

THE SOCIOPOLITICAL CONSTRUCTION OF IDENTITY:
A MULTIDIMENSIONAL MODEL OF DISABILITY

by

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TABLE OF CONTENTS

ABSTRACT	10
REFLECTION ONE	11
CHAPTER ONE: INTRODUCTION AND BACKGROUND	12
Representation of voice	14
Disability in context	15
Purpose of the study	18
Conceptual frameworks	19
Research questions	21
Methodology	21
Limitations of the study	22
Summary	24
REFLECTION TWO	26
CHAPTER TWO: REVIEW OF RELEVANT LITERATURE	27
Introduction	27
Theoretical context of identity development	28
Identity	28
Psychosocial identity development	29
Identity development for subordinated identities	30
Women’s identity development	31
Racial identity development	33
Gay, Lesbian, and Bisexual Identity Development	36
Transition Theory	41
Multiple identities	44
The Americans with Disabilities Act	45
Disability Studies	49
Disability Models	52
Medical Model	52
Functional Limitations Model	53
Minority Group Model	55
Social Model	55
Conclusion	58
REFLECTION THREE	60
CHAPTER THREE: RESEARCH DESIGN AND METHODOLOGY	61
Introduction	61
Statement of Positionality	62
My lens	62

TABLE OF CONTENTS—CONTINUED

Insider to disability community	65
Professional dynamics	67
Social justice advocate	68
Methodology	69
Research questions.....	70
Developing the interview tool.....	71
Piloting the study	73
Site for research	74
The University of Arizona	74
Disability Resource Center	75
University commitment to disability	79
Selecting a sample.....	80
Sample.....	81
Data collection	84
Three-interview series.....	84
Data analysis	87
Phenomenological data analysis	87
Coding system.....	88
Validity of data	89
Triangulation of data.....	90
Prolonged engagement.....	90
Member checking.....	91
Transcriptions	92
Research journal.....	92
Peer debriefing	93
External auditor.....	93
Summary	94
 REFLECTION FOUR	 95
 REFLECTION FIVE	 96
 CHAPTER FOUR: FINDINGS	 98
Introduction.....	98
Sequence of identity development: challenging traditional stage-like models.....	98
Disability is critical to, but does not define, identity	109
Perspectives on disability.....	113
Disability positively enhances life	115
Philosophies on life.....	118
Anger.....	121
Oppression	128

TABLE OF CONTENTS—CONTINUED

Defining disability	135
Disability Culture.....	139
University of Arizona makes positive impact on life	140
Impact of rehabilitation.....	144
Disability-related career paths	149
Peer group	152
“In-group/Out-group” language and slang.....	158
Significance of wheelchair athletics	165
Conclusion	169
 REFLECTION SIX.....	 171
 CHAPTER FIVE: CONCLUSIONS AND IMPLICATIONS	 173
Introduction.....	173
Summary of major findings	174
Sequence of identity development: challenging traditional stage-like models	174
Disability is critical to, but does not define, identity	174
Perspectives on disability.....	175
Disability culture.....	177
Conclusion	178
A Multidimensional Model of Disability Identity	179
A new approach to identity development	179
Negotiating identity	181
Ignorance.....	182
Questioning	182
Negotiated identity.....	183
Implications.....	185
Implications for practice	185
Paradigm shift	185
Programs and services that promote positive disability identity— students as self-advocates	187
Campus marketing and recruitment	189
Implement or expand adaptive athletics programs	190
Training for campus leaders.....	191
Implications for institution.....	192
Gauging campus climate.....	192
Advisory council for disability issues.....	194
Disability Studies on campus.....	194
Universal Design.....	195

TABLE OF CONTENTS—CONTINUED

Implications for future research	196
Expansion of sample	196
Diversifying site.....	197
A multidimensional approach	198
Implications for activism and social movements.....	199
Apply Multidimensional Model of Disability Identity to other groups.....	200
Conclusion	200
 APPENDIX A: SUBJECT’S DISCLAIMER/INFORMED CONSENT FORM.....	 202
APPENDIX B: INTERVEIW QUESTIONS.....	206
APPENDIX C: SAMPLE E-MAIL COMMUNICATION TO STUDENTS.....	212
APPENDIX D: RESPONDENT PROFILES	213
REFERENCES	231

ABSTRACT

This paper explores the developmental process associated with developing a disability identity and the major societal, political, and environmental influences on disability identity development. This phenomenological study employs in-depth interviews to explore the interplay between the personal experiences of physically disabled college students with their social and physical environments to better understand the disability identity development process. Framing this study are the concepts that disability is a sociopolitical construct and that identity is formed through the interplay of individual and environment.

The multidimensional model for disability identity is presented to inform the formation of disability identity. Currently, no model exists solely dedicated to disability identity. This model introduces the term “negotiated identity” to reflect the interaction between individual and environment that is critical to the disability experience. This model sees a departure from its essentialist predecessors by allowing for a vast interpretation of disability identity and straying from the one-directional, stage progression of traditional models. Institutional, practical and research-oriented implications are presented to inform the work of higher education professionals.

REFLECTION ONE

I have a hazy recollection of one of my very first homework assignments. I was in the first grade and had to complete a worksheet about who I was with prompts like “What is your favorite food?” and “What color is your hair?” The one prompt that sticks out for me when reflecting on this assignment is, “What makes you different?” Without much thought, I answered, “I am different because I am handicapped.” I remember showing my worksheet to my aunt, with whom I am very close, and her telling me, in a very serious and concerned, yet caring, tone that I was not different because I was handicapped. She told me never to think that and to change my answer. I changed my answer...but was unsure as to why what I had written was bad.

CHAPTER ONE

INTRODUCTION AND BACKGROUND

One can open any scholarly higher education journal and be bombarded by articles and studies dedicated to understanding the experiences of underrepresented student groups. However, the disabled student¹ population is consistently overlooked. Despite the fact that disabled individuals represent at least twenty percent of American society (National Institute on Disability and Rehabilitation Research, 2005), disabled students are largely ignored in higher education scholarship, research and practice. The majority of services in place for this student group seek only to provide immediate solutions to issues of access or Americans with Disabilities Act (ADA) compliance. These services do not provide disabled students any social outlets or opportunities to embrace their identities as individuals with disabilities. The lack of representation in higher education research, and the limited scope of disability-related services available on most campuses, sends a clear message to disabled students that their experiences are not valued and further marginalizes this student group.

¹ To be consistent with the values of disability studies and a sociopolitical framework for understanding disability, this paper will alternate between using traditional and “person-first” language when referring to with disabilities. Traditional language would be the use of the word “disabled” as an adjective or qualifier—for example, referring to a student as a disabled student. This language is questioned in highly politically correct climates because it implies that the disability is that student’s most important quality.

To combat the idea that it would be offensive to refer to a student as disabled, the idea of person-first language was born. Person-first language puts the person first and their specific qualifier second—for example, student with a disability. Person-first language is used outside the disability context to describe other minority or underrepresented groups—for example, student of color vs. Latina student. If disability is socially constructed and the environment bears responsibility for the experience of disabled people, then person-first language implies that the disability is an individual’s own issue. Therefore, disability studies scholars and activists do not favor person-first language and tend to use traditional language to help normalize disability.

Disability Studies is a relatively new academic and political movement that looks critically at current systems and gives voice to disabled individuals. Disability studies scholars seek to advocate for disabled individuals by exploring issues of access, culture, community, and identity (Swain et al, 2003). This movement is highly political and forces the non-disabled to question their conceptions of disability, and recognize that society has failed to include disabled individuals, thereby marginalizing this group and further disabling them. Disability studies puts forth that disability is a social construct. This is even apparent when examining the word “disability.” This word immediately connotes something negative, lacking, or inadequate. The Oxford English Dictionary defines “disability” as “inability, incapacity, or impotence” (http://dictionary.oed.com/cgi/entry/50064804?single=1&query_type=word&queryword=disability&first=1&max_to_show=10). Disability studies scholars posit that it is those without disabilities, the dominant group, who shape the disability identity by imposing their parameters on the disabled experience. It is not the goal of disability studies to create a new term for disability, but to change the connotations of the word to those that are less negative or at least neutral.

Higher education scholars contend that the college experience influences and shapes students’ beliefs and self concepts (Pascarella & Terenzini, 1991). Identity development is a critical component of this experience. Practitioners benefit from much research on development theory and rely on models to inform their practice. Student development research has produced models of identity development around race, gender, sexual orientation, and religion, but none for disability. Without such a model,

practitioners do not have a framework from which to understand the experiences of disabled students and many claim to feel underprepared when working with disabled students (Kraus, 2002). This basic knowledge is a necessary first step to better support this population as they develop their disability identities.

REPRESENTATION OF VOICE

Because of the personal nature of this study, representing the voice of the students interviewed is critical. Two types of quotations are used throughout the narrative of this study: short quotations are incorporated to represent the students' language, particularly when students would use disability-specific slang, and long quotations are incorporated into the text of this narrative to convey complex ideas or examples (Creswell, 1998). The students' quotations are used formally to expand upon a specific theme, finding, or implication, but more so they are included because they are powerful. This is a student perspective that is not often solicited or represented in higher education. The ten students who participated in this study represent a distinctive and important student culture. They come from varied experiences but, on campus, are members of a true community.

As an individual disabled from birth, I could not conduct this research or write this paper without acknowledging my very intimate connection to the subject matter. It is obvious that any author is represented throughout his/her study through his/her choice of research questions or research design, however, I chose to introduce each chapter of this paper with a personal reflection related to the specific content of that chapter—a poignant experience that helped to shape my own identity or perspective on disability.

There are several options by which an author can choose to incorporate his/her own voice into the narrative of a study. Popular methods include reflective footnotes, or the use of an epilogue (Creswell, 1998). However, I chose to incorporate personal memories between chapters because that is how I conceptualized this research. It is certainly not my intention to compete with the student voices represented in this study, but simply to acknowledge my Positionality and to be true to my personal journey with this research and the way I experienced my own disability identity development.

DISABILITY IN CONTEXT

To contextualize the topic of disability identity, this study will review relevant literature in the areas of identity, identity development, disability studies including theoretical and practical conceptualizations of disability, and legislation pertaining to disability. Because no disability identity model currently exists, this study will discuss existing identity development models and relate them to disability. Similarly, disability models will be analyzed and critiqued for their relevance to a sociopolitical understanding of disability.

G. H. Mead's concept of identity will be explained as the foundation upon which all psychosocial and identity development theories were built. Mead (1934) defines identity as the interplay between the self and the environment. The idea that identity is fluid and responsive to its environment is critical to understanding disability identity. To further explore this point, identity development models that address the experiences of underrepresented, or traditionally oppressed, student populations will be systematically

reviewed. Specifically, this paper examines women's, racial, and gay, lesbian bisexual transgender identity development. Additionally, transition theory is discussed as identity may be affected as a result of a significant experience, such as acquiring a disability.

This review will discuss the values and goals of Disability Studies, an interdisciplinary academic area that incorporates history, politics, and activism. The evolution of concepts of disability will be discussed to provide an historical context for disability and the birth of Disability Rights and Disability Studies beginning with the medical model that focuses explicitly on a medical condition and does not allow for disability to be internalized into an individual's identity. Similarly, the functional limitations model holds disability as a personal deficit. The minority group model begins to move away from the idea that disability is an individual's limitation and looks to address how disability is a social identity. This piece of the literature review concludes with a discussion on disability as a sociopolitical construct and introduces the social model of disability.

While this study specifically explores the experiences of disabled college students, disability is obviously not a higher education-specific phenomenon. This review will discuss issues of stigma, stereotypes, and the media as they relate to disability and identity formation. It is important to explore the historical, social, political, medical, and institutional spheres in which disability exists in order to more fully understand how those with and without disabilities have learned to define it.

When looking at the evolution of disability in societal, political, and institutional contexts, it is critical to look at the impact Americans with Disabilities Act of 1990

(ADA). The ADA defines disability as: “a physical or mental impairment that substantially limits one or more major life activities of the individual.” Additionally, the “individual must have a record of such impairment or be regarded as having such an impairment” (42 U.S.C. § 12102). The ADA affects the lives of disabled individuals on a practical level, but also has bearing on their identity formation and the way disability is understood by society.

Acknowledging the environment’s role and responsibility in the disability experience, the ADA was created to ensure equal opportunities for individuals with disabilities and protect them from discrimination in access, employment, government services and programs, transportation, telecommunications, and public accommodations, including education. The ADA is the first legal recourse for disabled Americans and provides legal grounds to hold public services accountable to the disability community.

While the ADA is a positive document that does much to validate those with disabilities, it is highly controversial amongst disability scholars and activists. Many scholars and activists believe that the ADA is disempowering to disabled individuals in that it uses antiquated models to define disability. The ADA defaults to providing “reasonable accommodation²” and does not challenge the status quo. The ADA requires individuals to come forward with their concerns and then determines an appropriate solution to access. Appropriate does not guarantee a convenient or equitable solution.

² Reasonable Accommodation requires that any accommodation made for an individual must not cause “undue hardship” for the institution. It utilizes formulas around cost, convenience and efficiency that benefit the institution over the individual.

This mentality is the antithesis of disability studies and the disability rights movement, which will be discussed more thoroughly later in this paper.

PURPOSE OF THE STUDY

The purpose of this study is to explore the disability identity development of physically disabled students and outline their developmental process. Specifically, this study will pay close attention to the social and political influences that shape students' identity development. This study will examine the role of the disability community and students' emotions such as anger and pride and purports that such outlets are critical to identity development when looking at disability through a sociopolitical lens because these outlets are necessary to effect change on a personal, community or institutional level.

Through qualitative inquiry, this study seeks to explore the interplay between the personal experiences of physically disabled college students with their social and physical environments to better understand the disability identity development process. Using a sociopolitical understanding of disability, special attention will be paid to social, institutional, and political influences on identity throughout the in-depth interviews.

The current lack of knowledge and familiarity with this population yields a lack of understanding, resources, and validation of the disability experience. By putting forth implications for practice and research, this study seeks to inform student affairs practitioners, faculty, and administrators on how to more genuinely understand and

support disabled students so that they may create more inclusive campus environments with more effective resources, programs, and services.

This study is significant because it focuses specifically on the identity development process for disabled students. No literature of which I am aware exists to explain the disability identity development process in a higher education context. While there has been considerable research conducted on the identity development of underrepresented populations, no such research has been dedicated to understanding disability identity development.

Identity development models provide information on students' development through different phases of their lives. They outline milestones, common challenges, and provide a context for how to understand students. Currently practitioners and professionals cannot benefit from research on this population. No framework exists from which to understand the experiences of disabled students; this study seeks to provide that model.

CONCEPTUAL FRAMEWORKS

Two main conceptual frameworks provide the lens for this study: (1) identity, and (2) disability as a sociopolitical phenomenon. Of particular influence is the work of G.H. Mead (1934) who introduced the concept of identity. He put forth that the identity with which one is born is shaped by the environment in which one thrives. The interplay of individual and environment is critical when looking at disability and, therefore, to this study.

The idea that the experience of disability incorporates both social and political factors is essential to this study. Conceptualizations of disability have evolved over time. Historically, disability was viewed as a negative abnormality or deficit and as an individual's problem. With the birth of the disability rights movement and the development of disability studies, disability is now considered to be a social construct. Through a social justice lens, disability is shaped by dynamics of privilege, power, and oppression and can be compared to the experiences of other subordinated social groups. Disability is no longer considered to be a personal problem, but something that is influenced greatly by the interaction of that individual with society. There is no better example of this argument than The Americans with Disabilities Act of 1990 (ADA) discussed earlier.

Several theoretical models guide this study. Specifically, identity development theories for traditionally subordinated or minority groups, transition theory, and disability models provide the theoretical context for this research.

This study reviews popular models of gender, race, and sexual orientation to provide a context for disability identity development. Models are summarized and related to the disability experience. While transition theory is not directly related to identity development, it is clear how transition would influence identity particularly for those individuals who are not born with a disability but acquire one.

Additionally, this study reviews historical and current models of disability. These models provide a timeline with which to understand disability. The older models provide an historical context around the still existing stigma associated with disability. The more

contemporary models help reframe disability and shift to the sociopolitical conceptualization of disability mentioned above.

RESEARCH QUESTIONS

This study was designed to explore disability identity development. This study will employ qualitative methodology to explore the following questions: (1) How does the interplay between individual and his/her environment shape disability identity and what social, political, and environmental factors influence disability identity formation? (2) what are the characteristics of a disability identity?

It is the goal of this study to outline a developmental process as a result of the findings. This model would then be used to inform the practice of higher education professionals.

METHODOLOGY

Qualitative inquiry was employed in this study to explore the process by which students acquire their disability identities. A phenomenological approach was used throughout data collection and analysis. Data was collected at the University of Arizona (UA), a large, public, four-year, research-extensive institution in the Southwest United States. UA has one of the leading facilities for disability resources in the nation.

The sample for this study was comprised of ten full-time undergraduate or graduate students enrolled at UA. These students were all affiliated with the Disability Resource Center (DRC). The researcher engaged these students in face-to-face, personal

interviews and discussed their experiences with disability throughout different stages of their lives. To fully understand the developmental process of students, interviews were structured in phases, with each interview section addressing a different aspect of life or identity. The interview process for each student lasted approximately two hours, for a total of approximately 20 hours of interviews.

Data was analyzed for themes that related to identity development, and social and political influences. Open coding was also used to capture themes that emerged throughout various interviews. Data collection and analysis will be further discussed in the third chapter of this paper.

LIMITATIONS OF THE STUDY

This study has four main limitations in the area of campus site, sample composition, applicability of findings outside of higher education, and data collection. The UA campus served as the site for this research. UA markets itself to disabled students with its state of the art disability facilities and adaptive athletics programs. UA serves as a premiere facility for disability resources and even recruits wheelchair athletes internationally. The campus provides a high level of access to disabled students and is a seemingly ideal backdrop for this study. However, UA's reputation may influence the types of disabled students who choose to attend.

The sample was comprised of ten UA students, all of whom were registered with the Disability Resource Center (DRC). Of these ten students, only two did not participate in athletics or hold student employment in the DRC. Also, all students stated that the

DRC influenced their decision to attend UA. This pattern may suggest that these students are disproportionately focused on the provision of services for disabled students and may explain their participation in the study.

In an effort to preventatively combat this potential outcome, interviews were highly reflective and questions spanned students' entire lifetimes; questions did not focus entirely on the present. Having students reflect on their backgrounds and overall identity development may have yielded greater insight into their journeys and not solely on their current states of development. Reflective questions may have enhanced the study by providing richer, multi-dimensional answers. This limitation may have implications for future research, as conducting this type of study on campuses that do not have such strong disability facilities and opportunities may drastically change alter the student sample and their responses.

An additional limitation of this study is that because it was conducted at a university, the findings may be difficult to generalize to the larger disabled population. Perhaps identity development would be vastly different for those who did not attend college or have access to such fine disability resources. To address this potential concern, all implications were framed in a context of higher education. This study was intended to inform higher education professionals, however, it could be expanded to include the experiences of non-students in the future with the potential to make this model more universal and easier to operationalize.

A final limitation encountered while collecting data was that interviewing each respondent multiple times proved difficult for the respondents. The desired interview

protocol was to speak with each student three times to allow for them to reflect on the content of their interviews between meetings. However, half of the students who agreed to participate in the study were not willing to meet more than once due to their hectic schedules. The majority of the students in the sample were athletes and had daily commitments to their teams either in practice, working out, or competing in games. Therefore, half of the students interviewed were interviewed only once. Regardless of the frequency of their interviews, each student dedicated approximately the same amount of time to the study, whether their interviews occurred in one sitting or in a series. Each student received follow-up e-mails to solicit any additional thoughts based on their interviews as a way to offer all respondents time to reflect.

SUMMARY

The current lack of research on disabled students is not only concerning, it is a clear representation of the lack of attention given to this student population. This study seeks to give voice to the experience of disabled students—a group often misunderstood and overlooked within higher education scholarship and practice—by exploring their experiences with disability. Identity development is a major focus in higher education research and with the current lack of information on disability identity development, practitioners and professors are not able to adequately understand disabled students. This study is critical to higher education practice because it produces a model by which professionals can better understand disability identity.

Beyond examining disability identity development, this study also discusses the societal, political, and cultural contexts in which disability identity is formed. It is

essential for higher education professionals to understand these contexts in order to understand the realities of disability and the experiences of disabled students. By learning contemporary conceptualizations of disability and challenging existing notions of disability, professionals will begin to reframe disability. Professionals must challenge the status quo or they will continue to inadvertently relegate disabled students to the margins of the campus and higher education community. This study will provide implications to inform future practice and research so that disabled students will have an equitable and successful experience in higher education.

REFLECTION TWO

I believe that the two years I spent working toward my Master's degree were pivotal in my exploration of my disability identity. Toward the end of my undergraduate experience, I started to connect my personal experiences with disability to something larger, something systemic. However, I did not have the language or the awareness to articulate my suspicion. I had never heard the term "social justice" and did not know a single other disabled person. Upon arriving to the UA, my life changed. The campus and surrounding community were accessible, I could not leave my apartment without seeing other people using wheelchairs, and disability, in general, was a part of the culture. Once I began learning identity development theories, I felt extremely validated. Although there was no model for disability, I strongly connected with the experiences outlined in several models for underrepresented populations. This validation was empowering. At this time, I became extremely passionate about social justice and diversity education and began questioning and confronting just about everything. I used this new fervor to look critically at the multitude of models and frameworks around identity development. I distinctly remember a conversation I had with my advisor in which I asked him why that final stage in development theory was necessary—that stage that assumed you were no longer angry, no longer proud, no longer vocal. Why was it necessary to move through your anger, your pride? Who wrote these theories? Was that final stage just a way to anesthetize people into shutting up or acquiescing? My advisor responded with one of his classic retorts:

"What do you think?"

