disabilities, for whom equitable access to current society is limited.

These assertions on the critical nature of adolescence in identity development have been extended by research, such as the longitudinal study of 200 adolescent female-identifying and male identifying individuals by Galambos, Almeida, and Peterson (1990), that introduces complexity to these ideas by examining the ways in which identity development varies across gender. The gender intensification hypothesis was originally proposed by Hill and Lynch (1983), which submits that behavioral, attitudinal, and psychosocial differences between adolescent boys and girls increase with age and are the result of increased socialization pressures to conform to traditional masculine and feminine sex roles. While the claims of this hypothesis have been questioned (Priess, Lindberg, & Hyde, 2009), it can still be argued effectively that masculinity enjoys a higher status than femininity and that masculine characteristics are considered most desirable. Thus, it may be the case that females seek or are encouraged to exhibit masculine characteristics more often than males seek to exhibit female characteristics during this intense period of identity formation (Priess et al., 2009). In their study, Galambos et al. (1990) found that there was an increase in sex-role attitudes across early adolescence. The rationale for this increase in sex differences, particularly among boys, is born out of the fact that masculinity is a critical aspect of self for boys and has a

positive impact on their self-esteem and peer acceptance (Massad, 1981). Galambos et al. further explain that social pressure to conform to sex roles differs among boys and girls, and since masculine behaviors, preferences and interests are socially valued, boys experience an escalation of masculinity as they move toward adulthood.

Psychologist Carol Gilligan (1979), in her critique of Kohlberg's model of moral reasoning, as male-centered and uninformed by women's perspectives, stresses the ways in which girls develop differently than boys. She contends that girls place more importance on attachment and relationships and that boys place more importance on individuation and separation. As an example of the relational differences among adolescent boys and girls, Way and Greene (2006) found, in their study on trajectories of perceived friendship quality, that girls started high school with more intimate and close friendships than boys, with boys catching up by the late high school years. This suggests that girls learn the necessary cognitive and interpersonal skills to nurture close relationships at an earlier age than boys. Despite these differences and relational advantages that girls seem to have over boys, masculinity continues to be valued more highly among the genders, and therefore exert a stronger influence on adolescents' development than femininity. This fact may have particular implications for adolescent men with disabilities who may not fit with these masculine standards, and therefore have difficulty identifying with them.

Considerations of the ways in which men with early onset disabilities experience processes of identity formation would benefit from the examination of similar identity formation processes in other marginalized and stigmatized populations of men, such as gay men. The identity development of these two populations can be seen as similar

through the possession of a stigmatized identity from birth, or the realization of such an identity in early childhood. Many theoretical models for identity development among homosexual men have been established, mapping the stages through which these men pass in their processes of identity development. Vivienne Cass's model of homosexuality identity development includes five stages (Ellis & Peel, 2010). The first stage involves identity confusion, or an awareness that homosexuality is pertinent to oneself and/or one's behavior. The second stage is identity comparison or an incongruity between the self-perception as homosexual and others' perceptions of one's homosexuality, which results in feelings of alienation from peers and a sense of self characterized by a lack of belonging and being different. The third stage is identity tolerance, or an increased level of commitment to self-image as homosexual and acknowledgement of all needs associated with being homosexual, such as social, emotional, and sexual, resulting in heightened alienation from the heterosexual world and actively seeking out of other homosexuals and connecting with a homosexual subculture. The fourth stage, identity acceptance is the stage in which the individual has more frequent contact with homosexuals, and begins to prefer homosexual social contexts and begins to establish friendships within these environments. The fifth stage, identity pride can be seen when the individual displays a strong commitment to homosexual culture, and begins to develop a sense of group identity while also preferring a homosexual identity over a heterosexual identity. The sixth and final stage is identity synthesis, the stage in which homosexual identity is integrated into other aspects of self, and is no longer seen as the only identity, but is simply one aspect of the individual's identity (Ellis & Peel, 2010).

Vivienne Cass's model of homosexual identity development is only one of several, all of which have many common elements, such as an awareness of homosexual feelings, exploration of homosexuality, taking on a gay or lesbian identity, and integrating a gay or lesbian identity into one's more general sense of self. While many of these stage models exist, there are many critiques to be made of them. Primary among the critiques of these models is the fact that identity development for each individual is different, and does not always follow a linear pattern as these models suggest. Many people move in between these stages several times, or do not follow the strict trajectory laid out by these models. Therefore, it is imperative to acknowledge that identity formation will manifest itself differently in every person.

Despite the shortcomings of these models of identity development, it may be fruitful, in studying the identity development of men with early onset physical disabilities, to draw upon the existing theories laid out in these homosexual identity development models to help orient ourselves in understanding similar processes in this population of disabled men. To reemphasize, it should not be suggested that disabled men or gay men follow a strict trajectory of identity development as detailed in these models, nor that the development of identity among gay men and men with disabilities are identical, but there may be elements of each that may be common to both populations. For instance, a man with an early onset physical disability may share similar experiences as homosexual men in the identity comparison stage, in which the individual, homosexual or disabled, becomes aware of the incongruity between perception of self as gay or disabled and others' perceptions of them, thereby resulting in alienation from peers and a sense of self as not belonging or being different.

F. **Theorizing the Impacts of Early Onset Physical Disability on Masculine Identity Formation**

Gerschick and Miller (1997) conclude that while the age of onset of a disability may have differing effects on men with physical disabilities and their formation of identity, they argue that those with early onset disabilities may experience less difficulty in forming a positive masculine identity as they have never been forced to conform to the dominant expectations of masculinity. This argumentation views the project of identity formation solely as an individual one that occurs independent of social influences. However, Shakespeare (1996) contends that the negative identity formation of people with disabilities is a result of socialization and occurs through processes of interactions with others. He argues that people with disabilities are not simply able to triumphantly draw strength from their label of 'other' in the formation of identity. Rather, it is a process fraught with difficulties in the establishment of a positive self-identity. Thus, it can be argued that regardless of age of onset, hegemonic masculinity remains a prevalent social ideal by which men are measured in their ability to meet its standards. Therefore, men with early onset physical disabilities still come into contact with these standards as they exist in our society, and can be expected to contend with these models of masculinity and, often, the recognition of their inability to fulfill them, particularly throughout their development. Shuttleworth et al. (2012) contend that while people with early onset disabilities may not have to deal with biological disruption and a sudden assault on their personhood, they do have to grapple with a "more radical transgression of normative embodiment" from an early age, while also integrating their

identity in the face of powerful cultural symbolism that their disabilities can evoke (p. 183).

It can be argued that the tendency that disability can have to be an emasculating attribute is not exclusive to men with acquired disabilities; men with early onset disabilities are still likely to confront these standards as well, not only in adulthood but throughout their developmental years as well. Struggling with these issues throughout the most intense years of identity formation can be seen to force one to call into question their validity as men, without having a previous positive relation to hegemonic masculinity, as might be the case for men with acquired disabilities. Engel (2003), in his collection of stories relating to law and identity in the lives of Americans with disabilities, elucidates this argument in the story of Bill Meier, who acquired a spinal cord injury as a young adult. In an interview with Meier, he recognizes the privilege he had in having a successful managerial career prior to his injury, as well as fact that he might not have been able to be hired into his current job, if he had begun applying after his injury. Therefore, drawing upon the nuances of this account, it might be suggested that men with physical disabilities acquired in adulthood possess a certain measure of privilege of masculinity as a product of living part of their lives in a non-disabled body.

It can be hypothesized that when men acquire a disability later in life, after they have gone through their intense developmental years of adolescence, may have the benefit of drawing upon an identity that was more aligned with hegemonic ideals of masculinity. Therefore, this population of men already has a sense of their masculinity with which they are able to both navigate their identities and explain away their current situation as a result of an external factor, rather than a characteristic with which they

have always dealt. However, it can be suggested that men who were born with a disability or acquire a disability at any time prior to adolescence are, in some ways, blocked from a positive relationship with hegemonic masculinity throughout their developmental years. This can leave one to question one's legitimacy as a man entirely, as these questions are present throughout these formative years, and thus this struggle becomes characteristic of one's identity during this time. This preoccupation with these questions may restrict one from achieving a positive sense of self as one's very existence is constantly questioned. However, this sense of blocked access to hegemonic masculinity throughout the developmental years, while challenging to navigate, may be able to present a challenge to the hegemonic norms of masculinity.

Through the representation of men who may be viewed as a contradiction to these rigid standards throughout adolescence, but who still seek to establish a positive identity for themselves, it can be hoped that we can begin to question the exclusivity of this concept, and give legitimacy to alternative masculine identities. Due to the potent opposition to hegemonic masculinity posed by disabled masculinity, studying the experiences of this population should be studied in future research as they may be effective tools in creating a space for alternative forms of masculinity to emerge and therefore in deconstructing the oppression that hegemonic masculinity asserts.

Through the study, recording and representation of alternative forms of masculinity, the possibility of liberation exists for other subordinated masculinities to emerge as positive ways of embodying masculinity, while relying upon non-hegemonic masculine ideals. In so doing, we may begin to understand the ways in which this population functions according to their particular physicality and therefore, incorporate this knowledge into

the formation of a social and political environment that is more accommodating to this population. Then, it can be hoped that these men may be able to lead more satisfying lives through easier access to processes of positive identity formation.

The majority of research conducted on men with physical disabilities has focused on men who acquired a disability in adulthood. Little research has been conducted on the ways in which men with disabilities acquired at birth or men with early onset disabilities or navigate their sense of masculinity and their gender identity throughout their developmental years. During this critical time of adolescence, individuals form their identities in a concrete way, making use of the prevailing ways of performing their gender. For persons with physical disabilities this process is complicated by the presence of a physical condition that leads to one or more parts of their bodies operating differently from normative understandings of bodily function. and thus, present difficulty in aligning with with hegemonic performances of gender. For men, this sets up difficulty in navigating their gender performance that is typically characterized by able-bodiedness. There is a need for increased research into the ways in which men with early onset disabilities construct their identities in an effort to highlight the characteristics that they accentuate in forming their identities and create meaning in their lives, given their experiences. The primary goal of this research should be to allow these men and future generations of men to experience greater affirmation of their identities and experiences at an earlier stage in their lives by deconstructing the oppressive and rigid standards of gender performance to which men are expected to adhere.

The theorizing about the identity formation within this population of men with early onset disabilities may give narrative to the ways in which men with early onset physical disabilities navigate their worlds throughout the developmental years and focus on the ways in which they create meaning within their lives. These narratives can help to clarify how these men confront hegemonic masculine ideals but find alternative ways of defining themselves throughout their lives as boys and young men. Consequently, efforts can begin to be made to use this research in constructing positive conceptions of growing up as a male with a disability, allowing other men to experience affirmation about their identity as a man with a disability. In achieving this, it may be possible to contribute to the dismantling of oppression that hegemonic masculinity exerts over all men, as well as women, in defining positive ways of identifying oneself.

G. **Responses to Hegemonic Masculinity**

Research such as the study by Taleporos and McCabe (2002), which examines the association of sexuality and psychological well-being in individuals with physical disabilities, suggests that the presence of a physical disability within the life of a man can contribute to a negative body image often characterized by feelings of physical inadequacy and unattractiveness, as well as the internalization of negative social attitudes towards physical difference. Therefore, a framework (Gerschick & Miller, 1997) that has been developed to categorize these responses may provide a useful structure for understanding similar processes in men with early onset disabilities. The insights provided by examining this framework provide an opportunity to explore how men with early onset disabilities utilize similar processes in constructing their identities as well as to examine how they may respond to hegemonic masculinity in alternative ways.

Gerschick and Miller (1997) reveal three types of responses to hegemonic masculinity among men with physical disabilities, which primarily reflects the lives of men living in industrialized western societies. Gerschick and Miller developed a typology of these three types of relational responses to physical disabilities among men, including reformulation, reliance, and rejection, that is referred to as the “Three R Framework”, which provides a more specific way of understanding disability identity formation among men. This framework was developed through interviews with men with various physical disabilities and the ways in which they negotiated their masculine identity. The three responses found within this research include reformulation, reliance, and rejection.