CHAPTER TWO

REVIEW OF RELEVANT LITERATURE

Introduction

Literature pertaining to students with physical disabilities in higher education is scarce. Literature that discusses the concept of disability identity is virtually nonexistent. In this chapter, I seek to review significant works in the areas of identity, identity development, disability-related legislation, and Disability Studies in an effort to provide a comprehensive understanding of disability. The chapter begins by discussing concepts of identity and models of identity development for subordinated social groups. These essentialist models stress the movement of an individual toward a defined end. They systematically advantage certain types of action, reflection, and achievement, while marginalizing others that do not conform to their ideal. These models are then discussed and critiqued in terms of the multidimensional and dynamic phenomenon of disability identity. Subsequently, I discuss legislation surrounding the Americans with Disabilities Act (ADA), and conclude with a discussion of historical and current models used to understand disability and the interdisciplinary academic area of Disability Studies. Although my research is grounded in a context of higher education, disability is not a higher education-specific phenomenon; many historical, social and political spheres shape the disability experience. Thus, I survey a representation of literature to contextualize the findings and implications put forth later in this paper by summarizing relevant themes from the literature, inside and outside of higher education.

Theoretical Context of Identity Development

Identity

It is impossible to define identity without acknowledging the relationship between the self and the environment. Identity is dynamic and is created by the culture and society in which it exists. George Herbert Mead (1934) pioneered the idea that individuals are a product of their society and crystallized the notion that not only is the self a product, but it is also a social process (p.277). Mead defined self in two dimensions: “me,” and “I.” Mead’s “me” is considered bounded and structured, the identity with which one is born. Mead’s “I” is fluid, and ever-responding to a changing environment (p.173). Therefore, identity is understood within a specific culture, and as that culture changes, so does identity. Mead’s constructivist theory asserts that identity is constantly being negotiated through the interplay of individual and environment. His philosophy gave birth to numerous models to understand identity development, many of which higher education scholars have embraced to inform their work with students. However, many popular essentialist models try to force identity development into fixed stages and therefore contradict Mead’s foundational ideas on identity.

Mead’s concept of identity is particularly relevant to current ideas around disability. Disability activists and scholars believe that disability is “an interactive person-environment social creation” (Fougeyrollas, P. & Beauregard, L., 2001, p. 171). In line with Mead’s ideas, this definition of disability acknowledges the personal situation or characteristics of the individual, while recognizing the role of the environment. The product of this dynamic relationship is identity. Therefore, the

interplay of person and environment is what creates disability. A disabling environment disadvantages those with disabilities, where an equitable and accessible environment would not. The environment has a critical role in shaping disability identity.

Psychosocial identity development

Erik Erikson is considered the father of social psychology. He first studied identity development from adolescence through adulthood (Erikson, E., 1959, 1963, 1968, 1980). Built upon the prior work of Sigmund Freud and Jean Piaget, Erikson sought to understand how one develops his/her sense of self, and the role the environment plays in that development. He defined identity as through congruence—an ability to experience one's self with continuity and sameness across situations. Further, he asserted that in order to know one's self, one has to discover what s/he is not (Howard-Hamilton, M.F., Copper, D.L. & Torres, V., 2003).

Erikson's model of identity development described eight sequential stages through which one develops his/her identity. These stages took place over the person's lifespan and each is distinguished by a psychological crisis that must be resolved by reconciling one's internal self with the environment (Erikson, E., 1959, Evans, N.J., Forney, D.S., Guido-DiBrito, F., 1998). The first four stages form basic identity during childhood. The fifth stage is the bridge between childhood and adolescence and sees an increase of external, societal influences on identity development. The remaining three stages deal with interpersonal relationships, community and affirming one's existence into old age.

While Erikson recognizes the fluidity of identity, his model is extremely rigid. His is an essentialist model that assumes one path for identity development. One can travel down his path of development in only one direction. Erikson looked at identity through the most general of lenses. He takes into account the environment's influence on identity development, but does not focus as much on the role individual difference plays in the interaction between person and environment nor does he acknowledge that the environment treats different people differently.

Identity development for subordinated identities

Erikson and his predecessors focused overwhelmingly on the dominant population (i.e., Caucasian, heterosexual, males). Acknowledging that existing scholarship on identity did not account for minorities, several theorists began to study how individuals developed a sense of identity around gender, race, and sexual orientation. The histories of these identity groups suggest that they have been oppressed by a dominant majority. This power dynamic shapes how underrepresented groups make meaning of and establish their identities. It also justifies the need for specific models to understand minority groups.

Lynn Weber (1998) identified social constructionism as a lens through which to understand the identities of subordinated social groups such as gender, race, and sexual orientation. Acknowledging the social construction of identity challenges the essentialist theories that have historically informed identity development. Disability has not been included in research on identity development, nor has it traditionally been considered a

social group like others (Gordon, B.O., & Rosenblum, K.E., 2001). The following models begin to acknowledge the role the environment has in shaping the identity development of oppressed groups. The racial and Gay/Lesbian/Bisexual (GLB) models specifically discuss connection to community and others with shared attributes, an important dynamic present also in the disability community. Identification of oneself with others who share common attributes is important for self-definition and can influence behavior, expression, and development (Deaux, K., & Ethier, K, A., 1994, Deaux, K., 1995).

Because of the basic connection shared by minority groups, these models can be used as a springboard to generally inform the study of disability identity. In the following section, representative models that examine identity development for subordinated social groups will be discussed and related to the disability experience.

Women's Identity Development

Ruthellen Josselson (1971) conducted research on women's identity development, and hers serves as a leading model to understand identity development in women. Josselson's theory provides a context to understand the female experience by separating it from that of their male counterparts.

Josselson identified four identity groups to explain how women form their identities (Josselson, 1987). Foreclosures: Purveyors of Heritage are women who graduate from college with a commitment to their identities, but have never dealt with an identity crisis. Their actions are largely influenced by parental beliefs and expectations,

and they do not challenge societal or family norms. These women seek security in relationships, over work, and rely heavily on support from family. Identity

Achievements: Pavers of the Way are women who make a clear break from their childhoods and families and create a distinct and separate identity for themselves. The women deal with feelings of guilt that result from severing their familial bonds, but move through this guilt to create a healthy identity. They are able to balance relationships, work, and outside interests. They tend to express their identity through their occupation.

Moratoriums: Daughters of the Crisis describe women who internalize the perspectives of their families and cannot rationalize any additional ways of being. These women are intensely close to their mothers and have difficulty developing a strong sense of self.

Identity Diffusions: Lost and Sometimes Found is Josselson's fourth group of women. They do not weather crisis and cannot commit to their identities. They are intensely dependent on others for direction and have the most trouble developing their identities and in forming relationships with others.

Josselson's model is important because it pioneered the exploration of identity development for women. However, similar to Erikson's definition, Josselson defines women by what they are not, versus what they are. She utilizes disempowering language in her presentation of a rather limiting number of profiles with which all women must identify. Josselson does not acknowledge the role of the environment on identity development for women. Women do not experience their environment in the same that their male counterparts do, hence the initial rationale for her research, but this notion is not apparent in her theory. The environment shapes identity formation, and has an even

more critical role in doing so when individuals are oppressed in society. Gender is socially constructed, yet the environment is not expressly discussed in her research. Josselson's theory does not challenge the power structure around gender or acknowledge how this structure affects women's societal roles; it does not empower women or challenge the status quo. It simply describes themes across female personalities, themes that have emerged as a result of women being denied societal worth.

Disability, like gender, is socially constructed. Disability is also a subordinated identity. While Josselson's research is not as closely related to disability identity formation as the following models, her work is relevant in its ability to bring attention to a previously ignored group. Josselson did pioneer research around identity development for women and her research can serve as a framework to understand the identity development of other subordinated social groups.

Racial Identity Development

Several theorists have looked at the construction of a racial identity. Examining identity development through a lens of whiteness does not validate the experiences of people of color. Among the most frequently cited racial development theories is William E. Cross' Model of Psychological Nigrescence (1971). Cross defines Nigrescence as a re-socializing, a process of moving from non-Afrocentrism to Afrocentrism to multiculturalism. Cross puts forth that this transformation takes place over a lifetime, and is cyclical, rather than linear, like many identity development models (Cross, 1971).

The Model of Psychological Nigrescence is a five stage sequential process. Stage one, Preencounter, describes a time when individuals are either race-neutral, or so influenced by the omnipresent Eurocentric perspective, they adopt a “pro-white, anti-black” mentality (Cross, 2001, p. 175). In stage two, Encounter, these individuals have an experience, or feel the cumulative effect of several smaller incidents, that shatter their existing sense of identity. This encounter may be positive or negative. If positive, the individuals will actively engage in learning about their black identity. If negative, they will remain in Preencounter and not move forward in their black identity development. The third stage, Immersion-Emersion, has two parts. In Immersion, individuals will fully submerge themselves in black culture. Immersion is marked with much fervor and emotion. In Emersion, individuals become less dualistic, and begin to look critical at their black identities. Individuals in stage four, Internalization, let go of much anger and begin to resolve their former (neutral or anti-black) identity with their new black perspective. They develop more security around their identities and race becomes a more central part of their lives.

Cross’ original 1971 model, identity development ends with Stage Four: Internalization. He revisited his model in 1995 and added a fifth stage: Internalization-Commitment. In the fifth and final stage, Internalization-Commitment, individuals connect to the larger black community and may begin to confront political or social issues that affect the larger black population. Cross adjusted his model because it was criticized for assuming that the individual abandon all emotions and perspectives

developed along his/her identity transformation, thereby insinuating that this path would culminate with inaction.

While Cross' Model of Psychological Nigrescence was modified to correct for what was a rather anticlimactic identity transformation from a radical or political perspective, it still remains stifling. It maintains that Stage Five is a final stage of development and that identity development is predictable and linear. The very idea of numbered, sequential stages insinuates that identity development is rigid trajectory. Models like this essentialize identity development. Their rigid definitions of identity and how identity is acquired, do not allow for individual variations within groups. Essentialist models place value not only on a certain end result, but the path by which one arrives there. Cross' model does not discuss the interplay of individual and environment. Like Josselson, the original rationale for Cross' work was to explore the identity and identity formation of a subordinated social and political group, however the environment in which this groups exists is not an integral part of his model.

Cross' model, however, does articulate a direction of identity formation that is relatable to the disability. Cross puts forth a framework that is helpful when looking at disability identity formation because it lends credence to the reality that people of color experience the world differently than their white counterparts. This experience makes for a different identity development process. While this paper does reject a sequential path to disability identity development, the societal influences, personal emotions, and the role of community that Cross highlights in his model make the overall experience of Nigrescence similar to the experience of disability identity development.

Gay, Lesbian, and Bisexual Identity Development

The burgeoning field of gay studies has produced much scholarship to understand the experience of queer individuals in society. The GLB experience is one that is often ignored or oppressed in society, much like the experience of disability. Additionally, one may not recognize his/her GLB identity immediately from birth. This is similar to those who are born with disabilities but do not understand the impact of disability or internalize it until later in life. Many higher education scholars have studied the coming-out process and examined the campus climate for gay/lesbian/bisexual (GLB) students and its impact on coming-out (Rhoads, R., 1995, Dilley, P., 2005, Tinto, V., 2000, Waldo, C.R. 1998, Rankin, S., 2004, 2005). The leading theory on GLB identity development is that of Vivienne Cass. She incorporates both psychological and social aspects to explain the development of a GLB identity (Cass, 1984, p.143). Like, Cross, Cass utilizes a sequential, stage model to explain the journey toward a GLB identity.

In stage one, Identity Confusion, an individual first confronts homosexual thoughts and feelings. These initial thoughts cause confusion and anxiety. If individuals react positively to these new feelings, they will progress on to the next stage. Negative reaction will result in stagnancy. Once individuals accept that they might be gay or lesbian, they move into stage two, Identity Comparison. In this stage, they will begin to explore the gay culture and educate themselves on gay issues. At this point, individuals may or may not be “out” and are still making meaning of their potential gay or lesbian identity. In the third stage, Identity Tolerance, individuals will seek out the support of other gay or lesbian people. Like in stage one, positive interactions will help build

confidence and move them on to the next stage, where negative experiences will hold them back. In stage four, Identity Acceptance, individuals accept that they are gay or lesbian, and place a positive connotation on their identity. At this point, they may come out to certain people or in certain groups, but may remain closeted around certain people as well. The fifth stage, Identity Pride, individuals become very passionate about gay issues and develop a strong sense of pride. This pride is also accompanied by feelings of anger or hostility directed all things heterosexual. In the sixth and final stage, Identity Synthesis, individuals perceive their sexual orientation as only one of the aspects of their identity. They begin to balance the strong feelings of pride or anger from the previous stage. Individuals in this final stage are secure in their new identities and exhibit congruence, consistent behaviors between their public and personal lives.

Cass' model culminates with Identity Synthesis, a stage in which homosexuality is viewed by the individuals as one of his/her identities and is no longer considered the most salient. This final stage insinuates that an individual is able to and should, in fact, downplay sexual orientation. The progression of this model suggests that balancing one's sexual orientation would help the individual to be happier and more successful. However, this puts societal norms ahead of the individual, and places increased value on an individual who can conform to fit into a society which is unwilling to accommodate him/her. Stage Six does not allow for activists, art, scholarship, or even incidental frustration. Cass puts forth a homosexual identity that is locked into place, always on par with or downplayed against other identities. This rigid model does not allow for an individual to respond to or influence the environment.

Cass, like Cross, articulates a progression of identity formation for GLB individuals that can be loosely applied to the process of disability identity acquisition. Those with disabilities may experience a similar range of experiences, however this paper specifically underscores the critical influence of the person-individual relationship on disability identity, a dynamic which is ignored in existing identity development models such as Cross' and Cass'.

In 1994, Anthony R. D'Augelli criticized Cass' model for using a sequential progression of stages to define identity development. D'Augelli contends that identity is socially constructed and can be shaped by societal and institutional factors. Because GLB identity is oppressed and silenced in society, D'Augelli recognizes the barriers to identity development. He challenges Cass' essentialist perspective and frames his work around the influences of environmental factors on identity development. His ideas are more in line with Mead's concept of identity and with the contemporary ideas of disability that will be discussed in detail later in this chapter.

D'Augelli's model consists of six interactive processes, rather than stages. He believes that "lesbian and gay identity processes must be described using a conceptual model that explicates the complex factors influencing the development of people in context over historical time" (D'Augelli, 1994, p. 317). A critical component of D'Augelli's model is that individuals shape their environments as well as respond to them. D'Augelli considers three sets of interrelated variable when looking at identity formation: personal subjectivities and actions, interactive intimacies, and sociohistorical connections (D'Augelli, 1994, p. 319). Personal subjectivities and actions look at the

individual's behaviors and feelings. Interactive intimacies take into account the influence of family, peers, and friends. And, sociohistorical connections examine the social, political and historical context of homosexuality. The interplay of these separate spheres forms a complete homosexual identity. This is a more holistic view of identity development, very reminiscent of Mead's original ideas on identity.

Identity development is comprised of six interactive processes, not stages. Entering Homosexual Identity is the initial recognition that one's feelings are not heterosexual. Developing a Personal GLB Identity Status involves searching for validation of one's homosexual identity through reflection and questions. Developing a GLB Social Identity consists of developing a support network of individuals who know and support one's homosexual identity. Becoming a GLB offspring involves the disclosure of one's homosexual identity to his/her parents and establishing a positive relationship after this disclosure. Developing a GLB Intimacy Status is a process of achieving a positive homosexual romantic/intimate relationship. This is more difficult than the process surrounding achieving a positive heterosexual relationship because of societal and political norms. Entering a GLB Community is the process of committing to political and social action. D'Augelli recognizes that some will never take this step, and those who do may be taking great personal or professional risk in doing so. This last process is more progressive than the culminating "stages" seen in other identity development models. This process values activism and involvement, but does not mandate this type of action for a complete identity.

D'Augelli's ideas around identity are very much in line with notions of disability identity that are presented throughout this paper. He assumes that identity is socially constructed and that individuals can shape and respond to their environments. Each of the processes articulated above consist of not only the individual's action or perspective, but also the recognition, support, or influence of others or society in general. D'Augelli's ideas around identity are aligned with those of Disability Studies scholars and activists. He presents his six processes in a linear fashion, however, which forces its resemblance to the stage-like predecessors he critiques. Its form makes this model more challenging to understand than other models because it is presented linearly, but does not espouse a linear or stage-like progression. While D'Augelli's framework is powerful and relevant to disability, it is not intuitive and may be difficult to operationalize when looking at the identity development of subordinated groups.

The identity development models previously described, while not expressly related to disability, present frameworks to understand the experiences of forming, acquiring and internalizing identity, specifically identities surrounding the subordinated social groups of gender, race and sexual orientation. Disability is, too, a subordinated social group. Currently no framework or model exists to describe the process of disability identity formation and these models can provide general insights into disability identity simply by recognizing the differences and challenges oppressed groups experience when developing a sense of self compared to their dominant counterparts.

A variable for the disability experience that is not shared by other social groups is that one is not necessarily born disabled. A distinction for disability identity formation is

that the process may begin later than it might for other subordinated groups. Transition is an important element of disability identity that is not reflected in the models described above.

Transition Theory

Nancy Schlossberg (1995) developed a model dedicated to understanding transition. Though not expressly about acquiring a disability, this model is relevant to disability identity as many individuals are not born disabled³. Schlossberg defines transition as “any event or non-event that results in changed relationships, routines, assumptions, and roles” (Evans, N., Forney, D.S., & Guido-DiBrito, F., 1998, p.111). Transition is appropriate to capture the experience of learning to live with a disability, as disability may affect how one experiences the world, physically and as related to identity. Individuals who acquire their disabilities may have little awareness around disability, and what awareness they do have may be overwhelmingly shaped by negative messaging and images (Smart, J., 2001).

Individuals who acquire their disabilities as a result of injury or illness may need to relearn routine functions like driving or dressing themselves. Many may learn how to

³ For example, spinal cord injuries account for a large percentage of the disabilities represented in the United States. The 2006 US Census reports approximately 273,835,465 individuals age five and older live with a level of physical disability (http://factfinder.census.gov/servlet/DTTable?_bm=y&-state=dt&-ds_name=ACS_2006_EST_G00_&-mt_name=ACS_2006_EST_G2000_B18004&-redoLog=true&-_caller=geoselect&-geo_id=01000US&-format=&-_lang=en). Of that total, 10,000-12,000 new traumatic spinal cord injuries are reported each year. There are approximately 200,000 individuals living with a traumatic spinal cord injury in the United States (<http://www.disaboom.com/Health/spinalcordinjury/spinal-cord-injury-statistics.aspx>).

transition in a rehabilitation facility. It is likely that these individuals would have little awareness of disability prior to becoming disabled and that this lack of consciousness would shape their transition (Smart, J., 2001). Transitioning into disability is both internal and external. While individuals will need to relearn their own bodies, they may also have to deal with a change in the way they are perceived by others. Transition around disability is complex. Schlossberg's model is a relevant framework to inform this process.

To make meaning of transition, Schlossberg suggests that one must understand the type, context, and impact of the transition. Transitions can be anticipated or non-anticipated, and can also be non-events. An anticipated event may be college graduation, versus a non-anticipated event like the sudden death of a parent. Both instances mark the beginning of a transition, but were prepared for differently by the individual. A non-event is something anticipated but does not occur, like a student who does not gain admission to graduate school. This will alter their transition out of college and their entrée into the professional world. Acquiring a disability may be anticipated or not-anticipated. For example, some individuals may expect that the progression of an illness may result in a permanent disability. Or, an individual may simply suffer an accident which could cause their disability.

Schlossberg looks at the context of the transition to help understand it. She defines context as one's relationship to the transition. The person who becomes disabled is the individual this study was designed to understand. However, one must consider the impact disability makes on family members, especially parents and siblings. They also

experience transition and can influence the transition of the individual who has just become disabled. Schlossberg discusses impact as the degree by which this transition affects daily life. For those who acquire a disability, this degree may not be easily quantified. Further, the impact of disability varies per person, per specific disability. Impact is subjective and may only be described by the individual.

The framework Schlossberg puts forth to understand an individual's ability to cope with transition revolves around the "Four S's": situation, self, support, and strategies. Transition is a unique experience. Assessing personal resources in the areas of situation, self, support, and strategies may help to understand how and why individuals experience similar transitions differently. This particular notion is relevant to disability identity being fluid and dynamic. Not only do individuals internalize disability differently, they also respond to and interact differently with their environments.

Schlossberg's Transition Theory is used in counseling contexts, but may also be used to inform higher education professionals on how to support students as they learn to cope with a new identity, or with a myriad of other events that affect their lives. This theory is particularly relevant for individuals who have acquired a disability. Because one is not necessarily born disabled, it is critical to understand the context by which one may transition into becoming disabled and also take into account the place one is at during his/her transition.

Multiple identities

Thus far, this paper has discussed identity development models that look at dimensions of identity in isolation. To more effectively understand the complexities and vastness of identity, scholars have begun to acknowledge the concept of multiple identities (Reynolds, A.L., & Pope, R.L., 1991, Jones, S.R., & McEwan, M.K., 2000, Chavez, A.F., Guido-DiBrito, F., & Mallory, S, 2003). It is critical to look holistically at identity and acknowledge how individual identities intersect.

Susan R. Jones and Marylu K. McEwan (2000) acknowledge that individuals are comprised of multiple identities (race, gender, sexual orientation, religion, etc.) and further that these identities are constantly interacting and changing as one moves through the world. They argue that the interplay of the individual with his/her environment necessitates an ever-changing identity (Jones, S.R., & McEwan, M.K., 2000, p. 405). This work further underscores the aforementioned idea that identity is socially constructed.

Jones and McEwan developed a conceptual model for multiple dimensions of identity to explain that identities could not be understood in isolation. Through their study, they found that participants identified with all of their identities, but the importance of each identity changed across various situations or contexts. At the center of the multiple dimensions of identity is a core sense of self. Each identity is related to the individual's core and they assert that each identity moves closer or further from one's core depending on a specific situation. This idea is also connected to that of transition. As one transition into a new phase of life, in this case with a disability, the individuals

might hold disability closer or further from his/her core depending on immediate circumstances. This study was later modified by Elisa S. Abes, Jones, and McEwen (2004) to incorporate meaning-making into the model. They use meaning-making as a filter by which to more effectively understand the contexts that influence identity.

The Americans with Disabilities Act

As discussed in the previous section, disabled Americans are an oppressed social group. Not only does this power dynamic shape their personal and group identity, but it precludes their equitable participation in and access to societal resources. This section seeks to provide a legal and political context around disability by discussing the Americans with Disabilities Act (ADA).

Enacted in 1990, the ADA aims to provide and ensure an environment of equal opportunities for individuals with disabilities and protect them from discrimination in access, employment, government services and programs, transportation, telecommunications, and public accommodations, including education. Disabled individuals had been subjected to discrimination with no legal recourse; the ADA was drafted to offer these individuals protection and validation.

Built upon the foundation of Section 504 of the Rehabilitation Act of 1973, the ADA (Pub. L. No. 101-336, codified at 42 U.S.C. § 12102 et seq.) was created to expand on its terms and coverage. The ADA sought to end discrimination against disabled Americans in the private sector, in addition to the public—a significant shortcoming of Section 504. The ADA provides broader protection for disabled individuals in the areas

of employment, public accommodations, state and local government services, transportation and telecommunications, since these entities and activities need not receive financial assistance from the federal government, a requirement under Section 504.

Disability is defined in the ADA as: “a physical or mental impairment that substantially limits one or more major life activities of the individual.” Additionally, the “individual must have a record of such impairment or be regarded as having such an impairment” (42 U.S.C. § 12102). This definition also prohibits discrimination based on a past disability that no longer exists. The definition of “impairment” includes contagious diseases, learning disabilities, HIV (both symptomatic or asymptomatic), drug addiction and alcoholism (36 C.F.R. § 104), given that the individual is not currently abusing drugs and/or alcohol (Section 3.3.2.5).

The ADA is divided into five sections, each with a distinct focus. Titles I, IV and V cover employment, telecommunications and miscellaneous items respectively. Title II, highly pertinent to colleges and universities, requires nondiscrimination by the state and local government. It states that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity: 42 U.S.C. § 12132). In the context of Title II, a disabled individual is considered “qualified” when “with or without reasonable modification to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aides and services, [the individual] meets the essential eligibility requirements for the receipt of services or his participation in programs or

activities provided by a public entity” (42 U.S.C. § 12131). Title II is of particular relevance to institutions of higher education as they are mandated to comply with the ADA and make their services equally available to all students.

As stated above, the accommodations made to serve individuals with disabilities, as per the ADA, must be “reasonable” and must not cause “undue hardship” for the institution. The ADA specifies that a reasonable accommodation may include “making existing facilities used by employees readily accessible to and usable by individuals with disabilities; and job restructuring, part-time or modified work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment or modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities” (42 U.S.C. § 12111). A reasonable accommodation may not be the best accommodation for the individual, or grant their exact request. The ADA must provide equal access, but does not guarantee an equitable experience, based on this definition.

Undue hardship is deemed by the ADA as an action requiring significant difficulty or expense, when considering four factors: “(i) the nature and cost of the accommodation needed under this chapter; (ii) the overall financial resources of the facility or facilities involved in the provision of the reasonable accommodation; the number of persons employed at such facility; the effect on expenses and resources, or the impact otherwise of such accommodation upon the operation of the facility; (iii) the overall financial resources of the covered entity; the overall size of the business of a covered entity with respect to the number of its employees; the number, type, and

location of its facilities; and (iv) the type of operation or operations of the covered entity, including the composition, structure, and functions of the workforce of such entity; the geographic separateness, administrative, or fiscal relationship of the facility or facilities in question to the covered entity” (42 U.S.C. § 12111). While the terms “reasonable accommodation” and “undue hardship” are necessary to define, they are stipulations that will often prevent disabled individuals from receiving equitable accommodations. There is a difference between accessible and equitable for which the ADA does not necessarily allow. While these specifications may allow institutions to make changes more quickly and easily, they are what could be considered loopholes in the act and arguably the greatest weakness of the ADA.

For all that it does do, the ADA does not promote disability rights as a sociopolitical movement. In fact, it does much to minimize the disability experience by consistently relegating access to reasonable accommodation rather than working to create an environment that is equitable. Specifically, the ADA’s disempowering process and language promotes disempowering, antiquated ideas about disability and disabled individuals. Because the ADA is so often a reference point for disability issues and accommodation, its language has infiltrated the media and public institutions, including institutions of higher education, to perpetuate stigma and marginalization around disability (Haller, B., Dorries, B. & Rahn, J., 2006).

While the ADA offers protection and recourse for disabled Americans, it should be understood that it does not guarantee equitable accommodations or access and it does not challenge the status quo surround disability. Per the ADA, institutions need only

offer reasonable accommodation. Additionally, the ADA forces disabled individuals to consistently prove their disability and justify their specific needs. The reactive accommodations that comply with the ADA do not effect larger change, but merely provide immediate, short-term fixes. For these reasons, the ADA is hotly contested amongst Disability Studies scholars and disability activists.

Disability Studies

Disability Studies is a burgeoning, interdisciplinary field of scholars, researchers, activists and advocates that seeks to explain the multidimensional experience of disability⁴. It aims to “reframe the study of disability by focusing on it as a social phenomenon, social construct, metaphor and culture...[shifting] the focus away from a prevention/treatment/remediation paradigm to a social/cultural/political paradigm” (Swain, J., French, S. & Cameron, C., 2003, p. 33). Before the advent of disability studies, the voices of disabled individuals were rarely heard. The common perception of disability has been that of a biological or psychology inadequacy, or that of a tragedy, rather than a social phenomenon. “Disability scholars, researchers, and advocates recognize the importance of disability identity to personal empowerment, disability activism, and participation in [the] emerging disability culture” (Hernandez, B, 2005, p. 119). They seek to dismantle stifling perceptions of disability by moving toward a social

⁴ Currently, there are approximately 30 Disability Studies programs across the US, Canada, and the UK. Colleges and universities may offer disability-related courses, but it is rare to have a dedicated major or minor.

constructionist perspective and acknowledging the role of the environment (physical, historical, media, etc.) in shaping the disability experience and disability identity.

Disability scholars seek to draw comparisons between disability and race, gender, and sexual orientation in order to elicit a political and academic movement similar to that of other minority groups (Vernon, A., 1998, Davis, L., 2001). It was the civil rights movement that inspired the Disabled People's Movement of the late 1980's early 1990's that led to the eventual enactment of the ADA (Swain, J., French, S. & Cameron, C, 2005). Connections across minority groups are drawn over the experience of oppression. Disability scholar and activist James Charlton discusses the "passive acquiescence" to oppression in society (2000, p. 31). He defines oppression as a

phenomenon of power in which relations between people and between groups are experiences in terms of domination and subordination, superiority and inferiority....The primary method through which power relations are reproduced is not physical—military force or state coercion—but metaphysical—people's consent to the existing power structure. This is certainly the case for the hundred of millions of people with disabilities throughout the world (2000, p. 30-31).

Civil rights movements have achieved major legal and political accomplishments, and have also introduced the academic fields of Women's Studies, Africana Studies, and Queer Studies. Disability studies calls for a paradigm shift that is discussed in this section.

Disability scholars look outside strictly academic settings to understand disability. In order to understand disability, it is critical to look to the media. The media is a

powerful institution that does much to propagate ideas around disability (Ross, K., 1997). This is not specific, of course, to disability, as the media represent all aspects of life. Metaphors that allude to disability are omnipresent in society, and are rarely challenged in the media (Linton, S., 1998).

Of particular concern is how the media teach diversity (Cortes, 2000). The media replicate images of disability that become prevalent stereotypes and myths. Words and phrases such as “lame”, “lame duck”, “turn a blind eye”, “fall on deaf ears”, to list only a few, are used regularly and without pause in the media. Disability is most commonly represented in the news as a tragedy or a human interest piece, rarely as an integrated piece of news. Disabled individuals are consistently represented as heroes who inspire others with their strength, pitiful and in need of charity, or as villains (Barnes, C. & Mercer, G., 2001, Cortes, 2000, Smart, J, 2001). It is rare that a disabled character is a regular cast member on a television series, or that disability is not the only salient piece of that character’s identity. Telethons are particularly contentious amongst disability scholars and activists, as they reinforce the relationship between disability and charity (Smart, J, 2001, Braddock, D.L., & Parish, S., 2001, Barnartt, S., Schriener, K, & Scotch, R., 2001). It would be impossible for the media not to influence disability identity with such pervasive images and representations.

The negative and disempowering images of disability that are represented in the media are antithetical to the goals and values of Disability Studies. Rarely do the media represent disability as socially constructed or a sociopolitical phenomenon. They

continue to propagate antiquated frameworks to teach disability to those with and without disabilities.

Disability Models

Disability scholars fight to challenge the disempowering ideas around disability that are reproduced and perpetuated through the media, institutional policy, metaphor, and educational curricula. In order to understand disability studies or the plights of scholars and activists, models of disability must be discussed. The following are practical models that have been used to understand disability. These models have influenced the way those with and without disabilities have learned the disability experience. They are presented chronologically to provide a sense of the evolution of disability in society and the course for disability studies scholars.

Medical Model

The medical model holds the biological impairment of disability as its fundamental starting point and focuses on the limitations one faces as a result of the impairment (Williams, G., 2001, Brisenden, S., 1986). Proof of disability is necessary when seeking medical insurance, Social Security, disability leave, and reasonable accommodation; these processes have been shaped by the medical model (Smith, J., 2001).

The medical model reflects larger cultural assumptions about disabled people and reinforces stereotypes about disability by focusing on an injury, impairment, or

deformation (Swain, J., French, S. & Cameron, C., 2003, p.22). “The medical model reflects a framework of thinking about disability that has been and continues to be imposed by non-disabled people upon disabled people. It reflects and reinforces dominant ideas about individuals and their roles within society; it values conformity and asserts the significance of self-reliance” (Swain, J., French, S. & Cameron, C., 2003, p.23). Individuals who identify with the medical model isolate their disability to a specific body part, and do not internalize disability as part of their identity. Disabled individuals who conceptualize disability with the medical model search for a “cure” or accommodation to fix their specific impairment, and search for a way to be normalized into society. Those without disabilities who espouse this philosophy on disability will reject the idea of disability as a culture or community, and will not support the idea that disability is a sociopolitical construct. Instead, they will expect those with disabilities to assimilate to a disabling society.

Functional Limitations Framework

The functional limitations model holds disability central to an individual’s identity, asserts that there is something inherently “wrong” with a disabled individual and seeks to normalize or “fix” the student through services and accommodations (Jones, S.R., 1996, Smart, J, 2001). No burden of responsibility is placed on the environment. This philosophy is evident throughout the ADA and therefore is extremely apparent when seeking disability-related accommodations.

The functional limitations model assume those with disabilities are operating at a deficit and does not validate the disability experience. When thinking about disability from a service perspective, specifically within institutions of higher education, it is the functional limitations model that seems to guide practice. The functional limitations model does not force the environment to change, does not require expensive renovations or, and does not urge a paradigm shift, does not even demand equity, it justifies short-term, cursory fixes for individual students to better prepare them for their disabling environments.

“This framework offers explanations for individual powerlessness and strategies for dealing with limitations. Viewing disability from this framework seems to justify the status quo, keeping students with disabilities in positions of weakness” (Jones, S.R., 1996, p. 349). This paradigm utilizes an oppressive lens and fully contradicts the holistic approach student services professionals embrace to foster student development. By utilizing the functional limitations model, student services professionals serve students with disabilities simply by reacting to their differences. No large-scale change is effected and the status quo remains: disability is a problem within the individual and it is the responsibility of that individual to seek out adequate accommodations. For these reasons, the functional limitations model is rejected by disability scholars and activists, as it is antithetical to their movement.

Minority Group Model

The minority group model asserts that the experience of those with disabilities can be explained by their affiliation to a larger minority group. The model seeks to group individuals with disabilities together and assumes a shared experience akin to those of other minority groups who experience marginalization and oppression (Jones, S.R, 1996).

The minority group model has implications for political organization as well as identity. The notion of connecting oneself to a group identity is part of developing a self-concept. Hence, the minority group model proves difficult to operationalize due to the diversity of disabilities. Disabilities vary so drastically that it may be impossible to understand all disabled individuals as members of one group. However, by looking at disabled individuals as a group, the minority group model does provide a collective voice for those with disabilities, making it easier to be heard on an institutional and political level.

Social Model

The most progressive and current model available to understand disability is the social model. The social model calls for a paradigm shift, a shift from disability being viewed as an individual's impairment to considering disability a socially constructed experience. Disability scholars and activists work fervently toward this goal. The social model is described by authors John Swain, Sally French and Colin Cameron:

The dominant view of disability is individual or essentialist, that is as something wrong with the individual. A disabled person is thought of as someone who

cannot see, cannot hear, cannot walk, has Down syndrome, has a mental illness and so on. The words 'cannot' and 'has' are crucial. What is at fault is the individuals and what needs changing is the individual. There has, however, been what is sometimes referred to as a 'paradigm shift', at least for some disabled people. This is a shift in thinking of disability as a condition of the individual, to understand disability as a condition of a society in which people with impairments are discriminated against, segregated and denied full participative citizenship. It is a shift in 'disabled' being seen as a personal tragedy, to 'disabled' being a positive identity. And it is a shift from dependency and passivity, to the rights of disabled people to control decision-making processes that shape their lives (2003, p. 1).

The social model of disability assumes that society is systemically and systematically disempowering, marginalizing, and discriminating against those with disabilities. This dynamic advantages and values those without disabilities above those with disabilities by maintaining traditional patterns of power and privilege (Barton, L., 1998). The social model asserts that disability is socially constructed and calls for a reassessment of the role of a disabling society plays in constructing disability. Considering disability as a social and political construct elicits a challenge to society to take responsibility for the disabled experience.

Disability is socially constructed by environmental barriers. "To understand disability as socially constructed is to celebrate the uniqueness of individual differences

while directing attention toward social change and transformation of oppressive structures” (Jones, S.R, 1996). The definition of disability must be expanded to include both the experiences of individuals with disabilities and those without (Jones, S.R, 1996, p.352). For too long the burden of responsibility has been placed on the oppressed individual to fight for change and gain access to services and opportunities, when it could be argued that the environment within which that individual operates is inherently disabling. The environment “bears as much responsibility for adjusting to disabled individuals as those individuals bear in adjusting to the environment” (Aune, 2000, p. 66).

To address the environmental barriers that shape the disability experience, disability activists promote the concept of universal design. Ron Mace, the founder and director of the Center for Universal Design, defines universal design as “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (http://www.design.ncsu.edu/cud/about_ud/about_ud.htm). This concept was not born out of the disability rights movement, but out of architecture. However, it can be applied not only to structural design, but to instructional design and philosophical values around access. Designers and architects are beginning to recognize their responsibility to “proactively consider human diversity in the design of public spaces so that resulting environments and products are usable by the intended audience: the diverse public” (Scott, S.S., McGuire, J.M. & Shaw, S.F., 2003, p. 371). To understand the scope of universal design, consider wheelchair access.

If no one could walk, the community would be completely accessible for wheelchairs. Even more importantly, there would be no stigma, prejudice, or stereotypes about people who could not walk, the community would adjust to the inability to walk, with both universal accessibility and the corresponding absence of prejudice and discrimination (Smart, J., 2001, p. 7).

Specifically considering the impact of the environment supports the social model of disability. Environments are not only physical. Attitudinal barriers are equally as devastating for disabled individuals. Universal design should be considered by instructors, service providers, and disability advocates to create and foster equitable and safe communities for all.

Understanding models of disability is critically important to understand how one internalizes and acquires a disability identity. The social model, specifically, should be adopted by higher education professionals to create campus communities that share in the disability experience. Utilizing methods of universal design in physical structures and in instruction would result in the most welcoming and accessible campus to all members of the community.

Conclusion

Disability is vast, and is not isolated only to higher education. Hence, the challenge of this chapter. While literature on disability in higher education is scarce, literature directly pertaining to disability identity is practically absent from the scholarship. In order to provide a context from which to understand disability identity,

and the findings and implications later presented in this paper, this chapter reviewed literature around identity, identity development, disability legislation and disability studies. Specific attention was paid to major works in the field of identity and identity development, the ADA, disability studies and the practical models available to understand disability. While this chapter could not provide an all-encompassing review of disability literature, it served to provide a foundation to inform disability identity in a context of higher education.

REFLECTION THREE

Gimp. Crip. Biffer. This is the disability slang I learned from my interviews. It is common for friends to joke around and refer to one another with these names. As students would share this language with me, I had a visceral reaction and became extremely uncomfortable. I have always hated the word “crippled”; it is a word that is impossible for me to utter. The students who used this language seemed to be amused by it. They owned those words—the words that had been used historically to oppress and marginalize disabled individuals. They had reclaimed these words and appropriated them into the culture about which I was learning, which I finally believed existed. They said that while they could use this language, non-disabled people could not. This language created a boundary that they themselves were able to draw.

Perhaps I cringe at this language because it is too painful to hear. These have been labels I have never wanted to accept. Perhaps these words are now a reminder of the culture of which I may or may not be a part. It has been suggested to me that perhaps these words made me uncomfortable because I work in student affairs, an admittedly overly politically-correct, hypersensitive profession that abhors offensive language.

Perhaps my profession, built on a foundation of honoring the whole student, is precluding me from authentically connecting with students. Perhaps it is my professional identity that is preventing me from embracing my personal identity.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

Introduction

In order to understand the process by which students develop disability identities, I crafted a phenomenological study. When reviewing various methods of qualitative inquiry, a phenomenological approach seemed most appropriate to capture and analyze data related to the experience of disability as this particular methodology focuses on “investigating participants, viewing them as people who interpret the world and their experiences and who construct personal understandings of them” (Hopwood, 2004).

Existing identity development models and the notion that, similar to the experiences of other historically unrepresented groups, social and political influences shape the experience of disability were the ideas that framed my data collection and analysis. “Phenomenology serves as the rationale of perception in order to see life as these individuals see it” (Bruyn, 1966). Hence, I sought to engage disabled students in dialogue about their experiences with disability to inform the disability identity development process. Because disability is vast, and varies for each person, my interviews were in-depth and personal to capture each person’s voice and perspective. This chapter will outline in detail the design of my research, justification for its methods, and my Positionality.

Statement of Positionality

I want to open this section by explaining the dynamics of my Positionality in relation to the subjects and subject matter examined throughout my study.

“Phenomenological analysis requires the researcher to state his or her assumptions regarding the phenomenon under investigation and then bracket or suspend these preconceptions in order to fully understand the experience of the subject and not impose an a priori hypothesis on the experience” (Bruyn, 1966). I identify myself as a physically disabled student and student affairs practitioner whose personal experiences drove the initial interest in this study, making my statement of objectivity extremely challenging, if not at least naive. Qualitative research is inherently saturated with subjective, personal content. While this subjectivity yields rich, multi-dimensional data, it is the very reason qualitative methodology is consistently scrutinized by researchers and scientists who discredit such data for being impossible to analyze.

My lens

I have a unique perspective on the disabled student population—the subject of my research—because I have been a disabled student since I entered preschool at three years old. Hence, the personal desire to articulate this phenomenon in a formal, academic context. In addition to identifying as a disabled student, I work as a student affairs practitioner at UA, the site of my research. It has been my personal experience with disability that has driven this research. Personally and professionally, I have a

multidimensional perspective on disability that has shaped my data collection and analysis.

It still shocks me that I am completing a dissertation on a disability-related topic, as for most of my life I chose to distance myself entirely from disability or the disability community because of the negative connotations I had internalized about disability. When I was an infant, doctors instructed my family never to treat me like I had a disability. They cautioned my mother to never “take advantage” of disability services or “special” accommodations. These ideas shaped my personal perspective on disability. I rejected anything “special” and never wanted to be defined as disabled. It has always been important to me to challenge those traditional ideas about disability and voice the true scope of the disability experience. So I now put forth a model that aims to do just that.