The first response to hegemonic masculinity, reformulation, is typically characterized by focusing on strengths and abilities they still possess and might be difficult for others to perform. Examples of this may manifest themselves in such ways as maneuvering an electric wheelchair, driving a specially equipped vehicle, or orchestrating the affairs of their lives. Gerschick and Miller (1997) cite an example of Damon, who is a 72-year old quadriplegic and a survivor of a spinal cord injury. He requires round-the-clock personal care, but he still asserts his independence through coordinating all of the activities around his home. Thus, Damon has reformulated his sense of independence into a new conception such that it still aligns with hegemonic masculinity ideals of autonomy. Shakespeare (1999) found, in a study of the sexual politics of disabled masculinity, that one respondent, Eddie, challenged the idea that he was physically incompetent through engaging in fights. He seemed to be able to use his position in his wheelchair as an advantage at times during these fights, and thus

continue to align himself with hegemonic ideals for men, though he embodied these ideals differently than non-disabled men.

Second, men with physical disabilities who rely upon hegemonic masculinity internalize hegemonic ideals of masculinity, such as physical and sexual prowess and athleticism to normalize themselves in hopes of meeting masculine standards, despite the near impossibility of meeting these standards. Gerschick and Miller (1997) found that these men are more likely to have embedded feelings of inadequacy as a result of their impairment, perceiving the problem to be within themselves rather than as the result of an interaction with an inaccessible environment. Gerschick and Miller interviewed Michael, who is a 33-year old paraplegic who has deeply internalized the ideals of hegemonic masculinity. As a farm hand, football, and track star, he reported that his relations with the women he dated and physical strength were central to his self-conception. After his injury, he described himself as depressed and unwilling to ask for assistance. Taub, Blinde, and Greer (1999), in a study of the participation in sport among physically disabled college-aged men as a strategy for managing stigma, found sport and the performance of physical competence among respondents in their study to remain an important aspect of their identity and contributing factor to feelings of competence.

Finally, men who reject hegemonic masculinity altogether deny the importance of societal norms and create another set of standards for themselves, stemming from the belief that masculine norms are wrong. Gerschick and Miller (1997) further argue that men who rejected hegemonic masculine showed the most hope for change when they begin to understand that it is social conceptions of masculinity that are problematic,

rather than themselves. Therefore, they have been able to create alternative gender practices. The authors describe a 23-year old law student, Alex, who was involved in an accident at the age of 14, leaving him an incomplete quadriplegic. He reports that before the accident, he had always eschewed the superficial, athletically-oriented and materialistic atmosphere. When the accident happened, his peers were defining their social roles. The injury added to his outsider perspective, and as he reports, he learned a different set of rules in regards to sexuality and the according behavior. He describes himself as a “nonconformist” and blames the media for perpetuating hegemonic masculine ideals (Gerschick & Miller, 1997). This last response to hegemonic masculinity offers the most promising option for subverting the opposition that is posed by hegemonic masculinity by opening up the possibility to renounce the reign that this oppressive ideal holds over society. Shakespeare (1999) found that many of these seemingly disparate responses to hegemonic masculinity often coexist within the life of one man. Eddie, referenced earlier from Shakespeare’s study, also expressed that he developed the skill of becoming a good listener, which he found to be a more valued skill among his female friends, of which he had many. Thus, while he was known for his fighting, he also became to be known to other friends as a good listener, which he reported seemed to be at odds with hegemonic conceptions of masculinity, and perhaps reminiscent of gay men’s development of masculinity.

Research demonstrates that the responses to hegemonic masculinity among disabled men are diverse, depending greatly on the individual’s context and that similar research into other marginalized populations may prove useful in the understanding of the experiences of men with early onset physical disabilities. Examining these

responses and similar developmental processes in other populations may provide a framework for conceptualizing the experiences of this demographic, while also offering strategies for negotiating marginalized identities, particularly those present throughout developmental years.

H. **Neutralizing Stigma**

In an effort to integrate our understandings of the ways in which the intersections of gender and disability manifest themselves in the lives of men with physical disabilities, and to conceptualize the three responses employed by men with physical disabilities more fully, it may be of use to employ Erving Goffman's discussion of three strategies that individuals employ for neutralizing stigma (Goffman, 1963). Goffman claims that neutralizing stigma is necessary when an individual possesses a 'spoiled identity'. He describes that a spoiled identity is derived from an attribute that changes an individual from a whole and complete person to a tainted and discounted one, and disability is often seen as one of the attributes that results in a spoiled identity.

First, when a person has little or no power to control or change their spoiled identity, Goffman states that they will over-conform to the stereotypes of that identity. The individual acts like a *minstrel*, exaggerating the differences between the stigmatized and the dominant group. This is often felt to be the only power they possess and might include women who over-emphasize their femininity, acting helpless and dependent (Coston & Kimmel, 2012). *Minstrelization* is analogous to a man's choice to reformulate one's ideas about hegemonic masculinity and capitalizing on their abilities with a disability without challenging the ideals of the hegemony.

Second, if someone has a small amount of power, they might try to normalize the differences and exaggerate the similarities between the stigmatized group and the dominant group. Often, this strategy is used in order to allow the stigmatized group to enter institutions that were formerly closed to them, such as the entrance of women into the military, or Blacks running for office (Coston & Kimmel, 2012). This strategy correlates with a reliance upon hegemonic masculinity as it is the stigmatized individual's goal to minimize any perceived difference between groups and continue to insist on membership to the dominant group.

Finally, militant chauvinism is the stigmatized individual's course of action when they have the most power and is characterized by giving praise to one's own kind in mixed company and exaggerating stereotypical attributes one could easily cover (Goffman, 1963). This might include, as Goffman notes, a Jewish person aggressively using Jewish idiom and speech or the militant gay who is especially effeminate in public. This third strategy of neutralizing a spoiled identity parallels a rejection of hegemonic masculinity among men with physical disabilities in an effort to create an alternative conception of masculinity and assert it as preferable over the hegemonic. However, as Coston and Kimmel (2012) report in reviewing literature on men with marginalized masculinities because of other devalued statuses, men who attempt to devalue masculinity's importance altogether, ultimately end up conforming to hegemonic masculinity in one area of their lives or another. This leaves even these men who have rejected the ideals of hegemonic masculinity with feelings of inadequacy, incompleteness and inferiority. Morris, Corbin, and Shakespeare (Watson, 2002) suggest that the attempts to normalize or eliminate disability further oppress the

disabled. Thus, while men often end up conforming to the oppressive and often damaging norms of hegemonic masculinity in some aspect of their lives, this third response to hegemonic masculinity offers the most potential for liberation from these norms.

The combination of Gill's (1997) work on the four types of disability identity integration with the reformulation and rejection responses found within the framework of three responses described by Gerschick and Miller (1997), offer positive alternatives for the ways in which men with physical disabilities are able to navigate a 'spoiled identity'. Given these alternative responses to hegemonic masculinity, they may provide a guide for understanding the ways in which boys with physical disabilities also begin to navigate their identity formation process at a younger age. With the application of this information, we may be able to begin to theorize about similar strategies for younger populations of boys to establish positive identities for themselves at an earlier age. In so doing, it can be hoped that we will begin to open up new possibilities for alternative forms of masculinity to emerge as legitimate alternatives for boys growing up in future generations through a reconstruction of the social and political landscape in which these men exist.

I. **Direction for Research**

Many physically disabled men are often unable to engage with positive identity integration strategies and to achieve access to a positive identity in all aspects of their lives. It remains a struggle for many men with disabilities to reconcile their gender with their physical status, as they may find it difficult to escape its influence and to challenge those existing values. Evidence has been presented that demonstrates the presence of

hegemonic masculinity as an ideal that both exists in our society and is forced upon men with physical disabilities as a standard towards which they must unrealistically strive. The prevalence of these masculine ideals is driven by the development of capitalism and they continue to evolve with the ways in which the global, neoliberal economy constantly changes. This thesis theorizes that this process of successful performance of the male gender role is further complicated by the early onset of a physical disability. Further, two claims about the importance of this study are made; the critical nature of adolescence in the developmental process, which includes identity formation, as well as the fact that masculine characteristics remain the prevailing desired way of being. These two arguments give credence to the importance of studying the identity development of men with early onset disabilities in an effort to help deconstruct the oppression exerted by hegemonic masculinity and thereby assisting the development and acknowledgement of alternative ways of being a man. This thesis proposes that the research into men with early onset disabilities is not only important in understanding the lives of this population, but may also serve as an avenue for further deconstructing the oppression that hegemonic masculinity exerts on all areas of society.

In giving narrative to these experiences, it is of critical importance to draw upon existing typologies of responding to spoiled identity, disability and disabled masculinity in an effort to identify potential connections to similar processes in men with early onset disabilities. Several strategies for positively renouncing oppressive norms that force an individual with a disability to conform to unrealistic standards are presented. Gerschick and Miller (1997) describe the methods of rejection and reformulation that have been reported among men with physical disabilities to neutralize the stigma that they

experience. Carol Gill (1997) describes the fourth type of integration strategy, 'coming out', as the most integrative type of identity formation, in which a person with a disability integrates how they feel about themselves with how they present themselves. This type of identity integration represents a full acceptance and integration of one's identity as a person with a disability. These strategies of positive acceptance and integration of disability into one's identity should be used as examples applied in further research with men with early onset disabilities to understand the ways in which meaning is created within their lives by embracing non-hegemonic attitudes, behaviors, and preferences. Therefore a better comprehension of the ways in which boys with disabilities can begin to identify themselves more positively by reducing the stigma associated with having a disability may be achieved. This research seeks to collect primary data from men with early onset physical disabilities about their experiences in identity formation, and through the collection of this data, connect it with existing research on men, masculinity, disability, and identity formation in order to give precedent to the experiences of this population in hopes of destabilizing the oppressive force that hegemonic masculinity exerts on this population, as well as on others.

III. METHOD

The research questions adopted for investigation (see “Research Questions”) were explored through an open qualitative research approach, which allows for concepts, ideas, and themes to emerge directly from the data itself, rather than from the researcher’s preconceived assumptions. Using these methods, the experiences of men with early onset physical disabilities were researched to understand the impact of having a physical disability throughout their primary developmental years on their sense of masculinity and identity. This population has been largely understudied in masculinity studies as well as disability studies, and thus, this research was undertaken to illuminate their experiences. In order to begin to understand the perspectives of this population, open-ended surveys were used, and distributed through online social media outlets, listservs, and acquaintances of the researcher. Finally, the data were analyzed using a grounded theory thematic analysis approach.

A. Research Aims

The aim of this research was to investigate the ways in which men with early onset disabilities navigate their own sense of masculinity and their identity development generally. The research examined the ways in which having a physical disability throughout their primary developmental years impacts their sense of masculinity and identity, as this population is currently underrepresented in the literature. Therefore, men with early onset physical disabilities or physical disabilities with which they were born were the key informants of this research. This study explored how men with early onset physical disabilities negotiate masculinity and identity. Specifically, the research addressed the following questions:

B. Research Questions

1. How do men with early onset physical disabilities perceive/define traditional American standards for masculinity?
2. How do men with early onset physical disabilities describe how their own masculinity compares with traditional standards, and how do they feel about this comparison? If there is a difference, how has that difference affected them?
3. How have they re-defined masculinity for themselves or adopted non-traditional standards, if at all?
4. How do men with early onset physical disabilities compare their own development of masculinity with the developmental path of other men, and what are their feelings about their development?

C. Research Design

This project employed a qualitative methodology to investigate the key questions under consideration. A qualitative methodology was most appropriate for this project in order to develop rich descriptions of the data. Due to the underrepresentation of men with early onset physical disabilities and their development of masculinity and identity, qualitative research methods were needed to explore this area in more depth to better understand these experiences. Qualitative research methods are the most appropriate to “study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meaning that people bring to them” (Denzin & Lincoln, 1994, p. 2). Mertens (2010) contends that, by using a qualitative approach, the researcher can observe a situation in hopes of making sense of it and allowing categories of analysis to

emerge from the observations without imposing expectations on the situation. Thus, qualitative methods were the best possible way of coming to understand the experiences of men with early onset physical disabilities by eliciting thick descriptions of their firsthand accounts. This study seeks to contribute qualitative research to this literature in order to deepen the understanding of the experiences and perspectives of this population. Further, the research investigated the ways in which the narratives of men with early onset physical disabilities can challenge prevailing understandings of masculinity and male identity formation.