If one were to ask me how often I think about my disability, the same question I posed to the students who participated in my study, I would have to respond by saying that I think of it all of the time and none of the time. I am aware of my disability. I understand it. I have internalized it. However, I cannot isolate my disability from my identity. I cannot quantify it. This is my lens and has always been my lens. I find that I think about disability when I am reminded of it—when I confront an inaccessible building, when someone stares at me, when I cannot find a parking spot, but I am not preoccupied with disability all of the time. For this reason, I wanted to explore the dynamics of disability identity.

While I had endured 17 surgeries by my senior year of high school and had used a wheelchair since the age of 12, this was my life and I never considered that having a disability was that challenging—it is my reality and all I have ever known. I find that others, without disabilities, are incredulous about my perspective. My disability is not the most salient thing about me, but I feel that not only do others assume it would be, but to them, it is... at least initially. This dynamic was the initial reason that I wanted to give voice to the rich and vast experience that is disability—to try to make the perspectives of disabled and non-disabled individuals more congruent.

It was not until I started college that I began to understand that while I had a disability, society and the environment has a responsibility to improve conditions for me. I began to assess my campus and surrounding community and see all the inequities. I grew tired of needing to over-explain and communicate my needs preemptively. It was at this point that I created a disability sensitivity workshop for student leaders and student affairs professional so as to help them become better advocates for disabled students.

When I began graduate school, I was “fired up”, or so I was later told. The UA campus was the first place I had ever seen other people in wheelchairs. Disability is part of the campus dialogue on diversity. As I began to feel comfortable in this new environment, I became increasingly empowered to be an activist for disability issues because I was finally in a place that would allow for such momentum. I remain heavily involved with university diversity and disability efforts and absolutely believe my experience with disability has given me the sensitivity and awareness to understand other issues of power and oppression.

Insider to disability community

Throughout my research, I did much reflecting on what it means to be an “insider” to a cultural group, and specifically to be an insider to the disability community (Edwards, 1993). As an individual with a visible, physical disability, am I automatically considered to be an insider to the disability population? Are all individuals with disabilities insiders? The insider/outsider dynamic is rather intuitive in the context of cultures: an insider is a member of the specified cultural group, where an outsider is not (Merriam et al, 2001). But what does it mean to be a member? Initially, I fabricated an insider checklist in my mind. If I could answer yes to the following questions, I would be an insider: Do you have a disability? Do you have disabled friends? Do you do disability-related work? Yes, no, yes. To be true to the conceptual frameworks that have guided my research and to my own personal understanding of disability and diversity, I argue that there is no checklist, no formula. I am an insider if I want to be an insider. Because identity is dynamic, my levels of comfort or involvement may change, but that should not make me more or less disabled.

However, the important element of perception must also be considered. An individual’s perception on his/her status may differ from that of other group members. In this case, I was technically an insider, but because of my lack of social connections to the community, would the students believe that I was an insider? There was the potential that my perspective on my own insider-status, would not match those of students who participated in my study.

I entered into this study assuming, simply because of my wheelchair, that I would be considered an insider. Largely this held true. However, because I do not have a disabled peer group, participate in wheelchair athletics, or use disabled slang, one respondent challenged my position as an in-group member. When asked if this respondent would use disability slang around me he responded with:

No, because honestly I didn't view you as an insider really in my experience....you haven't really been involved in that whole disability kind of circle directly. That's why I asked you before if you had heard the term "biffer." My impression was that you probably hadn't. I don't know. I don't have a radar for it necessarily but....

This conversation was extremely enlightening for me. I had been disabled since birth, where this student had been disabled for only a few years. However, he was immersed in the disability community through academics, athletics, and peers, and I was only involved through professional positions. I remember initially feeling relieved that he did not consider me an insider. I reflected on this feeling of relief and instantly felt ashamed, ashamed that I was pleased that this student did not consider me a part of his culture. I arrived at a place of sadness, for I was still allowing the societal stigma of disability to shape my own perspectives. This is something I grapple with often, and will probably continue to analyze. I can say confidently that I do identify as disabled, but that, just as for many other minority groups, my experience is not the same as everyone

else in that group. I believe this conflict articulates the need for a disability identity model that allows for reflection, emotion, and fluidity.

I believe that my position as a disabled individual did prove advantageous, as it helped facilitate rapport with the interviewees throughout this study. I feel that my first-hand perspective on disability helped to put them at ease when discussing sensitive and personal issues. Throughout the interviews, many students indicated a level of familiarity with me. They would often say things like, “you know what I mean” and not feel the need to over-describe situations. Some stated that they felt more inclined to discuss their experiences with me because I was disabled. I feel that having a disability also initially helped the respondents trust the motives for my research. Once I debriefed and shared my research goals, all respondents were very supportive. I feel that my connection to the disability community helped create a safe space and yield genuine, rich results during the interview process (Edwards, 1993).

Professional dynamics

An important dynamic to discuss in this section is my position as a staff member at UA. Not only do I identify as a disabled student, but I am extremely familiar with the campus and community climate around disability. I have worked with disabled students, attended sporting events, and confronted issues of inequity in my professional scope. I feel that the combination of my personal and professional identities has provided me a comprehensive understanding of disability on the UA campus.

While I have professional experiences related to disability, professional is not personal. I do believe that there is a professional buffer that allows me to do disability work. It is easier for me to work to an end. I believe in disability work. I believe in social justice work. However, it is much easier to put on a professional cap to address disability-related policy or confront ignorance because it is simply less painful. I recognize that where I have sought out opportunities to represent disability issues on campus in the surrounding community, I have not sought out social networks in the disability community. This difference should be acknowledged as I discuss my personal and professional Positionality.

Because of my specific position in Residence Life, there was the potential for a power differential between respondents who lived on campus and myself. For residential students, it was possible that my professional position could have influenced their answers. While fear of retaliation should not have been a concern for any of the respondents, they may have been influenced in addition by my informal connection to the DRC or diversity-related professional commitments. To avoid this dynamic, I did not discuss the details of professional commitments during interviews and consistently presented myself as a doctoral student.

Social justice advocate

Born out of my experiences as a minority (disabled female), I consider myself an advocate for social justice, and even an activist. While social justice work is woven into the culture of student affairs, I feel that my identity as an advocate is separate from my

current professional role. In addition to my on-campus work with diversity and social justice, I also facilitate workshops in the Tucson community that educate around social justice and dismantling oppressive systems. I personally believe in critical theory and the significance of power and privilege in navigating societal and institutional dynamics. It should be clearly stated that the goal of my research is not to encourage all disabled students to be activists. The purpose of this study is to learn about the identity development of disabled students, not advocate for social justice or for a personal cause (Mehra, 2001).

Through journaling and conversation, I monitored the interplay of my Positionality and passion for social justice advocacy and tracked my own experience throughout this process. Just as I critiqued existing identity development models for being too rigid in their standards for development around managing emotions, I was aware that criticizing students for not being angry enough or proud enough would be antithetical to my stance on identity development.

Methodology

This study employed phenomenological qualitative methodology to explore the identity development process of disabled students. Originally developed by philosopher Edmund Husserl, the tradition of phenomenology builds on existing scientific method to include the study of consciousness (Wertz, 2005). Phenomenology is “an empirically based approach that aims to identify the qualitatively different ways in which different people experience, conceptualize, perceive, and understand various kinds

of phenomena” (Richardson, 1999). More specifically, the goal of this research was to understand the meaning of disability within the context of identity. I felt the most appropriate means do so was by crafting a phenomenological study. “A phenomenological study describes the meaning of the lived experiences for several individuals about a concept or the phenomenon” (Creswell, 1998). In line with traditional methods of phenomenological data collection, the interviews sought to engage students in dialogue around their experiences with disability to ascertain their consciousness around this piece of their identities. I followed traditional methods of coding and analyzing data employed by phenomenologists by extrapolating themes based on meaning with the goal of informing readers of the realities of the experience of disability identity. “The reader of the report should come away with the feeling that ‘I understand better what it is like for someone to experience that’” (Creswell, 1998) and that truly is the goal of this research.

Research Questions

The overarching goal of this study is to better understand disability identity and how one develops a disability identity. Because individuals do not exist in a vacuum, the study also looks to understand how one responds to his/her environment by examining societal, political and environmental influences on identity development. The study creates space for respondents to speak about their interactions in society and by doing so allows for individuals to respond to their environments. Existing identity development models do not allow for identity to be fluid or dynamic; their rigidity implies that when

an individual has completely developed his/her identity, they will no longer respond to their environments.

This study, in addition to explaining the developmental process, more broadly seeks to describe disability identity. By asking respondents to reflect on their lives, communities, peer groups, and involvement, they will shed light on the characteristics of a disability identity.

Specifically, this study seeks to answer the following research questions: (1) How does the interplay between individual and his/her environment shape disability identity and what social, political, and environmental factors influence disability identity formation? (2) what are the characteristics of a disability identity? These questions seek to frame this study so that it may capture the meaning disability holds for the students interviewed with the end goal of informing higher education professionals on the disability identity development process.

Developing the interview tool

Crafting the interview tool used in this study required that I not only analyze the theoretical frameworks that would guide the specific questions, but also draw upon my personal and professional connections to campus to analyze the disability community at UA. To challenge my own notions of disability and allow for the experiences of other disabled individuals, I consulted faculty, staff, and students on the interview questions as I developed them. I spoke informally with disabled students on campus and with DRC staff to better understand the culture and climate around disability. Additionally, I spent

time in the DRC observing students, traffic, and facilities. I have taken classes in the DRC and regularly attend meetings there, so I have a sense of the culture there and the space it provides for disabled students. I attended wheelchair basketball practices and games over the past several years to become more familiar with the athletics culture on campus, an area with which I have no personal understanding.

A major consideration in crafting my interview questions was how to allow for participation from both those born with their disabilities and those who acquired their disabilities in the study. This combined with the idea that identity is something that is developed over a lifetime and not something only to be captured in the present, encouraged me to incorporate questions that spanned participants' lifetimes, pre and post disability where appropriate.

Though the participants born with their disabilities are never able to speak from a non-disabled perspective, they are able to recall back to when they had no awareness of their disabilities. When something is a part of your life since birth, it is sometimes impossible to articulate it—I can attest to this personally and it was later reinforced in every interview with a student disabled from birth.

With that in mind, I structured questions to span the participants' lifetimes, asking them to reflect on their childhoods. This allowed all participants to recall a time when disability was a non-issue for them. This phase of the interview also served to learn basic background information about all respondents. The subsequent questions focused specifically on the respondents' disabilities and on their current opinions about disability culture, and disability in a societal context.

Piloting the study

I piloted an initial iteration of my study with four students approximately 18 months before I officially began to collect data. The pilot group of students was comprised totally of graduate students. I had access to graduate students because of my professional position as the Coordinator for Graduate and International Student Housing at UA. I asked these four students to participate specifically because they all lived in the apartment building I manage and I felt we had positive relationships. Because of their prior requests for various accommodations, I had worked with each of these students before and felt that they would add valuable insight to my study. We worked through immediate and more departmental or institutional issues such as: physical modifications to their apartments, concerns over the impact of inconsistent mail service on the delivery of their medications, and access during fire evacuation.

Because of their ages and perspectives on academics and research, these students were able to provide extremely constructive feedback around the initial interview questions. They noted that the study did not allow students to speak about the positive effects disability had on students' lives. One student who had endured spinal cord injury shared with me that disability completely changed his personality and improved his overall outlook on life because his accident provided him a sensitivity and perspective that he never would have had otherwise. All students spoke about the opportunities that they felt were afforded to them because of their disabilities, such as competing in athletics, traveling, and working on various projects or committees. They also spoke about their experiences in rehabilitation. Rehabilitation was something I did not include

in my initial interview questions because, based on my personal experience with disability, I was unaware of its scope and significance. Based on my four initial interviews, I added questions on how disability has positively enhanced students' lives and the experience of rehabilitation to my final interview questions.

Another valuable insight was around students' experiences internationally. Two students had lived abroad, one was born in Southeast Asia and one held a job that required her to travel to developing nations and assess medical supplies such as wheelchairs. These two students had a rich perspective on oppression based on the privilege dynamics they had witnessed and experiences abroad and did not believe disabled individuals were oppressed in American society. Both of these students stated that, comparatively, disabled Americans were in a much better place in terms of access, opportunity, and stigma than disabled individuals in other, less developed, nations, thus reinforcing the idea that disability is socially constructed.

Site for research

The University of Arizona

Research for this study was conducted at The University of Arizona (UA), a large, public, research-extensive university in Tucson, Arizona⁵. This university enrolls high numbers of disabled students. UA markets itself as extremely accessible to physically disabled students, as over 85% of its campus is accessible (personal communication with

⁵ Tucson is located approximately 60 miles north of the Mexico border. Located in the Sonoran desert, Tucson is dry and flat—two features of this Southwest city that make it extremely appealing to those with disabilities.

author, 2005). The Southwest generally tends to attract disabled individuals because of its flat terrain and extremely dry, temperate climate. Those with disabilities do not need to contend with rain or snow in the Southwest and that adds to its accessibility.

According to the 2000 census, the county in which UA is located reported 155,566 disabled residents of its 843,746 total residents⁶.

Disability Resource Center

The Disability Resource Center (DRC) at UA is a premiere facility and offers a wide variety of programs and services related to physical disabilities to the university community. Because this number is based on self-disclosure, a definitive figure is impossible to ascertain, however, the DRC, estimates that it serves over 1,500 students per year. The DRC considers disability to be a sociopolitical construct as evidenced in the vision statement posted on its website: The Disability Resource Center envisions a university community that values disability culture and ensures full participation (<http://drc.arizona.edu/about/visiongoals.html>). More explicit are the goals posted on the DRC website: Guided by a sociopolitical construction of disability and principles of universal design, [the DRC works to] design and deliver innovative services and

⁶ Individuals were classified as having a disability if any of the following three conditions was true: (1) They were five years old and over and reported a long-lasting sensory, physical, mental or self-care disability; (2) They were 16 years old and over and reported difficulty going outside the home because of a physical, mental, or emotional condition lasting six months or more; or (3) They were 16 to 64 years old and reported difficulty working at a job or business because of a physical, mental, or emotional condition lasting six months or more. Disability status was not tabulated for persons in institutions, people in the Armed Forces, and people under 5 years old. The percentage shown is calculated by dividing the number of persons with a disability by the number of civilian non-institutionalized persons 5 years old and over. (http://www.fedstats.gov/qf/meta/long_POP905200.htm).

programs; engage campus and external communities in the creation of inclusive environments; foster heightened disability discourse, awareness, and involvement; and, strengthen the efficiency and effectiveness of the DRC through the development of human resources and infrastructure.

This university is one of few in the nation to provide social or athletic opportunities for students with disabilities. The DRC has offered adaptive athletics since 1974. Goalball⁷, Quad Rugby, Men's and Women's Basketball, Tennis, Track and Road Racing, and Weight Training and Conditioning are the sports and athletics opportunities currently offered. The mission of the adaptive athletics programs reads: "As a Division I school of the NCAA, [UA] offers athletic opportunities to all of its students. The Disability Resource Center provides a comprehensive program of competitive athletics and recreational activities to ensure opportunities for equal access for students with disabilities. A variety of sport chairs are available for individuals to use, including some of the most current models from top manufacturers. Promotional and awareness activities place student athletes with disabilities throughout the community providing the opportunity for public speaking and personal growth. Our sport teams and events integrate both students and community members alike in some of the finest athletic and recreational facilities on any college campus today" (UA, 2003)⁸.

⁷ Goalball is a new sport for the blind and visually impaired that involves moving a ball larger and heavier than a basketball along the ground. This ball makes a sound as it moves and players seek to score goals against the other team.

⁸ During an interview, a student expressed resentment over the fact that UA will report to the public that it has wheelchair teams, but the university will not recognize the wheelchair teams as varsity teams, thereby preventing the athletes from attaining a contract with Nike and from getting their equipment and uniforms subsidized. Basketball wheelchairs are not covered by insurance and cost player several thousand dollars each (Personal communication, October 18, 2003).

The Men's and Women's Wheelchair Basketball Teams were created in 1974 and 2000 respectively. Wheelchair basketball players and other wheelchair athletes worked to put the group together and have it recognized as an official university club (Kraus, 2003). Today the teams remain small, with an approximate total of thirteen players combined, and works diligently to recruit eligible players and advertise their games and events.

UA students are automatically eligible for all adaptive athletics teams assuming they have appropriate skill and experience, and a reported disability (UA, 2003). The teams are also open to community members through the Adaptive Fitness Program, which allows individuals access to these sports and programs by paying an annual fee. In order to recruit leading wheelchair athletes, UA offers an athletic scholarship award. To be eligible for a scholarship one must have a cumulative grade point average of at least 2.0, be an active member of the student's primary sport, and actively participate in team development. In addition to the scholarship, an athletic participation award is also offered based on overall performance in and contribution to a certain sport. One athlete is chosen from each sport per year to receive this honor.

The university and local community embrace the Adaptive Athletic Program and this is evidenced by two annual traditions: "Red/Blue Scrimmage" and the "Run 'n' Roll." "Red/Blue Scrimmage" is an annual fundraiser for the adaptive athletics program in which the men's wheelchair basketball team challenges the men's varsity basketball team to a game of wheelchair basketball. Each year students fill the basketball stadium to

watch the men's varsity basketball team compete against the wheelchair team⁹. The Run 'n' Roll is a five kilometer race, open to the community and sponsored by local vendors, also to raise money for UA's adaptive athletics program. Both the UA and local community rally around these events, in a sense proving the legitimacy of wheelchair athletics, and the potential this program has to pave the way for further opportunities for wheelchair athletes and students with physical disabilities.

The DRC opened a new adaptive athletics facility in 2004 that offers cutting-edge athletics and sports equipment for students with disabilities. This facility is completely accessible and also allows disabled community members to utilize its resources.

In addition to athletic programs, the DRC offers services such as fitness training, wheelchair repair, American Sign Language (ASL) interpreters, test accommodations and adaptive technology, and Americans with Disabilities Act (ADA) consultation. The DRC employs nine Access Consultants. These professionals work with students individually to assess their campus experience in terms of accessibility. Because the Access Consultants do not operate from a deficit model, they look at the campus to see where improvements could be made to provide the optimum access for each student, and in turn all students. In the past, these positions were entitled Access Specialists. In an effort to be consistent with their mission, the DRC re-classified these positions to Access Consultants to separate their work from the idea that disabled students had "special" needs. Considering disabled students to be special or different implies that the disability

⁹ The title of the event has been discussed several times by the students and the community, as the word "lame" is largely considered inappropriate. However, the wheelchair team and students with disabilities in the community insist on keeping it, perhaps in an effort to reclaim the word "lame."

is their own problem and releases the campus from any responsibility to improve access in general, hence the switch to access consultants. (personal communication, October 23, 2007).

University commitment to disability

Another example of UA's commitment to disability on campus is the current proposal for an interdisciplinary Center on Disability that would incorporate disability research, resources and teaching, as well as formalize a Disability Studies program that would offer coursework, an undergraduate major, minor, and a Master's degree. This proposal has been developed collaboratively by the DRC, the College of Education, and the Division of Student Affairs. In North America and the United Kingdom, an estimated 30 institutions of higher education offer a Disability Studies disability-related research program <http://drc.arizona.edu/disabilitystudies/mission.html>. UA has an opportunity to build on its already strong reputation of providing excellent disability resources by establishing this innovative interdisciplinary center. Currently, UA offers several classes that focus on disability. During the 2007-2008 academic year, the University offered five courses dedicated to the disability experience¹⁰ <http://drc.arizona.edu/disabilitystudies/courses/index.html> .

¹⁰ The number of disability-related courses offered changes each semester depending on faculty preference and student interest.

In addition to the DRC and the momentum around the Center on Disability proposal, the University also has a President's Advisory Council for Disability¹¹. This group of campus and community members meets two to four times each semester to discuss disability issues that impact the campus and surrounding community. Members represent the disability community by identifying as disabled or through their professional affiliation. The charge for the council is to provide recommendations each year to the President in an effort to inform him/her on the climate for disabled individuals. The council may also respond to the President on items as requested. The council has worked to research emergency response technology for deaf individuals, have captioning at all live sporting events, and is currently working on creating a website to inform the disability community in Tucson and recruit and retain disabled students, staff, and faculty to the campus. Related to the council's work was the recommendation for increased universal design standards on campus. An example of this is the recent renovation of the State Museum located on campus. The museum now serves as a leading example of Universal Design.

Selecting a sample

Disability is a vast experience. To narrow the topic for this particular research project, the researcher chose to focus solely on physically disabled students with mobility-related disabilities with the future goal of expanding this study to include more

¹¹ UA currently has seven Presidential Advisory Councils that seek to advise the President and his cabinet on issues as they relate to diverse communities that have been in existence since 2000. These councils represent racial and ethnic groups, as well as the GLBTQ and disability communities.

disabilities. The researcher advertised this study by posting fliers in the DRC, and via e-mails to key staff members. These staff members served as gatekeepers to disabled students. They either worked directly with students at the DRC or worked in Residence Life as Hall Directors in residence halls that were ADA compliant and housed students with disabilities. These gatekeepers would approach students they felt were appropriate for the study and put them in touch with the researcher who would then invite them to participate in the study. Working through personal recommendations yielded the majority of participants for the study.