In order to begin researching a topic about which little is known, such as this one, Glaser and Strauss (1967) offer grounded theory as a method of discovering the most relevant concepts to the area of study. This method of research is characterized by the discovery of theory from data, which is systematically obtained and analyzed in social research. Grounded theory uses an inductive method of theory development, in which the researcher uses more abstract concepts to account for uniformities and differences within the data. It is also contrasted with other methods of theory development, which are deduced from preconceived assumptions, and instead allows the data, rather than existing research, to direct the interpretation.

At the outset of this research, it was intended that the researcher would utilize an approach that was a hybrid between framework testing and grounded theory. In this hybrid approach, the researcher would develop a list of codes from a review of the existing literature, and then analyze and code the data from the present study while comparing and testing it against the codes from the literature review. However, when the researcher began the analysis of the data for the present study, it was determined

that a framework testing approach would be an inappropriate method with which to analyze the data. This determination was made because the existing literature provided essential insights to guide the research, but the researcher did not feel as though it provided an adequate framework by which to test the data of the present study. Instead, the literature provided 'sensitizing concepts' (Patton, 2002), or an organizing guide to understanding the complex stimuli found in fieldwork. It is important for the researcher to have some way of orienting themselves to their observations of their particular study, and thus the researcher will use concepts taken from existing literature and check the data for findings that relate to the literature, without imposing hypotheses on it. An example of a sensitizing concept in the literature on masculinity and disability can be seen in the prior finding that some men with disabilities respond to hegemonic masculinity through methods of reformulation, in which they adopt ideas of masculinity that better align with their experience. This concept was used in the construction of the survey questions, as well as a way of understanding the responses from respondents who seemed to have rejected traditional standards of masculinity and adopted their own.

This study focused on the ways in which men with early onset physical disabilities interpret their experiences, in regards to masculinity, disability, and identity development by allowing the data collected from the participants' responses to guide the development of the main themes and sub-themes in data analysis. The researcher allowed the participants' describe their own experiences, and then, sensitized by a review of existing literature, interpreted those experiences, which led to the development of the themes. An example of the ways in which interpretations of the data

was done can be seen within the theme of 'Barriers', under the core theme of 'External Influences'. Many of the respondents discussed attitudes or stereotypes about traditional masculinity, as well as assumptions about men with disabilities. They discussed the ways in which, often, these two sets of perceptions are in conflict with one another, which the researcher interpreted as an attitudinal barrier for men with disabilities to being afforded full status of being a man.

D. **Sampling and Recruitment**

This study sought to recruit thirty participants. The research occurred through the distribution of internet-based surveys to men with early onset physical disabilities, who are ages 25-45 in the United States. The age range that was selected for this study based on literature that was reviewed suggesting that the teenage years and early 20s are the most intense years for identity formation, and thus, the investigator is most interested in gaining the perspectives of men who have already completed the most formative years of identity formation and may have more reflective insights on their identity formation processes. The surveys distributed to the participants included in-depth questions about the participants' experience, and identity development. There were six total respondents. See Limitations section for a discussion of the limitations of the sample size.

Recruitment was conducted through purposive snowball sampling, which occurs when current participants in a study help to nominate or recruit other participants who meet the eligibility requirements for the research (Morgan, 2008). This purposive snowball sampling methodology was undertaken for its value in seeking out participants for research who possess the targeted characteristics (Morse, 2004). Electronic

communication was distributed on listservs that reach men with disabilities, social media outlets to which men with disabilities subscribe, and through communication distributed to acquaintances of the researcher for forwarding (Appendix D for Online Posting Text). Electronic communication included distributing recruitment materials on the University of Illinois at Chicago's Department of Disability and Human Development listserv. Upon distribution of the research information to certain listervs, several members of those listervs forwarded the information on to others. Additionally, posts were made on several relevant websites. The sites to which the survey was posted are the following: University of Illinois at Chicago "Disability Studies Student Council" Facebook Group, "Society for Disability Studies Student Caucus" Facebook Group, "Disability Rights Coalition" Facebook Group, "Reframing Disability" Facebook Group, "Men With Disabilities" Facebook Group, "Any Men or Women With Disabilities" Facebook Group, "Any Men with Disabilities" Only Facebook Group, "Occupy Disability/Decolonize Disability" Facebook Group, "Disability + Positivity = Creativity" Facebook Group, "DisabilityVoice2" Facebook Group, "Disability Power and Pride" Facebook Group, "Sexuality and Disability Support Group" Facebook Group (Appendix D for the language of the communication).

The researcher decided to distribute surveys electronically and through social media outlets in order to broaden the scope of potential participants, reaching men from all regions of the United States, as this would provide a richer sense of perceptions of masculinity in the United States by surveying men in various regions of the country. The surveys were limited to men within the United States, as broadening the scope of distribution to include perspectives from men abroad was beyond the scope of this

project. This research sought to understand the experiences of men in the United States with early onset physical disabilities only. Further, as this is an understudied topic and population, online surveys served the exploratory purpose of this research. It was hoped that this research would open up new avenues of study, and encourage other research methods to be used to evoke more in-depth responses in future research with this population.

E. **Data Collection**

As previously mentioned, this research has always intended to be exploratory, as this population and topic are understudied. Thus, in order to begin to get a sense of the phenomenon of masculinity development among men with early onset physical disabilities, it was decided that a survey would provide an appropriate entry point to understanding the experiences of this population. Further, it was decided that distributing the surveys online would provide a broader range of respondents in more areas of the United States, which was the intended research area.

As Babbie (2011) explains, surveys are ideal methods for researchers who are interested in collecting original data whose intent is to describe a population that is too large to study directly. Further, surveys are also one of the best methods for measuring attitudes and orientations in a large population. Additionally, deliberate sampling can provide a group of respondents whose characteristics may be taken to reflect those of the larger population and carefully constructed standardized questionnaires can yield formally consistent data from all respondents. Thus, seen in this way, properly administered surveys provide a useful tool of social inquiry.

Conducting surveys administered through the internet offers several additional benefits, including the ability to survey large and widely distributed populations (Sue & Ritter, 2007). In this study, this was an important consideration, as the researcher was interested in sampling men with early onset physical disabilities from multiple regions of the United States. Further, with sensitive subjects, online surveys allow respondents to return them anonymously. In a similar manner to self-administered postal mail surveys, This anonymity may provide more honest or authentic answers from respondents who tend to feel safer giving such answers in an online environment. Again, anonymity was critical for this study, as these topics can easily be seen as potentially troublesome for some respondents, and thus, maintaining anonymity among the respondents was vital to building trust and cultivating genuine responses.

The survey was designed using SurveyGizmo, which was recommended to the researcher for its usability, reporting features, and security. The survey that was distributed was comprised of questions that address each of the intended areas of investigation for this study, including gender, masculinity, and identity development. The survey questions were divided into four main sections, the first being a brief introduction and background of the participant. The second section asked the participant to discuss perceptions of masculinity in the United States, as well as any changes they have seen to these perceptions over time. The third section asked the participants to evaluate their feelings of similarity or difference in relation to these hegemonic perceptions of masculinity, giving particular attention to four particular time periods including pre-adolescence, adolescence, young adulthood, and present. The final section asked the participant to discuss how *they* perceive what it means to be a man with a disability in

America, as well as how *society* perceives what it means to be a man with a disability in America and if there have been any changes to each of these perceptions over time. These survey questions were developed in reflection of a review of the literature as well as the interests and intentions of this research. These questions seek to elicit responses about the respondents' perceptions of hegemonic masculinity in America, their relationship to these conceptualizations throughout their development, and any changes in perceptions, either their own or those of society, over their lifetime (Appendix E for survey language).

F. **Data Analysis**

As previously mentioned, this research originally intended to use an approach in which a set of well defined codes in advance from external sources or quick reading of the transcripts, which Morgan (2008) identifies as an "index coding" approach. In an effort to follow this particular methodology, and to adhere to the framework testing aspect of the planned hybrid approach, the researcher began developing a codebook. However, it was quickly realized that this was not the most appropriate methodology, and as discussed above, a grounded theory approach was determined to be more suitable. The survey answers were reviewed and used to refine the data into two main themes, with three subthemes for each core theme.

Themes were identified through the process of thematic analysis, which is a method for identifying, analyzing and reporting patterns or themes within data (Braun & Clarke, 2006). Once the surveys were completed and returned to the researcher, each respondent's responses were put into a separate document and printed out for ease of access during analysis. Each document was labeled with its 'ID' number from the

internet survey software utilized during this research. This allowed the researcher to highlight and bracket the responses as needed, which was a crucial aspect of the analysis process.

The analysis process remained consistent with a grounded theory approach, such that the researcher allowed the data to direct the development of themes and sub-themes, while the literature sensitized the researcher to pertinent areas of the data. The analysis process began with an initial scan of the responses, which allowed the researcher to determine the sections of the responses that were directly related to the research questions. Therefore, the researcher bracketed all of these sections, and reviewed the sections several more times in order to further refine the sections into more specific themes and subthemes. The subsequent reviews of the data were done through a rigorous line-by-line close reading of the responses in an attempt to identify significant connections and differences between them in order to develop themes within the data. This method of analysis is called a constant comparison method, in which a researcher is regularly comparing their findings with existing findings and categories as they emerge from data analysis (Parry, 2004). For example, all sections that related to a respondent's perceived relationship to hegemonic masculinity were refined into feelings of difference and feelings of similarity, which were then categorized into sub-themes. The portion of responses that discussed a participant's feelings of difference were primarily discussed in relation to their feelings of difference from peers during childhood and developmental years, as well as feelings of difference that they currently feel. Thus, the responses discussing childhood helped develop the sub-theme 'Early Feelings of Difference', and the responses referring to adulthood fit with the theme of

'Reformulation of Masculine Embodiment', both of which ended up helping to develop the core theme under which these sub-themes were categorized. Similarly, responses that discussed a respondent's feelings of similarity were primarily discussed in relation their developmental years as well. They described the activities in which they engaged throughout this time in their lives that typified masculinity, and the value they placed on these activities. Thus, these responses helped develop the sub-theme of 'Developmental Adherence to Traditional Standards'.

Following a close reading of the responses, while identifying connections and differences between responses, the researcher developed themes and sub-themes based on the responses that were identified as being connected. For example, one respondent claimed that his Cerebral Palsy doesn't make him less of a man, another respondent stated that he was no different than anyone else, and a third respondent declared that his challenges don't come first, and that he doesn't feel different at all. These three responses helped to develop the sub-theme of 'Neutral Impact of Disability' (Table I for core themes, sub-themes and descriptions).

TABLE I
THEMES AND SUBTHEMES

Theme Title	Explanation of Theme
Core Theme: Individual Characteristics or Effort	Emphasis given to individual attributes or efforts to overcome obstacles to hegemonic masculinity
<u>Sub-theme 1: Neutral Impact of Disability</u>	Disability is seen as not having an impact on one's ability to embody masculine ideals
<u>Sub-theme 2: Developmental Adherence to Traditional Masculine Standards</u>	Throughout developmental years, value was placed on traditionally defined standards of masculinity
<u>Sub-theme 3: Perceived Improved Social Position of Disabled Men</u>	Belief of the improved social position of disabled men as a reflection of emphasis on individual efforts and characteristics
Core Theme: External Influences	Increased attention to how external influences impact sense of masculinity
<u>Sub-theme 1: Early Feelings of Difference</u>	Recollections of feeling different at an earlier age, impacted self-perceptions during development
<u>Sub-theme 2: Barriers</u>	Identification of socio-cultural, attitudinal, and structural barriers to masculinity
<u>Sub-theme 3: Reformulations of Masculine Embodiment</u>	Efforts to redefine own senses of masculinity in light of experiences with disability

Once the researcher developed all six of the sub-themes, it was determined that the core themes seemed to depart into two separate, larger categories. Thus, each of the sub-themes were clustered into two groups, and connected by common themes running throughout them. For example, the sub-themes of 'Early Feelings of Difference', 'Barriers', and 'Reformulations of Masculine Embodiment' all gave attention to external influences that impacted these men's access to hegemonic masculinity, and ability to be

socially regarded as a full man, which is taken from existing literature on the social construction of masculinity, as well as the respondents' own perceptions of hegemonic masculinity. In this process, the researcher remained diligent in allowing the data to guide the development of each of the themes, by extracting direct quotations from the responses to give evidence of these themes.