The students would need to personally identify as disabled to participate in this study. Once contact was made with each student, the researcher briefly explained the project and process to ensure that they would be willing to speak in depth about their experiences with disability. It was critical to the researcher to recruit a diverse sample, not only insofar as traditional demographics such as race, gender, and age, but particularly around whether or not the student was born with his/her disability or acquired it. Another factor to consider was the student's involvement in athletics.

Sample

The sample was comprised of ten UA students, five of whom were males, five of whom were females. All students were registered with the DRC. Two participants were graduate students and the rest were undergraduates, spanning freshman through senior class standings, ranging in age from 18 to 31 years old. One of the undergraduate students was non-traditional in that he was a 28 year old returning student. Of the ten

total participants, two identified as students of color and the rest Caucasian. Five of the participants were born with their disabilities, one acquired his disability during infancy, and the remaining four acquired their disabilities through spinal cord injury or illness. Four of the students born with their disabilities were born with spina bifida, and one with ostogenesis imperfecta¹².

All but two participants were currently involved with athletics. This particular trend will be expanded in chapter four. These eight students identify strongly as athletes and spend much time with their teammates even outside of regular athletics commitments. Many of the eight athletes were involved with athletics before college and all of these students considered UA's athletics program when choosing a college to attend.

Another interesting trend across the sample was choice of major. Seven of the ten students interviewed had chosen majors that would prepare them for a career in which they would work with disabled individuals, or in a rehabilitation or hospital setting. The disability-related disciplines represented in this study were: Family Studies and Human Development, Special Education, and Rehabilitation Counseling. These students articulated a commitment to "giving back", a desire to help children, adults, or patients deal with disability. They reflected on times when they either benefited from this type of help or times when they needed additional support. These students did not explain their future career goals as a way to combat oppression or work as activists, in fact, most

¹² Please refer to the appendix for a more detailed profile on each respondent.

students were not able to discuss oppression around disability at all in their interviews.

This finding will be discussed in chapter four.

Additionally, two students who were not in disability-related majors, chose their majors because of their experience with disability. One student chose Communications as her major so she could continue the work she has already begun as a motivational speaker around disability-issues. Another student chose to pursue a career in Public Health with a graduate degree in Epidemiology. While this student did not explicitly make a connection between his academic pursuits and his disability, he was disabled after a bout with hydroencephalitis during infancy.

One student identified as international. Born in India, he spoke much about Indian perspectives on disability. There are stark cultural differences between American and Indian perceptions on disability. Also, access and technology are far less advanced in India, particularly when he was growing up there in the 1980's. These perspectives support the notion that disability is a social construct.

And back home physical disability was still considered better than mental or psychiatric disabilities. I bring that up because I had an uncle in my family about whom nobody talked pretty much – so that was one aspect of it. The second aspect of it was growing up there were tremendous barriers – physical, mainly physical, very few social. I mean I was not admitted to a school because they thought physical disability [was] also equal to mental disability.

I mean mental not in terms of psychiatric but being difficult to get to a child with a disability so I didn't get admitted to one school. But the other school

that I went to didn't even ask for any documentation. Just like okay – you think he's good enough, it's fine with us...And the thing is back home then – things are improving now – but back home then there were no elevators...[My school] was a three floor institution. My dad carried me up and down every day for 10 years pretty much, and when I went up there I pretty much stayed in my seat. I didn't go to the bathroom for 8 hours. I had lunch there and everything. And that was pretty much because I wasn't using a wheelchair.

The concept of a wheelchair was very difficult for us. I don't know why. Let me say. Not that I don't know completely why. I know and I don't know. I know that yes physically there is no accessibility in the sense there are no ramps to go by so even if you have a wheelchair, it is difficult to go (Personal interview, March 6, 2007).

Data collection

Three-Interview Series

I engaged the ten students in my sample in one-on-one, face-to-face, semi-structured interviews in order to understand their experiences with a disability and the process by which they developed their disability identities. I selected this specific method because I felt that in-depth, open-ended interviews would yield the most comprehensive and insights into the vast and complex experience of disability. Each interview was digitally recorded and later transcribed.

My goal was to conduct three interviews with each student with each interview focused on a specific area of history or identity (Seidman, 1988). The Three-Interview

Series was popularized by Irving E. Seidman. Seidman (1998) employed three, separate, thematic interviews to gain a deeper understanding into how respondents make meaning of their experiences (p.11). According to Seidman, behavior only becomes meaningful when set in the contact of someone's life and the lives of those around them (p.11). "Interviewers who propose to explore their topic by arranging a one-shot meeting with an 'interview' whom they have never met tread on thin contextual ice" (qtd. in Seidman, 1998, p.11). This particular method of interviewing was selected to allow the researcher control over the flow of questioning, while incorporating more traditional ethnographic and/or narrative information. In actuality, I was only able to utilize the Three-Stage Method with five of my ten students due to their hectic schedules. This was addressed in the Limitations section in Chapter 1. For those students with whom I conducted only one interview, their interviews lasted as long and still focused on the three topic areas described above.

According to Seidman, the first interview in the series seeks to learn about life history. In the second interview, respondents are asked to discuss the details of the experience of relevance to the study. In the third and final stage of interviewing, respondents are asked to reflect on the meaning of their experiences. The justification for this final stage of interviewing is that participants must "look at how the factors in their lives interacted to bring them to their present situation. It also requires that they look at their present experience in detail and within the context in which it occurs" (Seidman, p.12). This particular method translates well to the qualitative exploration of disability. The first interview for this study focused on background, hometown, and schooling. The

second focused specifically on that student's disability. The third and final interview was the most reflective part and focused on student's opinions and emotions around disability.

Interviews were scheduled every one to five days to allow for reflection on and processing of the content. This afforded participants time to reflect between interviews, but not afford enough time to lose connection between the content covered in each interview (Seidman, p.15). The specific schedule of interviews depended on each student's specific schedule¹³. I hoped that spacing the interviews over one week may have also prevented respondents from losing touch with me and dropping-out of the study. After each interview, I encouraged respondents to record any additional, relevant thoughts and share them with me via e-mail or hard copy. I also asked for any verbal feedback in the second and third interviews, and in a follow-up e-mail after the final interview.

The first interview in the series focused on the student's background and life history. This served as a basic introduction to help orient the researcher to each respondent. For those students who were not born with their disabilities, this interview focused on life before disability. Questions spanned childhood, family, experiences in school and with peers, and home communities in an effort to understand the respondent's home environment and how these forces influenced their identity.

¹³ As acknowledged in the limitations section of Chapter One, not all students were able to commit to three separate interviews. Five of the students' interviews were conducted at one time. The single interviews were still conducted in the order of the Three-Interview Series, but unfortunately, these students did not have the opportunity to reflect between meetings. To compensate for this, the author contacted each student after their meeting to solicit any feedback or reflection. The researcher repeated this effort once transcriptions were completed.

In the second interview, I asked respondents to discuss the details of the experience of relevance to the study. For the purposes of this study, the second stage of interviewing discussed their personal disabilities. Questions explored the details of respondents' disabilities, and, if appropriate, how they acquired their disabilities. Further, I asked respondents to speak about how they thought about disability before they became disabled. For those born with their disabilities, they were asked to speak about any recollection of first understanding they were disabled. This stage of interviewing illuminated how and if students internalized their disabilities and the process of identifying as disabled, how they believe they are viewed in society or in their personal lives as individuals with disabilities, and any specific memories or experiences that influenced identity development.

In the third and final stage of interviewing, I asked respondents to reflect on the meaning of their experiences with disability and with the disability community. Students spoke about their current situation, peer group, involvement, career goals, values, and opinions. This phase of the interviewing was built upon the foundation created through the first two stages so that I could ascertain how respondents presently view disability, society as it relates to disability, and themselves.

Data analysis

Phenomenological data analysis

In phenomenological studies, when analyzing data the researcher must “begin with a full description of his or her own experience with the phenomenon in question”

(Creswell, 1998, p. 147). The goal is to understand the essence of a phenomenon by incorporating both the researcher's personal ideas about disability and the ideas expressed by respondents in their interviews.

Upon thoroughly reading every interview transcript¹⁴, I extracted significant statements across interviews that explained how the individual respondents were experiencing the phenomenon of disability. This process is called horizontalization (Creswell, 1998, p. 147). These statements encompassed experiences related to peer group, disability culture (athletics and other involvement), access, influences of media, and how respondents worked with emotion. Each individual statement is regarded as having equal value in an effort to build and comprehend a wide definition of the phenomenon and then clustered into meaning units or themes.

The themes are then described in a process referred to as textural description (Creswell, 1998, p. 150). The next step is structural description, in which I compared my personal understanding of the phenomenon to the ideas of the respondents. This makes it possible for a researcher to create an overall description of the phenomenon (Creswell, 1998, p. 148). This step was particularly important for me based on my unique Positionality which is described later in this chapter. These themes developed into the coding system used to further analyze the data.

Coding system

¹⁴ All interviews were digitally recorded with the permission of each respondent and were transcribed verbatim.

Once data was initially analyzed using the phenomenological methods described above, I developed a more specific coding system to further analyze data. My coding system was framed by the specific theoretical and conceptual frameworks that guided this study: the concept of identity, traditional identity development models and the sociopolitical nature of disability. To analyze the process students described by which they developed their disability identities, codes were created to look at sequence of development, milestones in development, and influences on development. While it is the sociopolitical model of disability that frames this study, less contemporary models still inform much of society. To explore perspectives on disability, codes were created to examine the content of interviews for sociopolitical themes as well as themes that related to disability as a deficit or a functional limitation. Specific codes included: sociopolitical, social construction, media, rehabilitation, medical model, disability as deficit, functional limitations model, and, interaction with environment.

A system of open coding was also employed throughout the data analysis process. Certain themes emerged throughout the interviews that were unexpected around use of disability slang, language use, and social outlets created by athletics. Based on my personal understanding of the experience of disability, I could not have included these concepts as part of the initial coding system. Because respondents consistently spoke about their experiences with athletics or used disability slang, the researcher essentially built codes around these unexpected ideas to incorporate them into her findings.

Validity of data

Every measure was taken to assure the validity of this data. There is a level of validity that comes with interviewing subjects over a period of time. Spacing interviews helps to achieve validity. The three-interview method “places participants comments in context. It encourages interviewing participants over the course of one to three weeks to account for idiosyncratic days and to check for the internal consistency¹⁵ of what they say. Furthermore, by interviewing a number of participants, we can connect their experience and check the comments of one participant against those of others (Seidman, 1998). The schedule of this specific interview protocol helps to determine whether the respondents’ responses are valid because it affords time to gauge consistency and allows the interviewer to compare content across multiple individuals. Additionally, member-checking, explained later, helps to achieve validity by maintaining communication with and connection to respondents after their interviews.

I was approved to work with Human Subjects first in November of 2004 and then again in December of 2006. This study was approved by the Institutional Review Board (IRB) in November of 2006 and was approved for continuing review in November 2007. Pseudonyms are used throughout this narrative to protect the anonymity of the respondents and the institution that provided the site for this research. All interview sheets and transcripts were kept in a secure location. This study was piloted in the fall of 2005 and revised in light of initial findings.

¹⁵ Internal consistency refers to the level of consistency a respondent presents across his/her series of interviews. It is critical for an interviewer to monitor content throughout the interview process to verify that there are no conflicts or questions related to the content of responses (Seidman, 1998).

Triangulation of data

Qualitative methodology has historically been criticized for its inability to present valid findings (Creswell, 2003, p. 179). I intentionally employed several methods of triangulation to limit biases and put forth strong data and findings.

Prolonged engagement

Fetterman (1989) posits that is “working with people day in and day out, for long periods of time, is what gives research its validity and vitality” (p.46). I feel that not only does my personal position afford me that first-hand experience in the disability community, but that I have had on-going professional opportunities within the community as well. Through my work with students in residence life to find accommodations, my position as co-chair of the President’s Advisory Council on Disability, and the time I have spent formally and informally in the DRC, I have been able to participate in the disability community as a professional.

These varied and continuing experiences have made it possible for me to gauge consistency and track patterns, which would support the validity of my research. For example, I am able to track concerns expressed by disabled students in the residence halls and by the community members on the President’s Advisory Council and compare them to my own personal concerns. The process of comparing themes across groups and doing so over time helps reveal valid findings.

Member-checking

While reflection time between interviews is a critical piece of the Three-Interview Series employed in this study and generally in qualitative methodology, I also consider it a form of triangulation. Students were able to analyze their own experience in the interview process and were afforded an opportunity to voice any concerns or incorporate new ideas into their interviews. Additionally, I e-mailed each respondent after the conclusion of his/her interview to solicit any additional feedback or thoughts.

Transcriptions

Once each student's set of interviews was completed, they were transcribed by a personal contact who was trained in medical transcription. I thoroughly read each transcription and compared each transcript to its audio counterpart to check for accuracy. I then e-mailed each respondent his/her interview transcript and asked for him/her to review it. This provided respondents an opportunity to respond, ask questions, or add additional feedback.

Research journal

I chose to keep a written and audio journal throughout my research. I e-mailed myself thoughts and ideas on literature and interviews, and after each interview I recorded my initial reactions. I kept track of my personal reactions to the study based on my experiences with living with a disability from birth. I noted that after certain

interviews, I would feel extremely excited or empowered. Speaking with students and learning about their experiences helped validate my research. However, after analyzing various components, particularly reading older articles and books for my literature review, I would tend to feel extremely self-conscious of my disability. I kept track of these emotions and this journal helped me better understand my own development and in turn provided me a richer understanding of the respondents' developmental process.

Peer debriefing

Dialoguing with other classmates in the process of conducting their doctoral research and writing their dissertations not only provided me with support, but I utilized it as another form of triangulation. I was a part of two different debriefing groups. I met regularly with two peers who were also conducting qualitative studies on diverse student populations and we would speak about our processes and provide ideas and suggestions for one another. I was also a part of an online group created by another set of doctoral students in my program. This website provided space to upload drafts of work, set timelines and goals, and ask questions. While this outlet was more passive than the dialogue group, it was also extremely helpful as it gave me exposure to three more perspectives.

External auditor

I feel very fortunate to have an exceptional professional mentor who served as an external auditor for me throughout my research and writing process. I shared with him

drafts, timelines, and questions. This individual was my former supervisor of three years and completed his doctorate in Higher Education two years earlier. He provided me with support and guidance throughout all stages of my research. Based on our relationship, he was also able to help me monitor my own biases and reactions to the more personal content of the interviews and research.

Summary

To explain the multidimensional and vast experience of disability identity, I crafted a phenomenological study built around in-depth interviews with ten disabled students at the University of Arizona. Phenomenology is predicated on the idea that research should reveal how individuals experience a certain phenomenon—in this case, disability. Interviews were constructed to explore how each student developed his/her identity around disability by structuring them in a three-part series, each interview section focusing on a different aspect of disability and life. My Positionality was discussed in great depth in this chapter. As a student, disabled from birth, and a staff member at the site of my research, I explained my personal drive for this study and the impact my identities had on my research and findings. In an effort to limit my biases around disability and present the most valid findings, I employed several methods of triangulation throughout my data collection and analysis. After methodically analyzing and coding the transcripts from my interviews, I was able to generate themes that informed disability identity development.

REFLECTION FOUR

For about two years in college, I was a voice major. It had always been my dream to be a singer, and I decided to switch into the music conservatory and study voice during my sophomore year...about two years before I decided to switch out of the conservatory and back to Social History. Dance class is a requirement for all voice majors, but I assumed that I would be excused from this course. I was so certain that I would not have to participate in class that I did not go to class for the first week and a half. However, I was mistaken. I was fully expected to participate in dance. Every morning before and during class I would feel nauseated, but I would participate. I learned how to do stretches and basic ballet positions, adjusting each movement to my own body. I could replicate first position with my arms and hands, instead of legs and feet, and I would sauté only from the waist up.

I actually began to like class after a few weeks had passed and I became increasingly comfortable. I grew close with the other voice majors in my cohort and our dance instructor was extremely entertaining—a leotard-wearing, cigarette smoking, retired ballerino, who went by the nickname of Buddy.

It was finally the time in the semester where we were ready to “go across the floor.” One by one we would have to move across the dance floor, completing certain movements in sequence. The dance studio was vast and all four walls were floor to ceiling mirrors. My turn approached and I became sweaty and shaky. I begged Buddy to let me pass my turn, but he would not be convinced. I began to move across the floor. It was not the movement that was upsetting to me, it was seeing myself in the giant mirrors

and seeing my classmates see me in the giant mirrors. I made it across to the other side of the seemingly endless studio and doubled over in tears.

I continued in dance class for as long as I was a voice major and did enjoy the subsequent classes and the overall experience. It was not the reactions of my classmates that pushed me to tears that day; they were more supportive and understanding than I ever could have imagined they were capable. It was not Buddy; he just wanted me to learn the fundamentals of dance and did not care how I applied it to myself. It was really seeing myself. What I looked like. In those giant mirrors. Next to all those other students in black leotards from whom you could not tell one from another.

REFLECTION FIVE

*Growing up, I knew that I had a disability. I knew I was different, but I did not feel connected to disability in a cultural context. In fact, I would intentionally distance myself from others with disabilities and would go out of my way to avoid using special accommodations. As recently as 2005, I would not go see *Murder Ball* in the movie theater because I did not want people to assume I was there only because I used a wheelchair. All this in an effort to challenge people's notions about what I should be. It was not until arriving at UA that I truly even started to identify as disabled or identify with disability. I had been convinced that disability had no culture or community. I would contend that there was no "pride" associated with disability the same way there was the GLBTQ community or other ethnic minority groups. I could entertain the idea of a disability community, but I rejected my place within it. Throughout my graduate*

coursework, as I learned more about social justice, I chose to focus many projects and papers on disability in higher education and I found this was helpful in validating my own disability identity. A few years into my doctoral coursework, I chose to do an independent study with the director of the Disability Resource Center who was also an adjunct professor in Special Education and Rehabilitation. She was instructing a course entitled, "Perspectives and Narratives on Disability." This was a really poignant experience for me not only because of the excellent class content and discussions, or because this professor became one of my greatest mentors, but because it was the first time I had entered the Disability Resource Center. At 26 years old, I admitted that taking that class was "the most disabled thing I'd ever done."

CHAPTER FOUR

FINDINGS

Introduction

This chapter presents the findings that emerged after conducting interviews with the ten students in my sample. Four major findings serve to answer the research questions: (1) How does the interplay between individual and his/her environment shape disability identity and what social, political, and environmental factors influence disability identity formation? (2) what are the characteristics of a disability identity?

This chapter will discuss each findings and sub-finding in detail. These themes explain how students conceptualize disability and what factors have influenced their experience. Interview quotes will be used not only to justify these findings, but to provide a better sense of the individual students' experience as they discuss disability and reflect on how they have claimed it. It is the goal of this chapter that these findings will present a picture of disability that is multidimensional. Further, these findings should illuminate how these students have and continue to not only respond to and negotiate their environments, but can be players in shaping it.

Sequence of identity development: Challenging traditional stage-like models

The process of identity development respondents discussed in their interviews challenges existing stage-like identity development models in that it allows for identity to be fluid and dynamic. Separately, respondents articulated many common themes related to learning to accept and internalize their disabilities. Initially students were unaware of

disability in that they were too young to understand the disabilities with which they were born, or they were not yet disabled. Once they began to internalize what disability meant to them, they would develop a multidimensional and dynamic disability identity. The sociopolitical model of understanding disability, as discussed in chapter two, considers disability to be a social and political construct that requires change to occur at an institutional level. It also implies that the experience of disability is shaped largely by a disabled individual's interaction with societal structures and environments. This interaction is ever-changing. Individuals may respond differently to their environments at different times, with different variables. Identity models must allow for this variance.

The following examples demonstrate respondents' initial lack of awareness around disability and then their learning to understand the personal and societal implications of disability. For those who acquired their disabilities, their realizations that they were disabled occurred at the time of their accidents. They can recall a moment when their lives changed. Largely, before they became disabled students who acquired their disabilities did not have any ideas around disability and knew hardly anyone who was disabled.

When asked, Brian said that he did not have any awareness of disability before his accident.

I didn't have a real perception of disability. I never knew really anybody who used a wheelchair. There was a girl in high school who walked with crutches.

Not sure what her disability is, but we weren't necessarily friends. I don't think

that had anything to do with her disability as much as it did with like I wasn't friends with any of her able bodied friends.

Jack said that before his accident he did not have an understanding of disability and could relate to how people approach him now that he is disabled.

I think just like any able bodied person feels. I didn't know how to approach it or handle it or interact with them. Like you aren't sure exactly what is wrong with them. You don't know what they can do for themselves.

He went on to describe his overall transition to life with a disability.

In the beginning it was just like I couldn't believe it actually happened at first. So it was like trying to get use to the idea that the accident did happen and I had actually just gone through what I did. Then it was just like trying to adjust. I got into sports pretty quick so that helped out.