In order to ensure the fidelity of the themes and subthemes to the data, the researcher's faculty advisor reviewed my proposed themes and sub-themes as well as my rationale for their development, with evidence provided for each theme. Upon review of my themes and sub-themes, the researcher's faculty advisor determined that the themes and sub-themes developed throughout the analysis process were appropriate and faithful to the data.

G. **Confidentiality**

This research, which was approved by the Institutional Review Board (IRB) at the University of Illinois at Chicago (Appendix A for IRB Approval Letter and Appendix B for IRB Amendment Approval Letter), was designed in such a way to keep all respondents to the surveys anonymous. The information about the research was distributed to various social media outlets, with a link included that led participants to the anonymous survey. Thus, no personal information was exchanged. The responses that were returned through SurveyGizmo were de-identified and all answers were not associated with any participant's identity. Therefore, the identities of the participants are unknown to the researcher, and will thus be unidentifiable in any further publications.

H. **Researcher Role**

As a man with a congenital physical disability, the researcher of the present study possesses an insider status to the research. However, the decision was made not to disclose this information to research participants, as the researcher wanted to appear as neutral as possible. However, this decision brings with it certain trade-offs, or advantages and disadvantages that can impact the study. Studying a population to which a researcher has an insider status, and not disclosing this status can allow the researcher to potentially be seen by some participants as more neutral. This may cause some participants to be less likely to censor themselves for fear of offending, criticizing, or hurting the researcher. If a researcher from a marginalized community is conducting research within that community, and discloses their insider status, some participants may feel a compulsion to protect or be careful not to offend the researcher, who may have had similar experiences of marginalization, and this may limit the richness of participants' responses. Alternatively, other participants may be more reluctant to share their experiences as in depth if they feel as though the researcher may not be as understanding of their experience, as an outsider to their demographic. Further, if a participant perceives the researcher as an outsider, it may be more difficult for the researcher to develop rapport with their research subjects, which may prove beneficial to eliciting responses. Therefore, for some participants, there may be more reluctance to participate in the research, entirely, if they do not perceive a potential for rapport to be established between themselves and the researcher. Thus, this can limit the number of participants who participate in the study, and therefore the breadth of responses

collected. As it can be seen, the decision not to disclose the researcher's insider status to participants within the study is of certain value, but also presents challenges.

Additionally, throughout the data analysis, due to the close relationship that the author has to the subject material, it proved critical for the author to remain reflexive and self-critical in order to bring valuable insights to the study but to also be aware of instances in which these personal experiences may limit the author's perspectives. In order to do this, the researcher remained faithful to the data by allowing the respondents' words to direct the development of themes, rather than basing themes upon the researcher's preconceived ideas derived from their own experience. While the author has experiences in the area of study, themes used for analysis were drawn directly from the survey data.

IV. RESULTS AND DISCUSSION

This research surveyed men with early onset physical disabilities on their perceptions of hegemonic masculinity in the United States or their perceptions of what it means to be a man in America today, their relationship to these perceived standards, and any changes in opinions about disability's impact on masculinity over their lifetime, whether their own or those of society. Survey questions asked participants about their similarities to, and differences from, traditional standards during specific periods during their development in order to see how these feelings may have changed over time, or had varying impacts during different periods. These questions were critical for understanding the unique perspectives of the studied population, as the impact of development has been an understudied topic within the subjects of disability and masculinity. Upon evaluation of the data, several major themes can be identified. First, it is prudent to understand the respondents' perceptions of hegemonic masculinity, or what it means to be a man in America as a means to understanding the hegemonic beliefs that influence the respondents' feelings about, or relationship to, them. After drawing conclusions about the men's perceptions of hegemonic masculinity in America, two core themes were drawn out, and three subthemes were identified within each core theme. The first core theme identified was "Individual Characteristics and Efforts" and within this theme, the three sub-themes identified included: "Neutral Impact of Disability", "Developmental Adherence to Traditional Standards", and "Perceived Improved Social Position of Disabled Men". The second core theme identified was "External Influences". Within this core theme, the three sub-themes identified include: "Early Feelings of Difference", "Barriers", and "Reformulations of Masculine

Embodiment”. In the discussion of the results, the researcher has assigned pseudonyms to each respondent, and therefore, the named used does not reflect the identity of that respondent. The identities of the respondents have remained anonymous to the researcher, and therefore, in any publication of the results from the present study.

A. **Traditional Stereotypes of Masculinity**

1. **Perceptions of American masculinity**

Following a question asking respondents to briefly introduce themselves, respondents were asked to identify traditional stereotypes of what it means to be a man in America. This was a critical initial question to pose to respondents in order to get a sense of their conceptions of masculinity in the United States, and how these ideas have influenced their own perceptions of masculinity, as well as their perceived relationship to traditional standards of masculinity. While the respondents varied in their responses to hegemonic conceptions of masculinity in America, many of these men reported similar impressions of masculinity. Many of these responses included a focus on confidence, emotional stoicism, financial and physical independence, defender or provider for family, and responsibility.

Several respondents gave attention to financial independence, including Ben, who said “To be a successful man he should make lots of money”, which was echoed by Eric, who included in his response “financial fitness or capacity” as one element that characterizes traditional stereotypes of masculinity in America. Similarly, several respondents emphasized physical strength or prowess as a critical element of masculinity in the United States, including Daniel who highlighted the assumption about men that “We are all physically strong.” Respondents also highlight emotional stoicism,

including Frank, who lists “Emotionally quiet” as an important aspect of what it means to be a man in America, which is echoed by Daniel, who identifies the assumption that “We are all uncaring and cold” as a pervasive belief about men in the United States.

These responses about hegemonic conceptions of masculinity are supported in existing literature, such as Connell (2005a), who identifies several attributes that characterize masculinity in an industrial capitalist system, including strength, a degree of insensitivity, and toughness. These responses are also supported in literature that suggests that masculinity has come to be defined by frantic able-bodiedness, aggressive sports, and risk-taking activities, career orientation, activeness, athleticism, sexual desirability and virility, independence, and self-reliance (Connell & Messerschmidt, 2005; Coston & Kimmel, 2012). The alignment of these findings with existing literature is critical, as it highlights the persistence of these perceptions and the potential for these ideals to have impacted the identity development and masculinity of men with early onset physical disabilities. In short, these findings give credence to the existence of traditionally-defined standards of masculinity and the potential for their internalization.

B. Responses to Masculinity

This section will analyze the data from the respondents regarding their relationship to hegemonic masculinity. The findings demonstrated a split between the respondents, according to the ways in which the respondents responded to hegemonic conceptions of masculinity in America. A portion of the respondents gave attention or Individual or Personal Characteristics and Efforts, and a discussion of this theme and sub-themes will now follow.

1. **Individual characteristics and efforts**

For some of the respondents, perceptions of their relationships with masculinity as a disabled man were typified by their focus on individual and personal characteristics or efforts to meet traditional standards of masculinity. For these men, disability did not seem to have impacted their own sense of masculinity, and traditional standards of masculinity were still held in high esteem. Further, these respondents perceived an improved social position of disabled men throughout society, and perceived greater opportunities for men with disabilities to be integrated into society.

Each of these sub-themes are categorized under this core theme, as they all relate, in some way, to the larger theme of individual characteristics and efforts as granting access to hegemonic standards masculinity. Disability's neutral impact on the respondents' sense of masculinity may reflect the fact that disability does, in fact, only minimally impact their ability to gain access to hegemonic standards of masculinity in American culture, but it may also reflect a determination to minimize, on the level of their individual attitudes, the impact that disability has on their experience of masculinity. Further, the second subtheme, developmental adherence to masculine standards also reflects an increased reverence for hegemonic masculine ideals throughout the developmental years, which are often defined by individualistic activities, physical prowess, and sports. Therefore, it can be seen that, throughout their developmental years, these men put an emphasis on individual activities and efforts to achieve an accepted sense of masculinity. Finally, a perceived social position of disabled men throughout society, can be seen to reflect an embodiment of the optimistic attitudes and lack of social critique that are often thought to typify masculinity. Seen in this way, each

of these sub-themes resonates with a focus on the level of the individual in these men's perceptions of access to hegemonic masculinity.

a. **Neutral impact of disability**

For many participants, it was noted that disability did not seem to have an impact on their perceived ability to conform to traditionally defined masculine ideals. Disability is not seen as an obstacle to being a man, or embodying masculinity; disability is merely seen as a difference.

Adam: "CP doesn't make me less of a man"; "I feel great; I can get around."; "I see my disability as helping me do more as a man in a wheelchair."

Ben: "It (disability) doesn't impact me at all. My challenges don't come first."; "I didn't feel like that at all (different because of disability)."

Charlie: "None really, in the way I was raised, I was no different than anyone, just needed to perhaps do things in a different way."

This sub-theme resonates with several previous research findings, including Goffman's (1963) work on neutralizing stigma, who proposes that for individuals who have some level of access to cultural hegemony, or power, they might try to highlight their similarities to the dominant group, instead of highlighting the differences. The findings in the present study can also be seen through the lens of Gerschick and Miller's (1997) findings who claim that one of the major responses among men with physical disabilities is 'reliance' or relying upon existing standards of masculinity in order to normalize themselves in hopes of meeting them. These responses can be seen as attempting to minimize the difference felt from non-disabled men or impact that disability has had on their own senses of masculinity and thus, continuing to rely upon hegemonic

definitions of masculinity for identity formation. While a definitive claim as to the reasons behind these responses to masculinity is difficult to make, these findings could also point to a contrast between Siebers' (2008) assertion of disability as a cultural or minority identity. Perhaps these respondents find themselves in the early stages of disability identity integration that Gill (1997) describes. These early stages are characterized by individuals coming to feel they belong in society and begin to direct their desires and actions into integrating into society. However, later stages in the process of establishing a positive disability identity include a more meaningful integration and acceptance of their differences, which then influence how they present themselves to the world.

b. **Developmental adherence to traditional standards**

For these respondents, it seemed as though, throughout their developmental years, they placed value on to the traditionally defined standards of masculinity, and favorably regarded the embodiment of masculine ideals. In their accounts of their own perceptions of masculinity, these respondents identified several elements of masculinity that exemplify findings in existing literature on masculinity. The following quotations were found in the data.

Adam: "Being a man was about sports."; "I thought being a man was going to be fun."

Charlie: "Became involved in scouting, hunting, fishing, camping. Learned martial arts."

These respondents, who included statements in their responses about their perceptions and opinions of traditional masculinity during their development, including

attention to the value placed on sport and physical activity. These findings reflect established research on traditional standards of masculinity (Connell & Messerschmidt, 2005; Coston & Kimmel, 2012), including warrior values and frantic able-bodiedness represented through aggressive sport and risk-taking, activities, career-orientation, activeness, athleticism, sexual desirability and virility, independence and self-reliance. Further, Connell (2005a) identifies prowess in sport as a defining characteristic of masculinity in United States mass culture. It is through sport and the rules of sport that male bodies are monitored, and in so doing, bodies are brought into competition with each other as a means of asserting superiority over the other.

c. **Perceived improved social position of disabled men**

The third sub-theme that repeatedly emerged from these respondents is a persistent belief in the improved social position of men with disabilities. This belief in the positive improvement of the social position of disabled men seems to align with their focus on individual efforts or characteristics. It reinforces the belief that disabled individuals can meet existing standards of masculinity and personhood through individual characteristics and efforts without offering a critique of these structures and attitudes.

Adam: "People with disabilities are now looked at as being capable of being more independent."

Ben: "I think it (society's impression of disability's impact on masculinity) has changed for the better, a little."

Charlie: "Grown stronger (society's perception of disability's impact on masculinity) since the passage of the Rehabilitation Act, the American's with

Disabilities Act, and disabled men's exposure to the general public and not "hiding at home".

Taken together, these responses reflect hopeful anticipation for the perceived improving position of men with disabilities throughout existing social structures, and characteristic of their approach to meeting masculine standards, a continual adoption of a positive attitude towards this improvement. This third theme that emerged from the data included an attention to the perceived improved social position of disabled men. This finding seems to reflect, again, Gerschick and Miller's (1997) finding of reliance on hegemonic masculine ideals as one of the major responses among disabled men to masculine standards. This argument can be made if seeing reliance upon traditional masculine standards includes a persistent optimism towards one's life and the context in which one is found, instead of offering a criticism of it. Thus, the perception of the improved social position of disabled men seems to be an implicit reverberation of masculine standards, perhaps serving as an example of one of the traditional standards that men strive to meet. This can be contrasted with the other sample of men, who offer critiques of existing social structures, and perceive a lack of access to traditional masculine ideals through them.

2. **External influences**

The second core theme emerged from another portion of the respondents, that of "Emphasis Given to External Influences". The respondents whose responses generally fell into this theme identified several common elements about their experiences with disability and masculinity that have shifted their focus from their individual characteristics or efforts to factors outside of themselves. These respondents

give attention to the impact that external influences have had on the development of their senses of masculinity, have offered a critique of existing standards of masculinity and have reformulated their own sense of masculinity to better align with their own experience.

The first sub-theme, early feelings of difference, reflects the responses of the participants that indicate that, from an early age, they felt markedly different from their peers and thus, seemed to internalize those feelings of difference prompted by an inability to meet certain benchmarks of masculinity at a young age. The second sub-theme, barriers, reflects the responses from the participants that give emphasis to various barriers they perceive in terms of accessing hegemonic masculinity, including attitudinal and material barriers, such as lack of skill in sports and socializing. Finally, the third sub-theme identified is that of reformulation of masculine embodiment, which indicates these participants' responses who have developed new standards or ideas of masculinity based on their own experiences with disability. These sub-themes constitute this core theme due to the fact that they give attention to factors beyond themselves that influence their conceptions of and access to hegemonic masculinity, and in light of those influences, offer critiques of them.

a. **Early feelings of difference**

One of the common experiences among the respondents whose responses fell within this general theme included early feelings of difference. They recalled feeling different at an earlier age, which impacted their self-perceptions during their development. These respondents report feeling different during their

developmental years in multiple ways, including ability in sports, dating, independence, and sexuality.

Eric discusses the ways in which he not only felt different himself from other boys during his development, but he also discusses how he was made to feel different due to protective parenting, and lack of sports prowess, which he implies, his peers valued.

Eric (Pre-Adolescence): “While I was adventurous, I was also reigned in by my mother who was, and is, overprotective. I have a very distinct sense of ‘having to worry’ about vulnerabilities that I did not perceive. In other words, I was discouraged from resembling stereotypes of masculinity.”

Adolescence: “I played sports (soccer and baseball) but it (age 12) is when I lost a significant amount of visions, meaning that while I played these sports I was very very bad at them. I felt alienated from my peers [...] and removed from this very early benchmark of masculinity.”

Frank discusses the differences he felt in terms of dating, sexual relationships, and dependence upon others. During his adolescence and young adulthood, this participant focuses on the ways in which he felt excluded from peers, unattractive to girls, and unable to socialize. He also discusses the ways in which he felt as though he had to mature more quickly than his peers, but yet still feeling bitter towards peers for their ability to be more independent. Finally, he discusses the shame associated with his inexperience with women.

Frank (Adolescence): “Felt like girls will never look past my disability and who I really am”; “Hated not being able to do everything.”; “Had to watch my friends do things I couldn’t”

(Young Adulthood): “Felt like a child not being able to drive myself”; “Had to see my friends party and date girls while I couldn’t”; “Had to see my siblings get more independent while I had to stay at home with my parents”; “Had to emotionally mature much faster than everyone else and accept adult responsibilities earlier”, “Became bitter about young people around me enjoying life.”; “Became ashamed of being a virgin and being inexperienced with women at an age where as a man you are judged by how many girlfriends you get.”

This first sub-theme within the second core theme that emerged from the data had to do with these respondents acknowledging early feelings of difference, particularly during their adolescence and young adulthood. The respondents who noted these feelings mentioned that they felt alienated from their peers due to an inability to play sports, or a lack of skill for sport, difficulties in dating, feeling dependent upon others, an imperative to mature more quickly and take on more responsibility sooner. All of these feelings of difference are compounded by feelings of bitterness and shame.

Early feelings of difference during the respondents’ development as boys with early onset physical disabilities can be connected to Hill and Lynch’s (1983) gender intensification hypothesis, which submits that behavioral, attitudinal and psychosocial differences between adolescent boys and girls increase with age and are the result of increased socialization pressures to conform to traditional masculine and feminine sex roles. The validity of this hypothesis has been questioned, but it can still be argued that masculinity enjoys a privileged position, and thus, those who do not fit its ideals may not be afforded the same privileges (Priess et al., 2009). This research can give explanation

to the potency of these feelings of difference that the respondents included in their responses.

This finding of the inability to meet certain benchmarks of masculinity during development can also be connected to Eric Erikson's (1968) model of psychosocial development. Adolescents, particularly, go through processes of development in which they find themselves seeking new ways of connecting the skills and roles they have acquired during childhood with the imperatives of current society. During this process, the original unit of reference, the family, is replaced with that of 'society'. Thus, it is during this time of adolescence when the individual begins to seek their place in the world and give more credence to the opinions of the society. Thus, it may prove critical to highlight or explore further these feelings of difference in adolescence as a means to understanding the impact of disability throughout the developmental years.

b. **Barriers**

The second theme that emerged within these respondent's responses was an attention to the barriers that they experienced as disabled men, including socio-cultural, attitudinal, and structural barriers. It is important to note that the identification of external influences signifies an alternate conceptualization of their relationship to traditional standards of masculinity. The conception of 'barriers' to traditional standards of masculinity signifies an attention to factors outside of themselves, rather than individual effort and attitude, as impacting their access to traditional masculine standards.

Daniel discusses the false perceptions that are often applied to people and men with disabilities, including that they are sub-human, asexual, or unfit marriage partners. In fact, he identifies the perception of his disability as a liability in some relationships.

Daniel: “Males with disabilities are often seen as less manly or less human than our non disabled counterpart.”; “We fall into overly simplistic fallacies such as: dumb; incapable of having sex, unable to be full marriage partners; not being capable of getting love, homogenous (i.e., the sexual spectrum does not apply to us).”; “It (society’s perceptions of disability’s impact on ideas of masculinity) has made it challenging to have relationships with women. Also, there have been strong reservations that I am not capable of marriage or being a full partner in a marriage.”; “It has taken a longer time for me to have a healthy relationship with a woman. [...] because my disability was understood by many (women) as a liability”

Eric identifies the cultural assumptions that have become associated with being a man, and clearly states that he does not fit this mold. Further, he highlights the perception that men with disabilities are often associated with femininity and can never be ‘a man’.

Eric (Present): “If being a man means consistently and flawlessly exercising autonomous independence for oneself and on behalf of others in the world, then I am not a man.”; “Think that men with disabilities in America today still [are] subject to “feminization” – hegemonic cultural belief that men with disabilities are not, and can never be, “a man”.”

Frank perceives an attitudinal barrier which infantilizes people and men with disabilities, that is, sees them as children or child-like for their inability to fit pre-scripted roles of manhood or personhood. He discusses the shame associated with the judgments about his lack of sexual and economic activity.

Frank (Adolescence): “Had to watch my friends do things I couldn’t”; “Felt like a child not being able to drive myself.”; “Had to see my friends party and date girls while I couldn’t”; “Had to see my siblings get more independent while I had to stay behind with my parents”

(Young Adulthood): “Became ashamed of being a virgin and being inexperienced with women at an age where as a man you are judged by how many girlfriends you get.”

(Disability’s Impact on Society’s Ideas of Masculinity): “Makes society deem you sexually asexual and unwanted.”; “Living at home and not being independent makes you seem like less of a man because society defines being masculine as being financially and physically independent.”; “Makes society’s idea of being judged as a man by how many women you sleep with hurt you.”; “As a man society also judges you on your income and status, but with a disability, it is much harder to be judged by this regardless of education”; “Society deems being a man in a wheelchair as being weaker, asexual, and less useful.”

These respondents, who noted several forms of barriers to their development of masculinity and difficulty adhering to hegemonic standards, mentioned barriers such as negative social perceptions or attitudes toward people and men with disabilities, which encompassed perceiving them as asexual, lacking intelligence, concern about their

fitness to be a marriage partner, being a liability in a relationship. Other barriers included lack of access to masculine ideals through lack of skill in sport, dependence, reliance on others, association with femininity, inability to drive, lack of access to socialization, sexual inexperience, and lack of financial independence.

The identification of these influences on a man's access to hegemonic masculinity as 'barriers' is a significant shift in thinking as compared with the first group of respondents who more readily identify individual characteristics or efforts as the primary means to accessing hegemonic ideals of masculinity. Particularly in regards to attitudinal barriers, it can be argued that culturally-supported social constructions of gender, identified by Butler (1990), Gerschick (2000), and Connell (2005a), propagate disabled men's blocked access to hegemonic masculinity. Butler contends that gender is constituted through performance, and that the performances, which are said to be innate within each respective gender, are in fact, the precise constituting elements of gender. Gender, as Butler argues, is not a fixed characteristic respective to two separate types of biological bodies, but it is socially constructed and enforced through diffuse systems of regulation. Gerschick (2000) expands upon this by claiming that the performance of gender is dependent upon one's ability to conform the body to socialized expectations and roles associated with each gender. Connell (2005a) emphasizes the importance of the materiality of the body; that they are substantively in play in social practices such as sport, labor and sex.

Therefore, the barriers that the respondents identify have long histories as socially constructed ideals of gender and exclusive concepts that non-normative bodies have difficulty accessing. This idea is elucidated through the argument (Demetriou,

2001) that hegemonic masculinity creates oppressed masculinities that exist in tension with, but never penetrate, the hegemony. Thus, it can be seen through the responses that these disabled men have experienced oppression of their masculinity or experiences as men with disabilities, and therefore acknowledged these blocked points of access as barriers to hegemonic conceptions of masculinity.

One participant, Eric, notes that a particular barrier is the 'feminization' of men with disability, or the perpetuation of the belief that men with disabilities are not, and never will be 'true men'. This claim connects with Rosemarie Garland-Thomson's (2002) claim to the gendered differences of disability through the argument that sickness, and therefore, abnormality is gendered female. This suggests that anyone considered to be 'abnormal' which would include people with disabilities, as well as people experiencing sickness, are associated with being female. Therefore, it can be surmised that this emergent claim from the data that disability serves as an emasculating force in the lives of disabled men is supported in theoretical research.

Finally, each of the respondents reported feelings of difference due to structural barriers as well. Such structural barriers can be conceived of broadly, including the inability to drive, to date, to socialize, be financially independent, to play sports, and others. While some of these structural barriers do include veritable structural barriers, such as inaccessibility of social gathering locations and lack of access independent transportation, some of these include cultural structures of masculinity, including sports, financial independence and even the experience of social competence. It can be argued that these barriers constitute social structures to which disabled men do not have access. This is supported in the literature through Connell (2005a), who claims that "the

physical sense of maleness and femaleness is central to the cultural interpretation of gender” (p. 52). Thus, masculinity is culturally conceived of as comprising certain muscular shapes, postures, ways of moving, and particular sexual possibilities. These conceptions of masculinity often find their meaning in the realm of sport, when bodies are put into competition with each other in order to assert dominance of one over the other. Prowess in this realm of sport is considered to involve the coordination of the entire body, rather than simply one organ. Thus, the opportunities for men with physical disabilities to access structural recognition and value within this realm are limited when there is an inability to coordinate the entire body in the service of sport as a way of asserting masculinity.

c. **Reformulations of masculine embodiment**

The last theme that emerged under the second core theme was that of “Reformulation of Masculine Embodiment”, which includes respondent’s efforts to redefine their own senses of masculinity in light of their experiences with disability.

Daniel discusses the ways in which he has become more interested in women’s issues, and aware of how women are treated in a patriarchal society. He also turns his attention to issues related to sexual orientation.

Daniel: “I become more interested in women’s issues as well as determine(d) to (overcome) many of the male stereotype. I began to empathize (with) the struggles women undergo in a male dominated society.”; “I tend to call out many bashing of women and other sexual orientation(s). I have become a strong advocate of equal rights for all regardless of sexual orientation.”; “More confident in my own sexuality as well as respectful and accepting of others.”

Eric discusses the ways in which he began the process of reformulation of masculinity. Through the meeting of other politically involved disabled people, he discusses the ways in which he has taken up a critique of existing ideas of masculinity, and instead, became critical of them.