Those born with their disabilities did not experience a life change, per se, but did experience a change in their own understanding. While those born with their disabilities have very early childhood memories of disability—surgeries, people staring at them, issues of inaccessibility, being inappropriately forced into special education—these memories did not hold any meaning until they began to realize that these situations were unique to them and were not shared by siblings or peers. Until they were able to make this comparison, they assumed surgeries, orthotics, and trips to the doctor were “normal.” They did not understand enough at the time to be upset by these challenges and it was not

until they learned the implications of such incidents that these memories developed meaning. Betsy remembers feeling confused as to why she needed orthotics.

My mom says she remembers the first time I really got it was like I asked her when I was 2 or 3 how old my mom was when she got her braces off or when she didn't need her braces anymore.

Kate remembers back to elementary school when she was not permitted to participate in gym class, although she had been involved in wheelchair athletes outside of school.

I do have a situation where in middle school in gym class one of my teachers – each marking period we played different sports, and one marking period we played basketball. Now I'm on an outside basketball team so I know how to play basketball. So this is kind of upsetting because I'm athletic and I play sports, and the teacher told me I couldn't play basketball. And I got upset because she told me you can just go to the library and do homework during gym. And I was like, no I can't. I'm going to play. And like she refused to let me play because she's like I don't want the other kids to trip over you and fall or something. I was like – what? Like they have eyes. They could watch out. I don't know... So she wouldn't let me play and every day I had to go to the library. After a while I was like this is ridiculous, so me and my mom had a meeting with the principal and the Board of Education, blah, blah, blah. It was like a big deal and finally they let me play. But it was like this big, long drawn out thing.

This was poignant for Kate because it was one of the first times she remembers being denied an opportunity solely because of her disability. Not only was she not permitted to participate in gym class, her teacher did not involve her or her family the decision to force her to go to the library during gym class. Now she recalls this as extremely disempowering and frustrating, but then she simply did not understand why she was being treated so differently for something that was perfectly normal for her. Now she is able to link this experience to the oppression of disabled people in society.

Similarly, Margaret reflects on elementary school, when her parents were fighting to keep her out of Special Education classes. At the time, Margaret did not understand the struggle because she did not feel different than her peers. She had to learn why her parents were advocating for her and what that meant.

I: When your parents were fighting to get you and your sister into the school, did you understand what was going on at the time?

M: I don't really think I did. I mean in my mind I think I knew a little bit but I really didn't feel like I did. I mean I knew it was kind of a struggle but just being in the classroom I remember being really excited being there so it didn't really faze me much and I didn't feel uncomfortable. That is one thing I really think about – is I never felt like I was in a wheelchair when I was in those classes, especially by my peers, and yet I had a special assistant for most of my elementary school years and then by middle school that was phased out. But I never really felt like I was different even though I would have physical therapy and things like that. Sometimes I would come to school and things would be a

little bit different for me. Being around my peers and the way teachers treated me, I didn't feel a big difference.

I: Do you still feel like that?

M: Definitely - and even more now. Especially I think more when I got to middle school when it became more me taking care of myself and me becoming more independent and not having an aide around to assist me and things like that.

Stephanie was born with spina bifida and has used a wheelchair since childhood.

She reflects on first beginning to understand that she had a disability.

I think as a kid I was very stubborn to come to terms with it. I guess I thought I was just like everybody else, and I think when I actually started using a wheelchair because I didn't start really using a wheelchair until 4th grade. It just was easier to get around. I didn't use it all that much when I was a kid but when I did I think that was when I really realized I was disabled. People would bring it up like oh, you have a wheelchair. I think at first it was just like insulting like oh, yeah, it's just like the way I get around and stuff. I think it was tough as a kid but then I got over it like you real fast. I was like you just have to realize – be strong and realize you are no different.

Ankur succinctly captures his understanding of his disability as a young child:

Yeah, I always knew I was not the same as the other kids running around. That was something I couldn't do but at the same time there was nothing different about it.

Throughout their interviews and in their discussion of identity, respondents described times when they have felt emotions related to their disability—both anger and pride were discussed specifically. Like for other cultures, anger and pride are significant to the disability experience. Emotions such as pride and anger are critical when looking at disability through a sociopolitical lens because these are the emotions that motivate change; these emotions can connect people with the social identity of disability. Emotional reactions may be the impetus for development, involvement, connection or education. Their pride for their athletic community or for personal accomplishments or their frustration over lack of access or ignorance, for example, may have led to their involvement in disability-related activities, their disabled peer group, or their interest in further education or outreach around disability. Such outlets are critical to their identities as disabled individuals because of their implications for disability culture, community, and activism.

Respondents discussed examples of regularly occurring situations or interactions that make them angry related to disability. Christopher discussed examples of “everyday” things that sometimes make him angry. He explained that because of the frequency with which these types of instances occur, he has learned how to cope and not

feel angry each time. Christopher's experience demonstrates the need to revisit uni-directional models of identity development. He is a successful adult who holds his disability on par with other identities. However, sometimes disability-related issues make him angry, usually brought on by another individual or a physical barrier.

Christopher, a 28 year old graduate student and wheelchair athlete, suffered a spinal-cord injury less than ten years ago and does not internalize his anger because small things happen so often that could cause him anger. He said that he encounters frustrating disability-related situations daily and that most of the time is not upset by them, but that occasionally he "snaps" and become angry. He reflected on how his perspective has shifted since he began learning to live with his disability and articulated the need for systemic change:

... at the time because I was still just learning how to run my body basically and try to manage my world, and I didn't feel like I was doing a very good job at the time but it was getting better. Now I feel I don't have those types of issues as much anymore, but I do feel like there are still the same stereotypes and stigmas and all that type of stuff. I don't internalize it as much anymore. I know it's there. I'm aware of it. I'm not here to fight it all the time. I feel there needs to be something. There needs to be social movement in this stuff...It can make a difference with the people that I interact with directly, but for me to challenge everybody that I meet out in public, there's no point in taking that much energy to try....

Like Christopher, Ankur explains his resiliency and his ability to recover from a frustrating incident.

I mean nothing bothers me anymore. What else is going to happen that is going to push me down, you know? Nothing. I am not going to waste my whole day thinking about it. It is going to stay with me for a couple of hours. I will have dinner, and I will be nice and fine again. So your ability to handle things increases a lot.

According to a more traditional model of identity development, perspectives like those of Christopher or Ankur would imply that they did not have healthy identities around disability, that they would still need to move through their anger to become more self-actualized and less emotional. Respondents believe that it is this anger that can lead to education and make change. They would rather discuss an incident with someone in an effort to prevent something similar from happening again or use their emotions as the drive for activism or involvement. Betsy aspires to be a consultant or public speaker to educate around disability issues. Because of her pride for the disability community, she uses her anger to educate others.

...as much as I try, people's ignorance a lot of times really bothers me. Like the patronizing where they pretend to understand you or they go the opposite way and they don't offer you equal opportunities...More of that kind of stuff like the ignorance of society really just to a point it just kind of – I know it's what I work to try to change, but it still bothers me sometimes. Well I guess just kind of a

gradual process [for those without disabilities]. You know like oh, not everybody has a disability. Oh, not everybody has a disability that you can see. Oh, you know, this is how people perceive this and then kind of maybe getting frustrated when people stare. But then I guess learning it is not their fault and turning that into something positive and teaching them so the frustration doesn't happen. That's why I think I have turned some of my not really anger but frustrations with society and their ignorance toward the disabled culture into like positive public speaking to really.

While pride and involvement might be considered more positive or productive than anger according to traditional identity development models, it is still a phase that traditional models require students to move through in order to arrive at a healthy identity. Older models contend that even a positive a preoccupation with a certain identity may imply that someone is obsessed with it and is not able to achieve a balance in his/her life. Looking socio-politically at disability and believing that large-scale education and change must occur to educate dismantle historical ideas about disability, disabled individuals would need to embrace their community and use their pride to become involved in disability culture and do work that seeks to affect change.

All respondents demonstrated that they had internalized their disabilities. Respondents understood their specific situations and were able to relate to the disability community. The students spoke honestly about their lives and would mention occasionally feeling frustrated or feeling extreme pride or connection to the disability

community. Because the disability experience is, in part, about one's interaction with society and environments, students would discuss encountering a frustrating situation and ways they handled it. They were able to handle themselves and continue with their day.

Where traditional identity development models put forth that one will move through phases of extreme pride or anger, students indicated that this sequence was not accurate for them; their identity development conceptualizations were not uni-directional. These students were able to have "healthy" identities but also occasionally feel anger, pride or associated emotions. For example, even once a respondent had internalized and accepted his or her disability, he or she may still become angry when faced with an inaccessible locale or with a passer-by who stares at him or her. Each respondent spoke readily about examples of frustration and anger, mainly around others' ideas of disability.

While there is a developmental process to acquiring a disabled identity, it is not strictly stage-like or concrete. Once respondents achieve a certain understanding of their identities they travel back and forth in their emotions or feelings toward their disabilities. This suggests only that identity is fluid or dynamic, not that these individuals are not able to accept their disabilities, as other more traditional identity development theories suggest. Further, this finding highlights the sociopolitical dimension to identity development by suggesting that emotions are critical to a rich understanding of disability; without such passion or frustration, individuals would not have the momentum or motivation to affect change on a societal level. Social and political movements, such as civil rights or disability rights, have demonstrated this dynamic and have paved the way for individuals to react and respond to their environments in ways they see fit.

Identity does not exist in a vacuum. Culture, community, systems, organizations and societal dynamics all play a role in shaping self-concepts and identity development. To assume that students would not react to these changing systems would be short-sighted. The following findings serve to describe the implications culture, environment, and attitudes have for disability identity development.

Disability is critical to, but not does not define, identity

While the respondents each have unique life experiences, they do share a common understanding that disability is critical to their identities. It is important to understand that not one respondent would identify only as disabled. This theme held true for all respondents regardless of how long they have been disabled. Disability is one of their multiple identities and, while they understand that they have a disability, they do not define themselves by it.

Respondents speak about how they identify with disability and the circumstances which force them to think about, or in some case remember, their disabilities. This dynamic is relatable to the experiences of other minority groups. Those who identify as members of subordinated social groups may not necessarily believe that their subordinated identities are most salient for them. Or, they may be most salient at certain times, influenced by circumstances, emotions, or the environment etc. For example, until a person of color is confronted with racism, perhaps his/her race or ethnicity is not at the forefront of his/her mind. When a woman enters a room full of men, perhaps gender becomes most salient to her. Race, gender, and other identities, like disability, are all

important to an individual's self-definition but their immediate significance may ebb and flow.

When asked if she identifies as disabled Stephanie, disabled from birth, explains that, "Yeah. I mean I would say I'm disabled but I don't really classify it. Like that wouldn't be the first thing I would say to somebody. But I do identify as being disabled. I don't think that's what makes me as a person or anything." When asked the same question, Jack said, "If I am with other people in wheelchairs, sure. I have always since I got hurt thought of myself as I am the same person I always was. I'm just shorter".

Respondents acknowledge that initially non-disabled people may focus disproportionately on their wheelchairs or disabilities and this dynamic may have bearing on their disability identities because the respondents themselves do not focus so much on disability. Respondents shared this observation without emotion and accepted it as part of their experience. However, they stated that to combat this reality, they would try to connect with others on a personal basis to educate them about the realities of disability. Stephanie described her experience:

"Well, I mean I think like people who don't know me just assume things like oh, she's in a wheelchair...I have really close guy friends around the dorm and they [at first] were just like oh, you know. They didn't think we went out and like went to parties or anything because I guess they just have this stereotypical view of people in wheelchairs... So I mean it's good to like talk to people and really make them – and you know they are very like – when you start to talk to people they really get interested like oh, I didn't really think of that. I think it is just one

way to like stop this discrimination against people in wheelchairs. You have to speak out. You have to inform them. They are not going to know any other way. And I think you know – I think my friends especially my friends in wheelchairs – they don't see me any differently than anybody else. We always see each other as the same. You know like my able bodied friends they are always like cautious. I think they see me like everybody. My really close friends at home and here – they see me just like everybody else....

When asked how often they thought about their disabilities, respondents overwhelmingly stated that they rarely consider their disabilities, unless confronted with an issue of access or another type of barrier. Because disability is one of their multiples identities, respondents answered that they think about disability all and none of the time. Of course, disability is apparent in their lives, but like their genders, races, ethnicities, students do not obsess over their disabilities. When asked how often Ankur thinks about having a disability, he answered,

“None and all [of the time] because at one point I'm not just going to forget and hope I can run. Okay, if I see something – if I am going somewhere, I'm not going to get out of my car and hope I can climb those 3 steps I need. It's going to be at the back of my mind. You do think about it and you don't think about it.

Isolating disability when looking at identity appears easier for respondents who were not born with their disabilities; for these individuals, there was a “before” period in

which they had no real concept of disability. Christopher, when asked how often he thinks about having a disability, shared,

Yeah. For me it's constant. It's constant. I get reminded all the time – not only externally but internally, too. For the most part I'm comfortable with how I live my life, but there is always a thought that pops into my head – if I could just get up and walk to the bathroom, it would be so much easier. That's not anything that I ever dwell on. It's just something that's present. You know whenever I have to make a decision just about anything, it's usually a consideration. Do I want to go somewhere? Is it accessible? Have I been there before? What am I going to have to face? Things like that. It is pretty much constant.

Because they had no meaningful connections to disabled individuals, disability was a non-issue, or something misunderstood. It was not until they became disabled that they were forced to think about disability and internalize it as part of their identities.

For those individuals born with their disabilities, disability has always been a part of their lives. They are not able to conceive of themselves without disability. When asked how often she thinks about having a disability, Kate said that she often forgets she is in a wheelchair.

As weird as it sounds, I forget sometimes that I am in a wheelchair. It is kind of weird. For example, I go out to dinner. If I go to dinner with the track team say, they will be like did you tell them that we are all in chairs – like we don't need a chair, and I'm like – oh, I forgot. Like forgot? I'm like – yeah, I just didn't think

of it. I don't know. I don't consider myself to be disabled. I don't use that word either... I mean I think people have to be aware of the fact that we have a disability and we are in chairs. But just when I talk about myself, I don't always – I mean I know I'm in a chair. I'm not blind to it. It's just when I'm out doing things, I'm not really thinking about I'm in a chair. You know?

Erin responded similarly when asked how often she thinks about her disability.

Probably never. I don't think about it every day. If there is something you need to go to the doctor for that has to do with your disability, then yeah, you are going to think about it. But I don't like usually wake up or spend my whole day thinking about it.

When respondents isolate their disabilities, the focus is shifted externally—to environmental barriers and the ignorance of others. This highlights the need to dismantle current notions around disability. This has implications for design, education, and access. Making changes that would increase access and independence for disabled individuals would only normalize disability for those with and without disabilities.

Perspectives on disability

Respondents were asked a number of questions in order to understand their personal perspectives on disability. There were specific questions to gauge how students connected disability to larger societal issues and questions to ascertain how students internalize disability. Students spoke about how they handle anger, and conversely

described the positive impact disability has made in their lives. They shared how enduring extremely traumatic experiences and living with disability have influenced their perspectives on life. Largely, students were reluctant to say that disabled individuals were oppressed in society, but could articulate numerous examples of oppression in their daily lives.

While there were no explicit statements confirming this interpretation, students may have been reluctant to identify as oppressed because they would not want to be perceived as taking advantage of their disabilities or be considered “that disabled person” who consistently speaks about oppression and discrimination. There was express mention of suppressing their anger so as not to upset others or become labeled as an angry disabled person. This theme is discussed later in this section. There is a common dynamic amongst those from subordinated social groups. Not only is there a stigma around being, in this case, disabled, but there is another layer of stigma placed upon the individual who is disabled and vocal.

A number of themes emerged related to community, society, culture, and personal philosophies and they are described in this section. The themes are closely related to one another and are grouped accordingly. The first two themes deal with how disability positively enhances life and how disability has affected students’ philosophies on life. These themes are related as many respondents attributed their positive outlook on life to having a disability. The last four themes are more negative and are difficult to clearly discern from one another. These themes deal with anger, oppression, non-disabled individuals perceptions of disability, and defining disability.

Disability positively enhances life

When asked about how disability has positively enhanced their lives, all respondents provided numerous examples. An overarching theme in this set of responses was the notion of disability enhanced their perspective on life, their level of empathy, and their ability to appreciate and be grateful for simple things. Respondents all stated that having a disability has made them more sensitive, better able to deal with prioritizing important issues, and able to connect with others interpersonally.

Ben, who survived childhood brain cancer, explains, “Well before [acquiring a disability], I was ignorant and now I’m grateful. I’m grateful for everything. I sat out in the sun this morning feeling grateful for the little things like that”.

Like Ben, Margaret spoke about her appreciation for life and her sensitive perspective.

For me I think it has a lot to do with the fact that it has made me recognize that if I walked, I probably would take it for granted. But the fact that I don’t, I don’t take it for granted. So I don’t take so many things for granted. I think about how lucky I am. I mean of course everyone has their days of like this is horrible. I just can’t deal with it. I think about it but I have a roof over my head. I have food. I have friends. I have family. I can watch TV. I don’t have to worry about someone coming up and like in Iraq – I don’t have to worry about bombs or anything. I am really lucky in that way. So, I think about the little things that I am lucky for, and then I think that really positively influences the kind of person

that I am because it makes me want to help others. It kind of helps me not focus on myself but focus on others and what I can do for them.

Jack, when asked how disability has positively enhanced his life, responded with,

It has made me more of an outgoing person. I appreciate people a lot more. I am able to help people more just because I have been through such bad things that anybody can come to me with a problem and I always give good advice and most everyone listens. It has helped me grow up a lot so I am a pretty mature person. I do take risks, but I don't do anything stupid. It has just helped me to learn to live my life correctly.

Christopher explained how his personality changed as a result of his accident.

When I got hurt, I went through a whole lot of changes in my personality. My personality was completely different from who I used to be, and who I used to be was a very kind of carefree in a way that I was blind to a lot of things. I was ignorant about a lot of things. I didn't put much thought into a lot of things. I was just kind of a jackass. That's how I felt about myself looking back...In a way. I mean I never felt like I was a very serious individual or that people took me seriously. In looking back I don't like how I presented myself. So getting hurt, having a disability and all the experiences just kind of pulled me back into reality in a way that I feel I was more in touch with a lot of things.

Another important theme is that of inner-strength and lack of fear. All students spoke about their ability to “handle things” and their overall resiliency. Brian said that since his injury,

I think I’m a much – I’m certainly a more well rounded person. Once I’ve been through what I’ve been through, I’m not afraid of anything anymore. I mean I constantly like – I don’t know – I’m kind of crazy...I’m not afraid of it at all.

These students have survived near-fatal accidents, surgeries, and illness and as a result believe that they are able to handle anything. They are more confident and have less fear as a result of surviving their accidents and living with disability.

It is important to note that all the athletes in this study spoke about wheelchair sports at this time. All athletes spoke about how wheelchair sports has given them opportunities to meet people, be part of a team, make friends, travel and compete nationally and internationally. Erin said,

Well, I think I get to do a lot more things than people without disabilities because I’ve got a lot more opportunities I think. I don’t know. I get to travel because of sports. I did scuba diving. There was a special program for scuba diving and for people with disabilities, and I got involved with that. A lot of activities and stuff.

In her interview, Stephanie, a wheelchair athlete who was born with her disability, captures the many ways disability has positively enhanced her life.

My friends always get so weird when I say this but I think it actually has enhanced my life... I know nothing other than my life but I think I've actually got to do more as a person in a wheelchair than I would as an able bodied person. I got to travel for swimming and track and all that stuff. I got to meet great people and go to events that I didn't think I was going to be able to go to like the Olympics and watch and stuff like that. I think I have been very lucky. I have got very good people in my life and I think that it is because I have spent that kind of life. I think it has really helped.

While this may be a perspective that those without disabilities are unable to understand, all respondents indicated that disability has enhanced their lives and articulated many things for which they are grateful as related to being disabled. However, there are also frustrating and difficult dynamics that arise because of disability. It is important to recognize that disability is dynamic and brings forth ups and downs as individuals react to others, their environments, and themselves.

Philosophies on life

A difference in attitudes toward life was apparent across respondents. Those individuals born with disabilities or who grew up with a disability tended to be self-identified over-achievers. These individuals made it a priority to do well in school and be involved in several extracurricular activities, as a way to disprove the stereotypes others' hold around disability; those who acquired disabilities later in their lives did not share

that need. Those who have lived their entire lives with disability may have been socialized in a way that forced them to prove people wrong in an effort to dispel common misconceptions or stereotypes around disability. They may have grown up defining disability by what they were not and this dynamic has implications today for their disability identities. Those who have more recently acquired disabilities may not yet have the need or perspective to compel them to be over-achievers and they might never espouse that philosophy.

Margaret is a student who was born with her disability and in her junior year is and has been involved with four extracurricular activities, and has held more than one job. Margaret, who was born with her disability, spoke about how much she loved school throughout her interviews. She is involved with several extracurricular activities and holds an on-campus job. She is now planning to study abroad next semester. When asked about her motivation, she responded with,

...I am all about proving people wrong. I think that has helped me because I was motivated towards it. I motivate towards wanting to accomplish. A lot I had to do for myself because I do not want to be someone who sat at home all the time. I wanted to be someone who actually did and see things. So luckily for me my personality is like that.