Eric: (Present-Similar): “Psychologically and emotionally supportive.”

(Young Adulthood-different): “In and through this time (studying abroad in England, meeting politically engaged disabled people), I became comfortable with who I was, taking a negative attitude towards “traditional” notions of masculinity, and to a large extent, personhood. That is, rather than feeling badly about being shut out of traditional roles, I became critical of them.”

Further, he offers a commentary on current conceptions of independence, as they characterize masculine ideals, by claiming notions of absolute independence as myths, and foregrounding the reality of interdependence in modern western societies. He also echoes participant four’s newfound attention to other minority experiences in light of his own.

Eric (Different-Present): “I recognize that no one in modern westernized society can make a legitimate claim to independence but instead should acknowledge their interdependence and emphasize (the) variety of interconnected relations that make life – their own and those of others – meaningful.”; “My ideas of masculinity/being a man shape and are shaped by an ever increasing attention to coalition politics and, in everyday life, working together. In this regard, being a man is no different (than) other categories – neither privileged nor unquestioned.”

Frank discusses the increased responsibilities that he faced at an earlier age, including emotional maturity, knowledge of social programs, as well as the impact these experiences have had on his character, including strength and selectivity of his relationships. While much of this reformulation might seem to align this participant more closely with the first core theme, this participant fully acknowledges the impact that external influences have had on him and have lead to his current manifestation of masculinity. Acknowledging how the integration of external influences has affected his development helps provide an understanding of how his experience of masculinity can be seen as a reformulation of traditional ideals, rather than thoughtless acceptance.

Frank: (Young Adulthood-Different): “Had to emotionally mature much faster than everyone else and accept adult responsibilities earlier”; “Had to understand that disabled life required being knowledgeable about social programs.”

(Present-Different): “Have to deal with different issues that people my age and not disabled don’t understand”; “Being able to live while handicapped is now seen as brave and tough.”; “It has made me realize what being a man truly requires because of what I’ve seen and endured.”; “Now I’ve realized what I’ve had to experience because of my disability makes me a stronger and tougher man.”; “Although I have to deal with many people who define me by my disability and don’t give me a chance to prove who I really am, the people who I choose to keep in my life treat me as an individual and define me by my true identity rather than by my disability/wheelchair.”

Frank discusses the ways in which his experience with disability “makes me a stronger and tougher man”, and “It has made me realize what being a man truly

requires because of what I have seen and endured.” While this respondent does focus on the ways in which disability has increased his personal and emotional strength, which might be seen as a closer alignment with hegemonic masculine ideals, and thus be seen as a focus on individual characteristics and effort, the acknowledgement of barriers in the process of reformulation signifies an attention to external influences in the development of these characteristics.

The third theme that emerged from the responses of the respondents who can be categorized as “External Factors” is a rejection of hegemonic masculinity standards and a reformulation of masculinity that more closely aligns with the experiences of men with early onset physical disabilities. Respondents in this category identified the ways in which they have not only felt different from hegemonic standards of masculinity, but have critiqued these standards and have reformulated their own conceptions of masculinity to ones that more closely align with their experiences.

An acknowledgement of barriers to hegemonic masculinity allows these men to externalize the reasons why they have been excluded from traditional conceptions of masculinity, to critique them, and to reformulate a sense of masculinity that more closely aligns with their experience. Many of these men discuss the ways in which they have reformulated their own sense of masculinity based upon their experiences. One respondent describes his increased attention to women’s issues, issues related to oppression based on sexual orientation, and how a patriarchal society impacts other marginalized minorities. Another respondent expands upon this by claiming that his ideas of masculinity have evolved into an increased attention to coalition politics, and in everyday life, working together.

More specifically, reformulations of traditional senses of masculinity include a critique of the pervasive myth of independence, and a call for the recognition of the reality of interdependence in modern westernized societies. Eric says: “I recognize that no one in modern westernized societies can make a legitimate claim to independence but instead should acknowledge their interdependence and emphasize (the) variety of interconnected relations that make life – their own and those of others – meaningful.”

Additionally, these respondents report their reformulated senses of masculinity include emotional availability and support, accelerated masculinity, accepting adult responsibilities earlier, knowledge of social programs, and an increased selectivity of relationships.

These findings can also be seen to be reflection of Eric Erikson’s (1968) description of the adolescent who has had difficulty finding where their talents and abilities fit with the needs of the current society. According to Erickson, the primary project of adolescence is to find where one can contribute their talents and abilities to the society into which they are coming of age. When this process is complicated by, among other things, disability, the individual seeks to find a place where they can contribute their talents to ideological projects in which they are inspired by the ideological potential of their society. It seems apparent that for many of these respondents, their experiences of difficulty in finding where to make their contributions or develop their own skills have led them to alternative characteristics or projects to those encompassed by hegemonic masculine ideals, such as the development of emotional availability and support as well as an attention to other minority experiences.

In this way, these men react to these standards by diverting their energies away from meeting them, and into other areas that hold more meaning for them.

The findings in this last sub-theme directly connect to Gerschick and Miller's (1997) framework for responses among men with disabilities to hegemonic masculinity, applied to men with early onset physical disabilities, most specifically to the responses of rejection and reformulation. Gerschick and Miller describe the process of reformulation as a focus on the strengths and abilities that they still possess, and might even be difficult for others to perform. In their research, they cite examples of driving an adapted car, or maneuvering an electric example. In the responses given for the present study, reformulation is characterized in terms of emotional availability, support, and maturity, as well as an increased attention to other marginalized minorities.

Rejection is described as an altogether denial of the importance of societal norms, and the creation of another set of standards that are reflective of disabled men's experiences. Gerschick and Miller (1997) further argue that those who rejected hegemonic masculine standards altogether showed the most hope for change, when they begin to realize that it is societal conceptions of masculinity that are problematic, rather than themselves. Eric illustrates this rejection clearly: "If being a man means consistently and flawlessly exercising autonomous independence for oneself and on behalf of others in the world, then I am not a man. And, what's more, I am okay with that."

These processes of rejection and reformulation can be seen in connection with Gill's (1997) four types of disability identity integration, and perhaps connected to the fourth type, in which people with disabilities going through a process of "coming out" or

integrating how one feels with how they present themselves to the world. It seems evident, from the data, that for some of these men, they have gone through a long process of considering the ways in which their experiences compare with traditional conceptions of masculinity, and seeing the disparity, have begun to claim that difference and vocalize critiques of those idealized standards.

Most respondents were consistent in their accounts of their development of masculinity, indicating that their own constructions of masculinity have remained relatively constant over time. For these participants, reflections on their own more recent experiences and constructions of masculinity seem to parallel those of earlier years as well. For example, Ben says, in response to a question about how his perceptions of the ways in which disability impacts masculinity have changed over time: “No change over time: remained pretty constant over time”. Other participants were not as explicit in their answers in regards to changes over time, but gave answers that suggest their constructions and perceptions of their own masculinity seem to have remained relatively unchanged due to certain aspects of their lives that help them align with more traditional conceptions of masculinity, such as mobility, or the ability to get around.

Other respondents did indicate some changes in their narratives of their own constructions of masculinity, such as Daniel, who reports that he didn’t have much concern for women’s feelings during earlier years, such as in pre-adolescence. However, he then reports that during young adulthood, many of his feelings of difference from traditional standards of masculinity stemmed from an increased interest in women’s issues and the ways in which they experience oppression in a patriarchal

society. Another participant, Frank, describes the ways in which, during earlier years, he was still able to walk, and thus felt more aligned with traditional standards of masculinity. However, later in life, when he was no longer able to walk, he experienced more feelings of difference from his peers related to his disability, which led him to become more aware of the social implications and perceptions of being a man with a disability within the culture of the United States.

In conclusion, the findings in the present study found that the men studied represented a split in responses to hegemonic masculinity. One portion of the men placed more emphasis on individual characteristics and efforts in accessing masculine standards, while another portion of the respondents placed more emphasis on external influences that affected their ability to access or meet such standards. Within each of these two core responses to hegemonic conceptions of masculinity, three sub-themes were identified that supported the respective core theme. Each of the sub-themes within the first core theme helps understand the ways in which these respondents do not see disability as affecting their ability to achieve hegemonic standards of masculinity, and the critical role these standards have, and continue to have a critical role in the development of their own sense of masculinity. For the respondents whose responses emphasize external influences or barriers to meeting hegemonic standards of masculinity, these sub-themes help us understand the ways in which early feelings of difference among these men have contributed to an acknowledgement of barriers and reformulations of masculine embodiment.

In reference the aims of this study, this data helps to contextualize the ways in which men with early onset physical disabilities perceive or define standards for

masculinity in the United States, as well as the ways in which their own masculinity and developmental path of their masculinity compares with that of other men. The responses also help to illuminate the feelings that respondents have about these similarities or difference. While the respondents of this study represent divergent responses to hegemonic ideals of masculinity, many of their responses have connections with existing literature, including Gerchick and Miller's (1997) "Three 'R' Framework", the present study offers results that may begin to illuminate understandings about the impact that the early onset physical disabilities may have for some men. For some men, this manifested itself in adherence to traditional standards of masculinity throughout their development, and thus, an ingrained belief in the power of individual characteristics in meeting masculine standards. For other men, this manifested itself in early feelings of difference, experience of barriers, and the eventual reformulation of masculine embodiment to align more closely with their own senses of masculinity, while offering a critique of hegemonic standards of masculinity. Finally, the data collected from these respondents help to understand the ways in which these men have, or have not, re-defined or reformulated masculinity to better align with their own experiences, which may have included the adoption of non-traditional standards of masculinity.

C. **Limitations**

The current study was an exploratory study conducted in order to explore this area in hopes building further research. Limitations include difficulties in recruitment, specifically in generating responses through online distribution of a survey. The target sample was 30, but with only six respondents, the research findings are limited. The

survey was posted in various social media areas, including Facebook groups, as well as through listservs and acquaintances of the researcher. Thus, participation in this research was not compensatory, with no incentives offered to participants, which may have yielded the low response rate. The recruitment post was sent out numerous times to the sites listed, as well as to the researcher's personal contacts throughout the course of two months. However, despite the researcher's repeated efforts to recruit participants, it was determined that recruitment saturation was reached when subsequent calls for participation yielded no new participants. Additionally, other limitations included the fact that no demographic information was collected from the respondents, which would have been helpful information to have in situating the responses of the participants. Finally, the responses collected from the survey were brief, due to the nature of survey data collection, which, by design, can limit the length of responses collected.

In future iterations of this research, improvements to the methodology would include targeting specific individuals who fit this demographic to recruit and from whom to gather data, utilizing interviews with participants. This would involve identifying specific individuals who fit the demographic criteria, and developing a more intentional consent process, in which the researcher would lay out the confidentiality measures to be taken in order to protect the responses from being identified with their participant. These improvements would help to ensure data saturation is reached and would hopefully provide richer responses. Additionally, this targeted approach would provide a more direct link between the researcher and participant that is absent in the mass distribution of surveys over numerous social media sites. In this methodology, the

researcher would need to do more work to identify possible participants, but it can be proposed that this strategy would yield more in-depth data, especially if focus groups or in-person interviews are used. One of the issues with distributing surveys over the internet to large groups of potential participants includes lack of a personal connection with the researcher, which may render a participant less likely to respond. Further, it may be possible that participants may feel as though others will respond, and therefore feeling as if they do not need to respond, therefore yielding a low response rate.

V. CONCLUSION

The intent of this research is to understand the identity formation processes of men with early onset physical disabilities, that is, disabilities with which men were either born, or ones they acquired prior to the primary identity formation years. Existing research on men with disabilities focuses on men with acquired disabilities and the ways in which they negotiate a new identity that is different than the one with which they grew up. However, the current study is intended to explore the ways in which men who were born with disabilities or acquired them in early childhood experience masculinity throughout their primary identity formation years and the ways in which disability impacts that process. It can be hoped that, through the examination of the identity formation processes of this population, we can begin to understand the ways in which disability is experienced as a significant marker of identity throughout the primary identity formation years. In so doing, it can be hypothesized that it will provide a more robust understanding of the social meanings that are associated with disability, and therefore, the attitudinal barriers that exist for all people with disabilities.