Ben, who became disabled during childhood, may not be as involved on campus, but he is an avid athlete, rock climber and musician. Betsy was born with her disability

and has been extremely involved in wheelchair athletics, choir, acting, and public speaking throughout her life.

Respondents who acquired their disabilities later in their lives shared a different outlook from their counterparts mentioned above. Brian said that he feels like surviving his nearly fatal accident makes him feel like he is, “playing on house money.” At the age of 28, Brian is an undergraduate seeking two degrees, with no clear graduation date in sight. He spends his time in college hanging out with friends or doing athletics. He does not share the sense of urgency that Margaret, Ben, or Betsy do. “I’m a pretty happy-go-lucky guy. I’m enjoying myself. I don’t know. I’m reading too much Harry Potter or something”.

Christopher also became disabled in his early twenties and feels lucky to be alive after his near-fatal accident. While he is not as laid-back as Brian, Christopher is content with going to school and working one assistantship. He is also an athlete, but he does not put pressure upon himself to prove something to those with limited understandings of disability.

Jack, an 18 year old who acquired his disability four years ago, says that since his accident he has become more outgoing, and less inhibited, nervous, and shy.

After I got hurt, I just took things – I didn’t take anything for granted. I didn’t take anything for granted anymore. Like I appreciated my family and friends before but after you get hurt, you learn how much they mean to you and how much they are really there for you. I actually became a little bit crazier after I got hurt. Before I got hurt, I was kind of a quiet kid. I’d sit back in class. If you

talked, I would talk but after I got hurt, I loosened up a lot. I take life like it comes.

The justification for this finding may be that those who acquire a disability also acquire a perspective on life that makes them simply happy to be alive. Those disabled from birth or a young age have needed to prove for their entire lives that they were more than their disabilities. While these patterns are about attitude and life philosophies, they may also relate to coping and what makes it possible for individuals to survive and live healthy, productive lives.

Anger

When asked if/when students felt angry about having a disability and to describe what kinds of situations made them angry, all students were able to recall and describe specific examples in which they felt angry or frustrated. When respondents discussed anger, their focus was shifted externally. Common examples were: encountering a building that was not accessible, people staring at them, and strangers offering to help them with trivial tasks such as opening the door or loading their cars with groceries.

A specific theme throughout their discussion on anger was that those without disabilities assumed that they needed help completing routine tasks. Students spoke about the high frequency at which they encounter others who assume they are not able to be independent. This is a prevailing stereotype about disability that is perpetuated in the

media and throughout society; it is not surprising that those without disabilities would consider those with disabilities in that way.

Christopher explains how he is frustrated by the perspectives of non-disabled individuals.

I get frustrated at people's randomness in society. They come up to me and feel a need to make some comment to try to relate somehow. Oh, my kid uses a wheelchair – it's okay. Or I used a wheelchair for two days – I know what you are going through. I get frustrated by those comments a lot. One day I was in like Rite Aid or one of those pharmacy stores buying some toothpaste or something, and this guy walks up to me and I was just pissed off I think that day and I kind of regret saying what I did. But this guy made a comment to me, and I snapped at him. He just walks past me and he was like – oh, a wheelchair, huh? That's pretty cool. And I didn't really know what he was really getting at so I gave him this look like what the? And he was like oh, I didn't mean anything by it. He's just like I used a wheelchair – I had to use a wheelchair for a few months and so I feel like I know what you're going through. I'm like – a couple of months, huh? Well, I'm going to be in this for the rest of my life. It was just kind of an angry statement I threw at him. He was like...I thought you were like me. I thought you had a brain injury. Things like that. I remember I was in a restaurant once here in town with an aunt and my dad, and the waitress comes up and I'm sitting at the table. She looks at the wheelchair, looks at me and she is like why are you in a wheelchair? Just flat out – not hi, what's your name. Doesn't care to know

anything about me other than she wants to know why I'm in a wheelchair. My disability is not coffee talk time for you. If you want to get to know me, we can sit down and have a conversation and if it comes up and I feel comfortable sharing it with you, I will but otherwise....

Brian explains his experiences with others and relates to the film *Murder Ball*.

I mean obviously I guess the key word is ignorance as most prejudices and things go. I live a pretty happy go lucky life. My interactions with people are largely good. Occasionally – the only way they piss me off – or I guess there are more ways but the way it tends to happen a little more often than anything else – is if I'm with able bodied people. Say you go into a restaurant, they'll ask the able bodied person if you have a reservation or what your name is. Or if I go to the store with my sister – and I don't know maybe it is a guy-girl thing or whatever – but like they will either look to her to pay, and I'll pay and then they will hand her the change, and that just sends me off sometimes. I mean it doesn't happen a lot but those types of things that still happen and maybe I read into them that they think I'm incapable of pulling some of this regular everyday stuff off. It gets to me...That's like one of the lines from *Murder Ball*. One of the guys is at the store like food shopping or whatever and somebody asks him like – he's like finished food shopping and is like putting groceries in his car – and somebody approached him and says are you going to be able to get home alright or something like that.

And he's like would I come to the – would I even come here if I wasn't going to be able to get home?

Jack gives an example of being approached by strangers who assume he needs help with every day tasks and was visibly frustrated when discussing it. He also describes how talking to someone without a disability one-on-one helps educate them about his true experience.

I think like definitely the way some people -an able bodied person - will look at them. I know some of the things that people have said to me like I will be at the grocery store and I will be loading something or doing something in my car and someone will come up and like do you need help...I think at first until an able bodied person actually sits down and gets to know a person who has a disability I really don't think they know what to expect or like what to do. Just like what I do is make humor about my accident so I'll be telling my story but I will always put a comic spin on it. So everybody is like that sucks and I'm not really, it got me into college you know. So I tend to do it like that. I think it is kind of the same for everybody. They just don't know what to expect at first until they actually talk to you for a little while.

Erin used an exasperated tone when she spoke about others' assumptions:

Like, they will ask you if you need help with weird things like getting wheelchairs in the cars or you know. It's like no! I got here! I think I can get back in.

When asked how they cope with feelings of anger, most students said that they could not be angry because the person making them angry was not doing so on purpose. Respondents would not allow themselves to be angry at others' ignorance or waste time or energy being angry. Betsy, an 18 year old born with her disability, repeatedly said, "it's not their fault" when discussing people who made her angry. She is involved with wheelchair athletics and public speaking and attributes her involvement in these activities as a way to educate non-disabled individuals on disability.

It's not their fault that they are not exposed to this. They don't understand it. It is like I don't understand a lot of things, too, so I would be just as ignorant seeing other...That is why I figured teaching them I would be putting it out there. It's out there and the knowledge is available so we have less of these people getting mad at each other and frustrated.

There was also a theme that indicated respondents would feel angry but then intentionally suppress their anger so as not to offend or upset others. Brian was

discussing his opinion on the longstanding UA and Tucson wheelchair basketball competition, “Lame for a Game¹⁶.”

I’m not Mr. PC by any means, but you get people who really almost go anti-PC who go – Yeah, that’s the way it was, and that’s the way it will always be and we will call you lame or cripple or whatever and it’s kind of funny. And then there’s I think the backlash – I know for me because people ask me about it – and I thought it was stupid. I don’t think I was insulted by it so much as I thought there could be a better name. But if somebody talks to me about it, and anyone who first talks to me about it, I don’t want to be angry wheelchair guy.

Margaret, when asked if and when she feels angry about having a disability, explained that she tries to mask her anger or ignore frustrating situation because it is too difficult for her friends and family to see her upset. She tends to deescalate her anger and immediately justify a situation, so as not to be upset or upset others.

I know when we go out and people stare, my mom gets upset, and I’m like – I just kind of blow it off. I mean I’m used to it so it doesn’t bother me like it used to. I mean I think it’s absurd but I really don’t care kind of thing or I’ll look at them and say, hi or something. I remember a couple of months ago I was out with my friends and he said what was wrong with that guy? I said what are you talking about? He said - he was staring at you. I was like oh, whatever. He was like –

¹⁶ Lame for a Game was discussed in chapter three. This annual competition has been controversial within the disability community not only because of the word “lame” but because the competition itself does not give justice to the true sport and athleticism of wheelchair basketball. In 2007, Lame for a Game was cancelled because the team could not support it.

no. So, some of my friends get more angry than I do, but I guess because I am like it is just the way it is kind of thing. I just kind of get used to it rather than always being angry. Otherwise I could be angry about a lot of things. I would rather look at it positively and just move on kind of thing. If it is something big, then yes, I'm going to get angry. Well not angry, but I'm going to try to get something done and taken care of – like get it fixed. But I'm not going to keep it from letting me do what I want. I always put it in the perspective that yes, some things are not fair and some things are not wheelchair accessible. Like I want to go to England but I was talking to a friend, and she said it is not wheelchair accessible at all kind of thing. And I'm like well, that's okay. I may think about it. Other people have it worse off. And I think that helps me, too. It is not just me. It is other people who have to deal with things, too. I mean some people might say look at all you have to do, but so do other people and they have it a lot worse. There are a lot worse things out there than just this.

When asked to reflect on feelings of anger and dealing with anger, respondents were not able to articulate a time in their lives in which they were more or less angry. However, immediately post-accident, those who acquired their disabilities remember feeling confused and worried about ever living a normal life again.

And, of course, there was a time before students became disabled or before they understood their disabilities in which they were never angry because they did not have the awareness to feel anger related to disability. While all respondents were able to

provide several examples of what makes them angry related to their disabilities, this anger did not prevent them from feeling well-adjusted or empowered. They are able to deal with anger and some use that anger to educate others or become more involved in disability-related opportunities.

What is apparent throughout this discussion is that prevalent ideas that inform others' perceptions of disability are negative and disempowering. They do not match students' personal experiences with disability. The examples that the students used to describe what makes them angry as related to disability were examples of oppression. Students felt frustrated when their access was limited, when others treated them differently, or when assumptions were made about their level of competence.

Oppression

In response to questions about oppression around disability, there was a mixed reply. Though respondents could articulate many examples of oppression in their lives, many would not say that they were members of an oppressed group when asked directly. Three were able to say expressly that they felt oppressed and that disability was an oppressed social group. The remaining respondents either said that they did not feel oppressed, or answered ambiguously.

This inconsistent response may be explained by age. Two of the three respondents who stated that they felt oppressed are graduate students and in their late twenties. It may be that graduate students, or those in their late twenties, are more conscious of systemic oppression, and dynamics of power and privilege. Younger

students may not understand oppression enough to even identify or define it, let alone apply it to their own lives. Respondents between 18-20 years old would not put forth negative concepts of disability. Because they would not commit to anything negative, their answers were ambiguous and tenuous. As they were responding, they appeared confused and even frustrated that they could not respond with a positive or eloquent thought. That trend should not be attributed to lack of reflection, because these students were able to speak readily about disability throughout their interviews, but perhaps to their inability to connect disability to larger systemic issues of oppression and social justice. Betsy, a first-year student, explains her views on oppression and the positive perspective she employs to handle it.

I definitely think that there aren't as many opportunities – like you have to go find them. They are not as readily obvious. I am not going to be like the one though that goes - society is against us, blah, blah, blah. But there definitely is something out there that society needs to open up more to effect this change so that we can have all equal access and it is not such a big deal. I am not going to be the one to be like screw the world. I kind of think more optimistic where we are making progress. We still have to get there. You can definitely feel oppressed sometimes. But it is all about how you view it and how you channel that, too.

Jack did believe that disabled individuals were somewhat oppressed but was unable to articulate issues of power or privilege at a systemic level.

I think in certain ways they¹⁷ are. I don't know if like in a big way, but I think like definitely the way some people -an able bodied person - will look at them. I know some of the things that people have said to me like I will be at the grocery store and I will be loading something or doing something in my car and someone will come up and like do you need help. But it's like I didn't offer by myself just to ask for help. Just like I know most of the things people say they don't mean. They just don't realize, and they don't know how to say it.

Ben stated that those with disabilities are oppressed and likened the experience to racism. He also discussed the "positive" bias others hold about disabled people and how that is related to oppression. Ben articulates a common stereotype about disabled individuals—that they are heroes or inspirational beings.

Well it's really no different than judging people by the color of their skin. It's judging people by what they look like on the outside not the contents of their heart. Sometimes it can be but sometimes people are just looking around for it. I always say that people totally treat me different and treating me sometimes with a gross amount of respect. Just oh, my God, you're disabled. It's like they admire you. That kind of stuff.

For those students 18-20 year old students born with their disabilities, it was particularly difficult for them to see outside of their own personal experience and connect

¹⁷ Although Jack has disabled friends and is a wheelchair athlete, he consistently used "they" to discuss people with disabilities.

it to a larger issue, system, or community. For them, disability is normal and neutral; it is their reality. They have lived every day of their lives disabled and are only beginning to understand how disability is a social group and one that may be the target of systemic oppression. They are only able to acknowledge instances of oppression in isolation, and are only beginning to connect them to a larger sociopolitical issue.

Stephanie, who has been disabled from birth, provided two examples of oppression related to disability. She described that she first became aware of oppression when she was attending the opening ceremony of the Paralympics¹⁸.

As much of a big deal as it was, it wasn't as big a deal as the Olympics. It wasn't on TV. Still today it is not shown on TV as much. There are a lot of petitions going around and stuff like that. I think it's really sad that they can't make more of an effort to do it because I think watching somebody with a disability that can do it. I think it is more impressive. Not so much inspirational but I think it is pretty cool to watch. Maybe that's my impression because I have a disability. Stephanie's second example of how those with disabilities are oppressed was a time when her friend could not access a fraternity party because the fraternity house was not accessible.

When asked about oppression, Kate, born with her disability, was unable to answer the question. She needed time to think, but could not formulate a response:

¹⁸ The U.S. Olympic Committee's (USOC) Paralympic Division was formed in 2001 to increase support for and raise awareness around Paralympic sport in the USA. The USOC Paralympic Division coordinates the preparation and selection of athletes to U.S. Paralympic Teams, both summer and winter. Through these efforts, the USOC Paralympic Division promotes Olympic ideals throughout the American population, especially among those Americans who have physical disabilities (<http://www.usolympicteam.com/paralympics/about.html>).

“Well, let me think a second. Could we go back to that question later?” Margaret, also disabled from birth, tries to articulate her opinion:

...for me in some ways I want to say – yes, I feel oppressed sometimes but sometimes – no, because I think about everyone else like the whole equal rights for everything, you know? Kind of like in the grand scheme of things I guess not. Because I think like how everywhere is not wheelchair accessible. You know, the U of A definitely is but not all colleges are. Not all places in the United States are – kinds of things like that. It is kind of a mixed emotion, mixed feelings for me because I’m not really sure. Because I have been pretty lucky because I have been able to get where I want but I think about it. There is still so much out there that I want to see and how much of it am I really going to get to see? Because of wheelchair accessibility. I don’t know. It is kind of mixed, I guess. And I am not really sure exactly how my stand is on it kind of thing.

Christopher, a graduate student whose spinal cord injury occurred almost ten years ago, provided this general perspective on how difficult it is to internalize oppression:

To try to sum it up, I think societally, yes people with disabilities are oppressed, and I think that oppression is so ingrained in our society that even the people with the disability is oppressed even though they might not realize it - like they impose societal values on themselves in an oppressive way. Kind of like not thinking that we have the right to ask for something or demand something... So I do think it

manifests itself in a lot of different ways and one way that is the least empowering or restrictive I guess is the expectation level of somebody with a disability is basically zero. If you are entitled, you can get on social security benefits or whatever and you never have to work the rest of your life. You never have to make anything of yourself necessarily. And that's why it is always so inspiring when people see someone with a disability in school or working or driving or buying toothpaste.

He also described how before his accident, he was oblivious to how disabled individuals were treated. This statement articulates the development of his awareness of oppression, and is also related to anger and the common perception by non-disabled individuals that those with disabilities need help with routine tasks.

Well, I had about two and a half months of that rehab and that mentality and surrounded by that type of stuff, but then I got out in the real world after I got home. I started to see how I was viewed by other people and how I was treated. I became very perceptive of little different things. It was pretty obvious to me that I was being treated differently and patronized and pitied in certain situations which I internalized. I never lashed out at anybody, but I didn't just brush it off either. I remember one specific time – this was like the first time I kind of went back out to do things on my own after I left the hospital. Me and my dad went to Wal-Mart. I got into Wal-Mart, got a basket and got the stuff that I was shopping for. My dad was getting some of his stuff, too. And we both came up to the

checkout line, and I put my basket on the counter and she rang it all up. I had my wallet with my debit card in there. They had those standard things where you punched in your pin and everything. I had never used one of those at this point since getting hurt. So my hands don't really work all that well so I'm kind of fumbling with my card trying to get it out of my wallet and trying to figure out a way to slide it through the thing. The lady – the cashier – is standing there watching me. She is watching me fumble with my card, and she looks at me and then she looks at my dad and she is like – is he going to be able to do it? You know? And so I started noticing those types of interactions a lot. It doesn't sit well with me. I don't like this type of treatment. At the time I was 23. I was a 23 year old man. I had been living on my own since I was 17, being independent and I was just blind to that type of treatment of people.

Though not a single respondent specifically acknowledged this possibility, another potential explanation for their apparent discomfort in connecting disability to oppression may be a way of coping or survival. It may be too painful to identify as a member of an oppressed group. For these individuals, life is “normal.” If they admitted that they were oppressed, or systemically denied access and opportunities, how could their lives remain “normal?” Additionally, there is a backlash against civil rights that was not articulated by respondents. Not only may it be too difficult on a personal level to identify as oppressed, but it may put students at a disadvantage to do so because they may be perceived as trying to “take advantage of” their disabilities.

Defining disability

The previous theme may be directly born out of the oppressive language traditionally and currently used to define disability. These disempowering ideas are not only limited to the dictionary, they are perpetuated throughout society. As purported by Disability Studies, these are the definitions that inform how disabled and non-disabled people understand disability.

The dictionary definition of disability is oppressive. Merriam-Webster's dictionary (2008) defines "disabled" as: "incapacitated by illness or injury; also: physically or mentally impaired in a way that substantially limits activity especially in relation to employment or education" (<http://www.m-w.com/dictionary/disabled>). Synonyms for "disabled" in Webster's thesaurus are "challenged" and "incapacitated." It continues, "deprived of the power to perform one or more natural bodily activities, the disabled man was unable to climb the stairs without help" (<http://www.m-w.com/thesaurus/disabled>). It describes "disability" as: "the condition of being disabled; inability to pursue an occupation because of a physical or mental impairment; a disqualification, restriction, or disadvantage" (<http://www.m-w.com/dictionary/disability>).

When asked to define disability, respondents struggled. They used negative, oppressive, language or they were hesitant to provide a definition. Their responses to defining disability matched their earlier responses around oppression. Students were confused, and unable to generate a positive response. They could not define disability in a positive way. However, all respondents were able to speak about positive experiences

around their disabilities, opportunities having a disability has provided for them, and the support of their disabled friends.

Brian tried to provide the most neutral definition he could, so as not to make it seem overly value-laden.

That's a tough one. I mean I would probably try to make it – just take it what I would consider the most basic dictionary kind of answer – just like any sort of issue that negatively impacts a person's – I guess anything – a person's body in general whether it be physical or mental or sensory.

Kate was also reluctant to define disability with negative language. The language she defaulted to using to define disability did not match her experience with disability. She was also intentional not to say that the disabled person was the problem.

I guess a person who can't – I don't want to say can't do things the normal¹⁹ way – but has to make an adjustment – I guess an adjustment. They are prevented from doing things the normal way because of the disability. But I mean whether they are born with it or they got in an accident or something, they can't just do it the normal way that everybody else can.

Stephanie, like Kate, focused on the need for accommodations and not a problem with the individual disabled person.

¹⁹ It should be noted that students used the word "normal" only when discussing the definition of disability. Throughout their interviews, they did not use the word "normal" to describe able-bodied individuals or those without disabilities. However, perhaps the only way they know how to define disability is by explaining what it is not, by comparing it to the dominant group or to societal norms.

Like a physical disability I just define it as it is just something that you know – a physical disability to me is like you can't always do things the same way as a normal person, but it doesn't make you a different person. You just have to do it a different way. Like to get around in a wheelchair you are just a different way of walking I guess.

When asked if she felt that her definition matched the popular definition, she said,

Not really. I think that disability in general is probably a negative thing to some people like they really don't understand. But I do think it is getting better.

An alternative response to this question was that everyone had some level of disability because disability is a spectrum.

I guess – I don't want to say limitations. That's a good question, too. I say I guess that we all have disabilities whether it is you don't understand on certain social issues – you don't understand that. I guess maybe like limitations or difficulties you can overcome. I guess they don't go away but you can try to overcome them or something, I guess.

When I probed this idea with Jack and asked if using eyeglasses was equivalent to using a wheelchair, he shared a definition that described disability as continuum.

I: How do you define the word “disability”? How do you define it as a term?

J: How do I define the word “disability”? I guess I define it as something that physically or mentally prohibits you – no that makes you somewhat – it’s hard. I don’t know. I haven’t really thought about it.

I: Why do you think it is difficult to come up with a definition?

J: Just because there are so many ways you can look at disability in general. There are so many different types. I guess it is just something that can be looked upon that can make a person either seem different or –

I: Do you think there is a spectrum or do you think everyone has some level of disability?