This project draws upon various existing bodies of literature that have informed and guided the research and its design, including the areas of gender, hegemonic masculinity, disability, identity/identity formation, adolescent development, and stigma. Each of these areas contributes a critical component to the understanding of masculinity and identity development of men with early onset physical disabilities. Existing literature remains woefully silent on the topics surrounding men with early onset physical disabilities. Some researchers (Gerschick & Miller, 1997) suggest that the early onset of a disability may shelter men with disabilities from the expectations of hegemonic

masculinity. However, the researcher of the present study suggests that men with early onset physical disabilities are not immune to the normalizing standards of masculinity, and thus warrant the exploration of their experiences and perspectives in order to gain a more robust understanding of masculinity.

This study takes a constructivist approach to both masculinity and disability, and examining the impacts that disability has on the development of men with early onset physical disabilities. Much of the reviewed literature rejects an essentialized understanding of masculinity as well as disability. Authors cited understand gender as performative, or produced through performance, and regulated through practices of gender coherence and through diffuse channels of power, which are present throughout society. This understanding of the diffuse nature of gender regulation throughout all aspects of social life also helps us to frame a comprehension of hegemonic masculinity and the ways in which it exerts a controlling force throughout society and is a strong regulatory force on gender. An exploration of stigma, particularly Goffman (1963), helps us to understand the nature of living with a spoiled identity, and helps us to grasp the ways in which men with early onset physical disabilities experience feelings of alienation from hegemonic conceptualizations of masculinity. Studying stigma for this population is particularly prudent during the adolescent years, or the primary developmental years, during which the presence of a disability and the associated stigma may prove to have an effect on the developmental processes of these men. Further, Shuttleworth et al. (2012) recognizes the lack of attention given to men with early onset physical disabilities in existing literature, and the need for researchers to understand the nuanced

differences between the experiences of men with acquired physical disabilities, and those with early onset disabilities.

The results of this research yielded several significant findings. First, respondents were asked to identify traditional stereotypes of masculinity in America. The responses to this question produced several common themes, including confidence, emotional stoicism, financial and physical independence, defender of loved ones, and responsibility. These findings resonate with existing literature on this topic, which identify characteristics found in this data as critical components of masculinity. Further, they help provide a more robust understanding of the ideals and perceptions of masculinity with which they contend in their development of identity and masculinity, and give a backdrop against which to interpret these men's experiences.

The findings elicited in the present study demonstrate significant results about this population. First, the findings suggest that responses among men with early onset physical disabilities to hegemonic masculinity vary, and depend greatly on the individual's context. The present study, as it was exploratory in nature, did not have the resources to explore the many different factors that impact the development of identity and masculinity among men with early onset physical disabilities. However, several significant findings from this study warrant discussion and further research.

This research revealed some men focus much more of their attention on the ways in which their own individual characteristics and efforts provide them a means of accessing hegemonic masculinity, while other men give more attention to the external influences that influence their ability to access hegemonic masculinity. Among the men whose responses seemed to reflect an increased focus on individual characteristics and

efforts, it seems as though disability did not play a major role in their feelings about being able to access hegemonic masculinity. Further, while all men acknowledged the importance of the traditional markers of masculinity throughout their developmental years, these men did not offer any critiques or alternative views of these markers in any of their other responses, as other respondents did, which led the researcher to believe that these men adhered more closely to them. Finally, among these respondents, there seemed to be a more optimistic view of disabled men's place in current society. This led the researcher to believe that this perception reflected an attempt to embody a level of stoicism that would align with values around emotional control that characterize hegemonic masculinity.

For the men whose responses seemed to give more attention to external influences, the data seemed to suggest that there was an earlier awareness or feeling of difference from peers, which seemed to have a greater impact on these men than other respondents. Additionally, these men acknowledged certain barriers that exist for them in terms of accessing hegemonic masculinity. Among these barriers are social, cultural, political, and economic barriers that these respondents feel limit their ability to be regarded as full men. This is a significant finding, as it represents a further shift in conceptualizing one's access to hegemonic masculinity as dependent on external barriers, rather than on individual characteristics or flaws. Finally, in light of viewing external influences as barriers to accessing hegemonic masculinity, the respondents whose responses fall into this core theme offer critiques of hegemonic masculinity, and illustrate ways in which they have reformulated ideals of masculinity into ones that better align with their own experience.

Viewed as a whole, the responses furnished for this study demonstrated a variety of responses of hegemonic masculinity, with responses and their respondents being clustered around two major themes. While the present study reflects many findings in existing literature on the topics surrounding masculinity and disability, other responses lead the researcher to believe that experiences unique to this population warrant further research. For example, findings in this study reflect respondents' increased attention to coalition politics or other minority oppressions than have been reported in other studies of disabled men. Thus, exploring the ways in which the presence of an early onset physical disability among men may, or may not, influence one's sensitivity to other minority experiences may prove a fruitful area of study for future research into this demographic.

The researcher believes that these two core themes faithfully represent the respondents' responses, and are supported by each of the sub-themes. However, it should be noted that no one respondent should be said to entirely belong to one category or another, as many respondents gave responses that could fit within either core theme, which indicates the complexity of the issues at hand and the need for further research into its nuances. As mentioned previously, it is evident that context is an important factor determining one's developmental processes, and so, future research should explore these contextual influences more intently.

While this study began with the intention of following a hybrid methodology for data analysis, the researcher, upon initiating the data analysis process, determined that it would prove necessary to give greater attention to the survey data collected to develop core themes and sub-themes. It was determined that the existing literature did

not provide an adequate framework against which to test the survey data. Instead, the literature provided sensitizing concepts, which gave the researcher insights as to important areas of interest of which to be aware when analyzing the data. Thus, while the present study shifted to employ a grounded theory approach, it would be prudent for future research to explore the ways in which more specific contextual factors influence the development of this demographic, such as family relationships, peer relationships, impairment type, age, socioeconomic background, and others. Additionally, further research would benefit from the use of more direct methods of eliciting information from participants, such as focus groups or interviews.

Finally, the researcher proposes that research into the intersection of these two identities, in particular, can serve as a means of understanding hegemonic conceptions not only of masculinity, but personhood as well. This may provide an impetus for further study of the attitudinal barriers and stigma that exist for all people with disabilities through the examination of individuals who have partial access to a patriarchal hegemony, but who are not afforded social esteem, and thus can be socially perceived to embody a contradiction. The tension inherent in the intersection of identities that are socially regarded as contradictory has the potential to be a fruitful exploration for the field of disability studies to explore in order to examine the oppressive ideals that hegemonic masculinity exerts, as well as the esteem with which society holds disability.

APPENDICES

APPENDIX A

IRB Approval Letter

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Exemption Granted

November 14, 2013

Brian Heyburn
Disability and Human Development
2251 W North Ave, Apt. 1F
Chicago, IL 60647
Phone: (502) 609-2742

RE: Research Protocol # 2013-1087
“Hegemonic Masculinity and Identity Formation in Men with Early Onset Physical Disabilities”

Sponsors: None

Dear Brian Heyburn:

Your Claim of Exemption was reviewed on November 14, 2013 and it was determined that your research protocol meets the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b)]. You may now begin your research.

Exemption Period:	November 14, 2013 – November 14, 2016
Performance Site(s):	UIC
Subject Population:	Adult (18+ years) subjects only
Number of Subjects:	20

The specific exemption category under 45 CFR 46.101(b) is:

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably

APPENDIX A (continued)

place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

1. Amendments You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.
2. Record Keeping You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.
3. Final Report When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).
4. Information for Human Subjects UIC Policy requires investigators to provide information about the research protocol to subjects and to obtain their permission prior to their participating in the research. The information about the research protocol should be presented to subjects in writing or orally from a written script. When appropriate, the following information must be provided to all research subjects participating in exempt studies:
 - a. The researchers affiliation; UIC, JBVMAC or other institutions,
 - b. The purpose of the research,
 - c. The extent of the subject's involvement and an explanation of the procedures to be followed,
 - d. Whether the information being collected will be used for any purposes other than the proposed research,
 - e. A description of the procedures to protect the privacy of subjects and the confidentiality of the research information and data,
 - f. Description of any reasonable foreseeable risks,
 - g. Description of anticipated benefit,
 - h. A statement that participation is voluntary and subjects can refuse to participate or can stop at any time,
 - i. A statement that the researcher is available to answer any questions that the subject may have and which includes the name and phone number of the investigator(s).

APPENDIX A (continued)

- j. A statement that the UIC IRB/OPRS or JBVMAC Patient Advocate Office is available if there are questions about subject's rights, which includes the appropriate phone numbers.

Please be sure to:

→Use your research protocol number (listed above) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact me at (312) 355-2908 or the OPRS office at (312) 996-1711. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Charles W. Hoehne, B.S., C.I.P.
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

cc: Tamar Heller, Disability and Human Development, M/C 626
Sarah Parker Harris, Disability and Human Development, M/C 626

APPENDIX B

IRB Amendment Approval Letter

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

**Exemption Determination
Amendment to Research Protocol – Exempt Review
UIC Amendment # 1**

January 17, 2014

Brian Heyburn, MS
Disability and Human Development
2251 W North Ave, Apt. 1F
Chicago, IL 60647
Phone: (502) 609-2742

**RE: Protocol # 2013-1087
“Hegemonic Masculinity and Identity Formation in Men with Early Onset
Physical Disabilities”**

Dear Brian Heyburn:

The OPRS staff/members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research, and have determined that your research protocol continues to meet the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b))].

The specific exemption category under 45 CFR 46.101(b) is:

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

APPENDIX B (continued)

You may now implement the amendment in your research.

Please note the following information about your approved amendment:

Exemption Period: January 17, 2014 – January 17, 2017

Amendment Approval Date: January 17, 2014

Amendment:

Summary: UIC Amendment #1 dated January 3, 2014 and submitted to OPRS on January 9, 2014 is an investigator-initiated amendment:

- 1) Removing the follow-up component of the survey;
- 2) Expanding recruitment beyond Chicago;
- 3) Increasing the sample size from 20 to 30; and
- 4) Adding online recruiting strategies (various related Facebook sites).

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

5. Amendments You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.
6. Record Keeping You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.
7. Final Report When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).
8. Information for Human Subjects UIC Policy requires investigators to provide information about the research protocol to subjects and to obtain their permission prior to their participating in the research. The information about the research protocol should be presented to subjects in writing or orally from a written script. When appropriate, the following information must be provided to all research subjects participating in exempt studies:
 - f. The researchers affiliation; UIC, JB VAMC or other institutions,
 - g. The purpose of the research,

APPENDIX B (continued)

- h. The extent of the subject's involvement and an explanation of the procedures to be followed,
- i. Whether the information being collected will be used for any purposes other than the proposed research,
- j. A description of the procedures to protect the privacy of subjects and the confidentiality of the research information and data,
- f. Description of any reasonable foreseeable risks,
- k. Description of anticipated benefit,
- l. A statement that participation is voluntary and subjects can refuse to participate or can stop at any time,
- m. A statement that the researcher is available to answer any questions that the subject may have and which includes the name and phone number of the investigator(s).
- n. A statement that the UIC IRB/OPRS or JB VAMC Patient Advocate Office is available if there are questions about subject's rights, which includes the appropriate phone numbers.

Please be sure to:

→Use your research protocol number (2013-1087) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact me at (312) 355-2908 or the OPRS office at (312) 996-1711. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Charles W. Hoehne, B.S., C.I.P.
Assistant Director
Office for the Protection of Research Subjects

cc: Tamar Heller, Disability and Human Development, M/C 626
Sarah Parker Harris, Disability and Human Development, M/C 626

APPENDIX C

Recruitment Flyer

**ARE YOU A MAN BORN WITH A PHYSICAL
DISABILITY OR DID YOU ACQUIRE ONE DURING
CHILDHOOD?**

**ARE YOU INTERESTED IN PARTICIPATING IN
RESEARCH RELATING TO THE IDENTITY
FORMATION OF MEN WITH EARLY ONSET PHYSICAL
DISABILITIES?**

INFORMATION ABOUT THE STUDY:

- **RESPONSES WILL BE COLLECTED VIA ONLINE SURVEY**
- **LOCATION: YOUR COMPUTER!**

ELIGIBILITY:

- **MALES AGES 25-45**
- **BORN WITH OR ACQUIRED DURING CHILDHOOD A PHYSICAL DISABILITY**

IF SO, PLEASE VISIT THE FOLLOWING LINK:

**ALL OF YOUR RESPONSES WILL BE KEPT
COMPLETELY ANONYMOUS**

APPENDIX D

Recruitment Posting Text

Hello, my name is Brian Heyburn and I am currently working on my thesis project, which is focusing on the masculinity and identity development of men ages 25-45 with early onset physical disabilities, meaning disabilities that they were either born with or acquired before their primary identity development years (adolescence). In order to get a better understanding of this subject, I am asking men who fit this description to fill out a survey based on their experiences. All responses will be completely anonymous, unless you make your identity known in your response. I will have no way of determining a person's identity through the submission of their responses. Therefore, any information that is published will not be identifiable with a particular person. There are, however, several benefits to responding, including the opportunity to share your experiences as a man with a physical disability as well as the opportunity to contribute to a larger body of knowledge that may help break down the oppression that men and all people with disabilities face.

Participation in this research is voluntary and you may refuse to participate or stop at any time.

The principal investigator, Brian Heyburn is available to answer any questions that you may have at bheybu2@uic.edu.

The University of Illinois at Chicago Office for the Protection of Research Subjects is available if you have any questions about your rights as a subject of research. The UIC OPRS can be contacted at 312.996.1711. IRB Protocol # 2013-1087

The survey can be found by clicking on the following link:

<http://www.surveygizmo.com/s3/1492136/c881da2161db>

APPENDIX E

Online Survey Text

Thank you once again for your participation in this research. Your responses will help further a body of research into the experiences of men with early onset disabilities. Please complete the responses with as much detail as possible. If you feel uncomfortable answering any question, you may skip it.

1. Imagine you are meeting someone for the first time. How would you describe yourself in 1 – 3 sentences?
2. Discuss perceptions of American masculinity.
 - a. What are the traditional, stereotypes of what it means to be a man in America?
 - b. In what ways have the traditional stereotypes of what it means to be a man in America changed over your own lifetime?
3. Discuss your own ideas of masculinity in America
 - a. In what ways are you similar to the traditional stereotyped ideas (now and over your lifetime) of what it means to be a man in America?
 - i. Pre-adolescent
 - ii. Adolescent
 - iii. Present
 - b. In what ways are you different from the traditional stereotyped ideas (now and over your lifetime) of what it means to be a man in America?
 - i. Pre-adolescent
 - ii. Adolescent
 - iii. Present
4. Discuss what it means to be a man with a disability in America
 - a. In what ways does disability generally impact (either a good or bad way) society's ideas of masculinity/being a man in America?
 - i. Have these perceptions by society changed over time? Please give an example.
 - b. How has having a disability generally impacted (either good or bad) your own ideas of masculinity/being a man in America?
 - i. Have your own ideas of masculinity changed over time? Please give an example.

CITED LITERATURE

- Asch, A., & Fine, M. (1988). *Women with disabilities: Essays in psychology, culture, and politics*. Philadelphia, PA: Temple University Press.
- Babbie, E. (2011). *The basics of social research* (5th ed.). Belmont, CA: Wadsworth.
- Bartky, S. L. (1990). *Femininity and domination: Studies in the phenomenology of oppression*. New York, NY: Routledge.
- Bradley, H. (1996). *Fractured identities: Changing patterns of inequality*. Malden, MA: Polity Press.
- Bradley, H. (2013). *Gender* (2nd ed.). Malden, MA: Polity Press.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Butler, J. (1990). *Gender trouble: Feminism and the subversion of identity*. New York, NY: Routledge.
- Butler, J. (1993). *Bodies that matter: On the discursive limits of "sex"*. New York, NY: Routledge.
- Connell, R. W. (2005a). *Masculinities* (2nd ed.). Berkeley, CA: University of California Press.
- Connell, R. W. (2005b). Hegemonic masculinity: Rethinking the concept. *Gender & Society*, 19(6), 829-859. doi: 10.1177/0891243205278639.
- Connell, R. W., & Messerschmidt J. W. (2005). Hegemonic masculinities: Rethinking the concept. *Gender and society*, 19(6), 829-859. Sage Publications.
- Coston, B.M., & Kimmel, M. (2012). Seeing privilege where it isn't: Marginalized masculinities and intersectionality of privilege. *Journal of Social Sciences*, 68(1), 97-115.
- Davis, L. (2006). Constructing normalcy. In L. Davis (Ed.), *The disability studies reader* (2nd ed., pp. 1-16). New York, NY: Routledge.
- Demetriou, D. Z. (2001). Connell's concept of hegemonic masculinity. *Theory and Society*, 30(3), 337-362.
- Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of qualitative research*. Thousand Oaks, CA: Sage Publications.
- Elias, J., & Beasley, C. (2009). Hegemonic masculinity and globalization: Transnational business masculinities and beyond. *Globalizations*, 6(2), 281-296.

- Ellis, S. J., & Peel, E. (2010). *Lesbian, gay, bisexual, trans and queer psychology: An introduction*. New York, NY: Cambridge University Press.
- Engel, D. M. (2003). *Rights of inclusion: Law and identity in the life stories of Americans with disabilities*. Chicago, IL: University of Chicago Press.
- Erikson, E. H. (1968). *Identity: Youth and crisis*. New York, NY: W. W. Norton & Company.
- Fleischer, D., & Zames, F. (2001). *Disability rights movement: From charity to confrontation*. Philadelphia, PA: Temple University Press.
- Foucault, M. (1977). *Discipline and punish*. New York, NY: Vintage Books.
- Foucault, M. (1978). *The history of sexuality*. New York, NY: Vintage Books.
- Galambos, N. L., Almeida, D. M., & Petersen, A. C. (1990). Masculinity, femininity, and sex role attitudes in early adolescence: Exploring gender intensification. *Child Development*, 61(6), 1905-1914.
- Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *NWSA Journal*, 14(3), 1-32.
- Gerschick, T. J. (2000). Toward a theory of disability and gender. *Signs: Journal of Women in Culture and Society*, 25(4), 1263-1268.
- Gerschick, T.J., & Miller, A. S. (1997). Gender identities at the crossroads of masculinity and physical disability. In M. G. S. Davis (Ed.), *Toward a new psychology of gender*, 455-478. New York, NY: Routledge.
- Gill, C. J. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation*, 9(1), 39-46.
- Gilligan, C. (1979). Women's place in man's life cycle. *Harvard Educational Review*, 49(4), 431-446.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory, strategies for qualitative research*. Piscataway, NJ: Transaction Publishers.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon and Schuster.
- Hill, J. P. & Lynch, M. E. (1983). The Intensification of gender-related role expectations during early adolescence. In J. Brooks-Gunn, & A. C. Petersen (Ed.), *Girls at puberty* (pp. 201-228). New York, NY: Plenum.

- Marcia, J. E. (1980). Identity in adolescence. In J. Adelson (Ed.), *Handbook of adolescent psychology*, 159-187. New York, NY: John Wiley & Sons.
- Massad, C. M. (1981). Sex role identity and adjustment during adolescence. *Child Development*, 52(4), 1290-1298.
- McRuer, R. (2002). Compulsory able-bodiedness and queer/disabled experience. In B. J. Brueggeman, R. Garland-Thomson, S. L. Snyder (Eds.), *Disability studies* (pp. 88-99). New York, NY: Modern Language Association of America.
- McRuer, R. (2006). *Crip theory*. New York, NY: New York University Press.
- Mertens, D. M. (2010). *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative and mixed methods* (3rd ed.). Los Angeles, CA: Sage Publications.
- Morgan, D. L. (2008). Snowball sampling. In L. M. Given (Ed.) *The Sage encyclopedia of qualitative research methods* (Vol. 2). Retrieved from <http://srmo.sagepub.com/view/sage-encyc-qualitative-research-methods/n425.xml>.
- Morse, J. (2004). Purposive sampling. In M. Lewis-Beck, A. Bryman, T. Liao (Eds.), *Encyclopedia of social science research methods*. Retrieved from <http://srmo.sagepub.com/view/the-sage-encyclopedia-of-social-science-research-methods/n774.xml>
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (Vol. 3). Thousand Oaks, CA: Sage Publications.
- Parry, K. (2004). Constant comparison. In M. Lewis-Beck, A. Bryman, & T. Liao (Eds.), *Encyclopedia of social science research methods*. (pp. 181-182). Thousand Oaks, CA: Sage Publications, Inc.
- Priess, H. A., Lindberg, S. M., & Hyde, J. S. (2009). Adolescent gender-role identity and mental health: Gender intensification revisited. *Child Development*, 80(5), 1531-1544.
- Saldaña, J. (2011). *Fundamentals of qualitative research*. New York, NY: Oxford University Press.
- Shakespeare, T. (1996). Disability, identity, and difference. In C. B. G. Mercer (Ed.), *Exploring the divide* (pp. 94-113). Leeds, United Kingdom: The Disability Press.
- Shakespeare, T. (1999). Sexual politics of disabled masculinity. *Sexuality and Disability*, 17(1), 53-64.
- Shuttleworth, R., Wedgwood, N., & Wilson N. J. (2012). The dilemma of disabled masculinity. *Men and Masculinities*, 15(2), 174-194.

- Shuttleworth R. (2000). The search for sexual intimacy for men with cerebral palsy. *Sexuality and Disability, 18*(4), 263-282.
- Siebers, T. (2008). *Disability theory*. Ann Arbor, MI: The University of Michigan Press.
- Sue, V. M., & L. A. Ritter. (2007). *Conducting online surveys*. Thousand Oaks, CA: Sage Publications.
- Taleporos, G., & McCabe, M. P. (2002). The impact of sexual esteem, body esteem, and sexual satisfaction on psychological well-being in people with physical disability. *Sexuality and Disability, 20*(3), 177-183.
- Taub, D. E., Blinde, E. M., & Greer, K. R. (1999). Stigma management through participation in sport and physical activity: Experiences of male college students with physical disabilities. *Human Relations, 52*(11), 1569-1484.
- Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability. *Disability and Society, 17*(5), 509-527.
- Way, N., & Greene, M. L. (2006). Trajectories of perceived friendship quality during adolescence: The patterns and contextual predictors. *Journal of Research on Adolescence, 16*(2), 293-320.
- Weeks, Jeffrey. (1990). The value of difference. In J. Rutherford (Ed.), *Identity: Community, culture, difference*. London, England: Lawrence & Wishart.
- Wetherell, M., & Edley, N. (1999). Negotiating hegemonic masculinity: Imaginary positions and psycho-discursive practices. *Feminism & Psychology, 9*(3), 335-356.
- Winter, M. F., & Robert, E. R. (1980). Male dominance, late capitalism, and the growth of instrumental reason. *Berkeley Journal of Sociology, 24/25*, 249-280.

VITA

CONTACT INFORMATION

Brian Heyburn

903 S. Ashland Ave. Apt. 717
Chicago, IL 60607

Phone: 502-609-2742

brian.heyburn@gmail.com

bheybu2@uic.edu

EDUCATION

2012-Present: University of Illinois at Chicago

Master of Science in Disability and Human Development (expected summer 2014)

Thesis: *Negotiating Identity and Masculinity Among Men with Early Onset Physical Disabilities* Advisor: Sarah Parker Harris, Ph.D.

4.0 Cumulative GPA

2006-2010: Centre College

Bachelor of Arts in Religion

Thesis: *Hindu Sacred Space: Interdependence of Belief and Construction*

3.0 Cumulative GPA

APPLIED EXPERIENCE

2013-Present: University of Illinois at Chicago, Chicago, IL

Disability Culture Consultant

Supervisors: Roxana Stupp, Sara Vogt

CONFERENCE PRESENTATIONS

HEYBURN, B. (2013) Hegemonic Masculinity and Theorizing the Identity Formation in Men with Early Onset Disabilities. Presented at Engendering Change Conference on Gender and Sexuality, University of Illinois at Chicago.

AWARDS AND SCHOLARSHIPS

2013: Graduate Teaching Assistantship, University of Illinois at Chicago

2010: Max P. Cavnes Prize, Centre College

2010: Student Life Leadership Award, Centre College

2008: Richard Stanford Watson Jr. Memorial Award, Centre College

2006-2010: Founder's Scholarship, Centre College