J: In some ways, yes. I mean every person has some kind of characteristic that can make them seem like they have disabilities. I guess a disability to me is just something that makes you seem different. Every person has some aspect of that.

Ben also expressed that he felt disability existed on a continuum. He also tied his definition of disability strongly to notions of independence and how one is able to function in society. He did not ever discuss the idea that one’s environment could be modified to help them participate more fully and independently. He defines disability as, Something that – well how I define it is, I mean talking with my Rehab Specialist, he says I have a pretty extreme disability. I don’t know if that’s true because I know people that are in wheelchairs and have to have an aide come and help them at night and that’s pretty damn extreme. I can function on my own. I don’t need

any outside help except for some stuff but if I was living on my own, I could live on my own. So I guess I would define disability as - Well really I think it's a mind set sometimes because my friend – he is way smart, way smart. Take a class – just go to the class and not study for final and pass it – except for his homework. But me I have to study like crazy, and I still don't do so hot often in terms of finals. But if you put him and I on the street and see which one is alive in a week, it will be me. Because he is just so book smart that he would not function in real life. I'm not saying I am the end all be all of functioning in real life but I have a pretty good handle on it.

What is apparent is that formal, societal definitions of disability are incongruous to the real experiences reported by these disabled respondents, supporting the idea that disability is socially constructed. This finding lends credence to the sociopolitical model of disability and the need to affect change at an institutional level.

Disability culture

When asked if there was a disability culture, all respondents answered positively. Although it may not be as widely recognized or validated by larger society as other minority cultures, disability has a distinct culture, with community members, social norms, and rites of passage. Students spoke about their disabled friends and the support they gain from them. They described shared experiences, “in-group” language and the

dynamics of slang, and the athletes spoke about the positive impact athletics has made on their lives.

Brian shared a quote about disability culture that captures many of the respondents' sentiments on peer group, identity and how non-disabled individuals perceive disability.

Well, I think there is a really good quote...and I'm kind of paraphrasing it. It is from a book, and essentially what it says is if you ask an able bodied person what they have in common with a person in a wheelchair, they will say not much, nothing. But if you ask a person in a wheelchair what they have in common with an able bodied person, they say practically everything, and it's kind of that not seeing it from an able-bodied perspective that kind of makes us tend to band together a little bit more and desire the understanding from each other through our likeness.

Although disability is a blanket term for a broad range of experiences, respondents were able to describe the bonds that connect disabled individuals. These sub-themes are expanded in the following sections.

University of Arizona makes positive impact on lives

All participants indicated that the UA campus was highly accessible and that this climate increased their independence and helped them have a more positive outlook on disability. All participants were aware of the facilities offered at UA (either accessibility

or athletics) and this factored into their decision to attend. Respondents described campus and the surrounding community as highly accessible and stated that not needing to worry about physical barriers enhanced their personal experiences. Brian describes the level of access on campus and in the Tucson area:

Out here you don't have to think about anything. Back home it's like if you are going out to a restaurant you haven't been to, I'm going to have to call. You can't just whiz around the city. You can't just do all this crazy stuff. So yeah, it's really key. It's real great to be able to visit there [East Coast] but try to live up there and get around would be crazy”.

Jack also indicated that the accessibility at the UA influenced his decision to attend and continues to enhance his experience.

I: What were some of your expectations around like this campus and accessibility like did that enter into your decision to come?

J: I knew it was an extremely accessible campus. I knew everything was accessible. When I came out here in February, just everything was set up perfect.

I: How does it compare to where you are from? Like your high school and area?

J: My high school we actually had a lot of trouble with. Like they had redone it but it wasn't up to standards. My town in general wasn't totally accessible at all.

I: So it's a huge switch then?

J: Yeah. It's a big switch. It's nice coming to some place where you don't have any worries about getting around anywhere.

Margaret reflected on her transition to the UA. She participated in the New Start summer program and it was the first time that she remembers feeling that her having a disability, using a wheelchair, or needing accommodations was not a “big deal.” She described that newfound acceptance to be very freeing.

...I mean that was one thing that was really impressive to me coming here is how easy people took to the fact that I was in a wheelchair and needed extra accommodation. It wasn't like a big strain or I never felt like it. It was like okay, we can do that - like it was normal. And for me I wasn't used to that, I guess in some ways because it always seemed kind of difficult to get accommodations and were insecure of being able to have those accommodations. It was really beneficial.

Additionally, several students mentioned that it is very common to see other disabled people and others using wheelchairs and that this made them feel like having a disability was not that unusual. They felt comfort in knowing there were others on campus with disabilities.

Having attended other institutions, Ankur described the impact the accessibility of UA has made in his life.

That's the thing. It is not one thing or two things or a couple of people. It is the whole experience. Now when I drive in Tucson and I see somebody in a wheelchair, I'm like yeah, there you go. I mean in Tucson I have never – on campus especially – a student made this observation. You don't go a block

without seeing a chair. And that makes me happy. Okay, cool. I mean I feel like the campus caters to us. It is much more accessible... That helps you with your esteem so much. You don't feel like you are out of place anymore. Another thing is whenever I have an AB [able-bodied] friend and we are hanging out with friends who are in wheelchairs and one is an AB, the AB will find a chair to sit on. They will find a wheelchair to sit on. You just don't feel out of place if you see so many people in chairs. It is a spiral effect. If your esteem improves on one side, you carry it over to your other fields of life. It really doesn't have anything to do with disability anymore. But the thing is you take the confidence there and yeah, I can do this. You can be more assertive. That is the whole thing about being in an environment that is conducive.

The sense from respondents was that UA promoted a healthy disability culture through its high quality services, high level of accessibility, and strong athletic teams. Students indicated that UA and its surrounding community supported a positive disabled identity because they were granted access to almost any desired place or opportunity. The disability culture and identity promoted throughout UA and Tucson helped them develop a more positive personal concept of disability. This specific finding implies that, like other identities, disability is socially constructed.

The impact of UA's highly accessible campus, supportive and progressive staff, and strong athletics enhanced the experience of all respondents. Related to many of their definitions of disability, when an environment is accommodating, access and

independence are increased and the negative aspects of disability are lessened. If disability is largely defined as the lack of ability to participate or function within society, an environment that offered equitable access and attitudes, would be less disabling, as evidence on the UA campus.

Impact of rehabilitation

Students who recently acquired their disabilities all spoke highly of their experience in rehabilitation (rehab). They each spoke of specific people they met or experiences they had in rehab that helped positively shape their outlook on life and disability. Brian volunteers at his rehab facility every summer. Christopher is in graduate school preparing for a career in Rehabilitation Counseling because of his experience in rehab. Jack met two of his best friends in rehab who he still talks to two to three times a week for support.

In rehab, these students were taught how to live with their new disabilities. They participated in intense physical and occupational therapy, and watched videos on how disabled people function in society. Brian described the infamous video in which patients watch disabled people have sex. He remembers this experience as awkward and comical, but also somewhat helpful in helping him see that disabled people could do “normal” things.

But in that the most infamous of the videos is like the disabled form video, and it's like different examples – you are with an able bodied person or two people

with disabilities and kind of like how they do it and examples, and it's with real people and real sex. Sounds like HBO. But that was the craziest video.

Brian also spoke about role models that he encountered in rehab—older people who had suffered injuries and now led productive lives.

I met some people in there – other people newly injured or whatever but they didn't really have an idea. The people who—the weirdest part of it were like the mentors who were around. There was a guy who was a quad – spinal cord injured, and he was pretty cool. He was almost like the little – kind of like the devil's advocate kind of representation cause he kind of like - he's like yeah, - at that point I didn't know could I still drink, could I still do anything. This guy lived a fairly normal, festive life to put it mildly and talked about it all the time. Talked about going out and having fun and stuff like that. So that was really cool.

Christopher reflects on his initial experiences in rehab as being very trying for his overall sense of self and well-being.

I didn't feel like I had very good direction, and I was really frustrated. And struggling with identify, too. What is my life going to be? What am I going to be doing? What am I capable of? All this stuff. I remember they brought me into the therapy gym one day and I got on the mat table and they are helping me like do range of motion and stretch me out. I was wearing a catheter with a leg bag, and they were stretching my leg up and somehow that thing in the leg bag came open and poured it all over myself. Those are those moments that I was just like

this sucks. Usually I was pretty positive and optimistic, but those were the times that I was just like this really f-ing sucks. So, those were kind of upsetting times.

His attitude shifted as he learned to function independently.

It's hard to say what it was like right at the time of when I got hurt. Thinking back on some of the thoughts I had about myself when I first got hurt, I feel that they were somewhat reflective of the great sociological impression of disability or at least my perspective of it. So within about four weeks of when I got hurt – realizing that my condition was permanent but not understanding what my capabilities were going to be – I thought I was going to be in a nursing home. That's what I thought my next transition would be. And I thought I would be a burden to my family, and I didn't want to move back because of that. So I was like - yeah, I'm going to a nursing home, and that's probably what is going to be left of me. Then I started getting this whole empowerment idea when I started doing rehab because that is what they would push. They would push us to do everything for ourselves – to try to maximize our abilities – physical therapy, working out, transferring, wheelchair mechanics, mobility. They would go on community outings where we would have to try to do things on our own without asking people to help us out. Just try to figure out ways to reintegrate our new abilities back into reality. ...it was all physical and occupational therapy. I never worked with any kind of psychologist or counselor in that hospital to really talk about those kinds of things. I probably wouldn't have been very open to talking

about them at the time. I feel like now I would be much more open, but at the time I wasn't. I did therapy there for about two weeks and I finally got transferred to the bigger rehab center. When I finally got there I was starting to be able to do some things a little more independently – starting to be able to work on my own transfer without any assistance. It still took a long time, but I was making progress. That gave me a lot of peace of mind because it kept me occupied with stuff.

Students drew much support from the rehab staff. They also made friends in rehab and began socializing for the first time with an all-disabled group. Jack is still in touch with his doctors and nurses and met one of his best friends in rehab.

My rehab doctors I still keep in touch with. I was in the hospital 6 months and it got to be like a second family to me. [I met] my buddy Jay he got hurt about a month before me so he had his arms so he would show me how to push right. He taught me a trick on how to take corners – just grab onto the walls and keep your momentum going. He taught me how to wheelie. There were a couple of fall down experiences with that. Probably the hardest part at first for me was learning how to get back up because at my rehab center they won't let you leave in a wheelchair until you know how to get yourself back up.

Ankur never experienced rehab because he developed his disability in infancy. However, through his peer group at UA he acknowledges the importance rehab has

played in so many lives. He described being invited to someone's "injury day" party, which commemorates the anniversary of becoming disabled—something that was imparted in rehab, and is regarded as a rite of passage.

This was my first year here. Everybody set out after breakfast – are you going to go to Joe's²⁰? I said why? They said it's his injury day. And I was like wow. Are you guys going to celebrate it? Isn't that something you just leave a guy alone, you know? What do you mean? They said no, come with us. There was a cake and a celebration...I think that's so much a part of the culture now – that's it not mentioned as much because it is part of the culture now. I went to somebody's a month ago. It was a big celebration. It's like a birthday. It is considered a birthday. It is a new life. It is a different life. Everybody remembers their injury day and everybody remembers their birthday now.

For those who acquired their disabilities as a result of an accident, their experience in rehab was extremely significant in helping them re-learn how to complete daily tasks and in normalizing disability. Students reflect on rehab with mixed emotions, as it was understandably extremely difficult to begin to comprehend the numerous ways in which their lives had just changed. The rehab experience is critical as it serves the transitional point for individuals who are learning to live with disability and can serve as a common experience for members of the disability community.

²⁰ This name has been changed to protect anonymity.

Disability-related career paths

Out of the ten respondents, seven of them have chosen majors that would enable them to have disability-related careers. In his memoir, *Moving Violations*, John Hockenberry (1995) introduces the term “Crip Job.” A Crip Job is the phenomenon that a disabled individual would choose a career that relates to disability. Hockenberry asserts that this phenomenon is not something that disabled individuals plan for, but just occurs naturally out of interest and passion.

The disability-related majors represented were: Family Studies and Human Development, Special Education, and Rehabilitation Counseling. Additionally two students were not in disability-specific majors, but planned to use their degrees to support a career that contributed to the disability community. Betsy’s major is Communication, but she chose this specific major intentionally so that she would be able to hone her public speaking skills and become a motivational speaker on issues of disability. Ankur is completing his Ph.D. in Epidemiology. While he did not say so specifically, it is possible that his interest with infectious disease is related to his own disability which was caused by viral encephalitis during infancy.

Stephanie, having just switched out of the pre-nursing program into Family and Consumer Science, explains her career aspirations:

I have always wanted to give back. I have had a lot of great doctors and a lot of good support networks through my hospitals. They have always been there for me and my sister, and I always wanted to like help children with disabilities. So after talking to a couple of people, I decided that I wanted to become a child life

specialist in a hospital and work with children that are going through like surgeries and stuff like that. Because I think it would be like easier for me to talk to them than an able bodied because you have been through it...I kind of want to get into the hospital field and then go back. So I might go back and become an RN or something like that later on in life. I really like the hospital setting, and I think it would be great. I actually want to go back and move to Atlanta when I get older and work in the same hospitals that I went to.

Like Stephanie, Margaret also chose a major that would enable her to work with children with disabilities. She initially wanted to be a doctor, but then chose to switch her major from Pre-Medicine to Family Studies and Human Development so that she could be a child life specialist and work specifically with children in hospitals. She was not aware that this specific major existed and it met her needs more completely.

Margaret reflects on switching her major:

I think the reason I wanted to become a doctor was because I wanted to help children. The reason I wanted to be a pediatrician was because I knew what it was like to be the patient, and I wanted to be the doctor and help because I knew there were doctors who were great and other doctors were weren't so great. I wanted to use that understanding of what it was to be the patient in being a doctor and then I knew childhood specialists existed because in [Tucson Medical Center] they had it and a lot of the hospitals use it.

Christopher is working on his Master's in Rehabilitation Counseling. He chose this career path specifically because of his own experience in rehab. He says that before he became disabled, he would not have been aware of such a discipline.

C: I kind of grew into it. You know I've worked with rehab counselors since I got hurt. In the rehab hospital is when I first got introduced to vocational counseling. I got my own counselor when I started going back to school, and they helped me with transportation, that type of stuff. So I became aware of it at that point. When I came here I started to get a better understanding of it. When I first decided that I kind of wanted to get into counseling, rehab counseling, my idea was to work in a spinal cord injury inpatient type of place for people with new injuries. I liked the idea of working there. I had done some peer mentoring type stuff and kind of enjoyed the work. That was my overall goal of my route to get to that position to go through rehab counseling. Didn't really want to get into the social work part then. I'm kind of interested in that, too, now but I don't know if that will ever happen. Then I just started working like doing prac apps at different areas and learning about the field. I worked at Dorothy Pratt and Associates on Broadway. I worked at the Salvation Army with drug and alcohol rehab. Doing my internship now between here and the VA in their voc rehab systems. It has just kind of grown on me. I'm liking it more and more as I get deeper and deeper into it.

I: Do you think that before your disability you would have had any conception of this field at all?

C: No, I didn't even know it existed. I had no clue. I think I was pretty sheltered. My vision was pretty narrow before I got hurt and I started having all these new experiences. I have just realized there is so much out there that I never even considered. And I still realize that now too, but at least I feel like I have a better understanding of the world in a positive way.

During their interviews, students spoke to the idea of a disability community and disability culture. Their choice of majors and intended career paths is another aspect of disability community. Disability community is not solely related to social outlets, but also formal academic disciplines. Born out of their own experiences with disability, the majority of these students selected a major that would prepare them for a disability-related career. One might be surprised by this trend as students could have very easily chosen a major that would distance themselves from disability. However, the fact that they chose to embrace disability in their academic and professional spheres speaks to their level of commitment to the disability community and culture.

Peer group

The majority of respondents indicated that they had a peer group that included both disabled and non-disabled individuals. They said that they kept these two groups separate, as they formed connections with each group in different places. They indicated that they met their disabled friends either through rehab, athletics, or upon moving to UA. They stated that because of the many social or athletic outlets UA offers disabled

students, they developed a supportive group of disabled friends through the UA. Most respondents stated that their friends from home were not disabled. Participants who acquired their disabilities later in life stated that prior to acquiring their disabilities they knew either zero or one person with a disability.

In her 1997 book, “Why Are All the Black Kids Sitting Together in the Cafeteria?”, Beverly Daniel Tatum explores the phenomenon of peer groups formed around identity groups. One can substitute “Black” for any other minority group and ask the same question. Respondents spoke about their experiences with this phenomenon as it relates to disabled individuals. They stated that they valued their disabled and non-disabled friends, however they were able to speak freely about medical conditions, bodily functions, and disability-related concerns with their disabled friends. They all found this support to be critical in their lives. They appreciate not having to explain the details of their disabilities to their disabled friends.

Brian reflects on his own observations on the way disabled individuals tend to have an affinity for spending time with other disabled individuals.

I have always noticed [groups of like cultures] at this rec center back in New Jersey and it still happens here. I would sit there and I would watch I don't know like eight or ten like Asian guys come in. They were like a band, and they were playing their own game against each other. I feel guilty about it but I process it like this, “That's weird, why do Asian people have to hang out with Asian people or whatever like that?” And then I look around, I like turn around, and there are twelve guys in wheelchairs playing basketball in the same game. So it's like you

can really equate it like that. It took a small epiphany for me to see it like that but it happened, so I guess that's progress.

Christopher describes the level of comfort he shares in discussing bodily functions with his teammates:

...like if you were coming to rugby practice or if you were to go off to dinner with a couple of guys from the rugby team, it is bound to come up in one point or another. I wet myself or I shit last night or whatever. It's just really common conversation.

Brian explained his need to have support from others with disabilities to learn about himself. What is particularly interesting in Brian's reflection is that his focus on disability shifts internally to externally when he is in an all-disabled group.

I think you have to be around somebody else even if it's you. I don't think I learned nearly as much about myself in the first year and a half of dealing with my disability as I did after I went to like the camp and started making other friends in chairs. And then I really feel that I understand a lot better... Yeah, if you are around just able bodied people all the time, it's like you don't notice yourself as much as you notice your surroundings.

When asked about her disabled peer group, Kate describes the value of being able to talk to others with disabilities.

Yeah, I think it is important because you can talk to other people. Not that I sit around and talk to my friends about being in a wheelchair because that is just not me. I learned some important - I don't know how to explain it. Like maybe when I first started driving or something. I mean just how to do it almost. Not how to drive but just how did you do it? Like when I first got my chair, I didn't know how to get in my chair. Like how did you do it? Just experiences and stuff but not to sit around and oh, how do you like being in a chair? You know? Not like that. Just different experiences – just to talk to people about it, I think is good.

Stephanie described that her peer groups is comprised of both those with and without disabilities, but that it seems more natural to be friends with other disabled students.

I think it's kind of like harder to make friends with able bodied people here in my opinion. I mean I have friends that I met at the dorms that are really good friends. I would say I would have more people in wheelchairs because I am around them more often I think, and through sports and I have known them longer. They are a really good social network. I think they are a bigger part of my life. I look at them just as normal as anybody else. But yeah, I would say I was closer with people in wheelchairs because we go through the same things. I do have friends that are able bodied as well.

Jack made the assumption that all disabled people liked to be around other disabled people, which speaks to his level of comfort with other disabled individuals and the support he draws from the community.

I think everybody who has a disability in some ways is always more comfortable around somebody else who has a disability. I know in basketball tournaments when we travel with basketball, we would always just be really close. We would always kind of just mess with each other so it is a whole different thing. So I had to get used to that after I got hurt. It is different than hanging out with my regular friends I have known here. It is a little bit of a different culture....I'm like we go out, you don't have to worry. If you go out with people with disabilities, you don't have to worry about somebody staring at you. You don't have to worry about any stupid questions.

He describes specifically how his disabled peer group has helped him understand the implications of his injury.

For me it has actually been a big part – having friends with disabilities, especially ones who have been in accidents just because it made it easier for me after I got hurt to have somebody to talk to who had been through either what I had been through or something similar – whether it was back injury or neck injury, something like that – any spinal cord injury. One friend who I got really close with – my buddy, Joey goes to the U of I. He broke his back as well so me and

him got pretty close. My buddy Jack has spina bifida. Me and those 2 got really close. My buddy Jay is like an older brother to me.

An important distinction can be made within the sample for students born with their disabilities or who have been disabled from a young. Those students disabled from birth who were involved with disability organizations (conferences, athletics, etc.) grew up around disabled peers and continue to be comfortable within the disability community. Further, they value their involvement in such organizations and the support they were able to draw from disabled friends. Students who were not exposed to the disability community at a young age were more resistant to become involved in college and had to learn the value of a disabled peer group.

Margaret was born with her disability but has never formally been involved with associations or athletics. She is extremely involved on campus, but does not have a disabled peer group.

I'm thinking I'm not really close to a lot of people who are in wheelchairs. Most of my friends – well all of them are not in wheelchairs. Like I know people who are in wheelchairs and who are acquaintances, but I don't know anyone. I don't hang out. And then I notice a majority of the population who are in wheelchairs do hang out and they do have like that sports thing that keeps them together but other people too I've noticed that. You know they all hang out, and I don't. I've never like been involved really much in that community which I've been thinking about. I guess maybe because I was mainstreamed the whole time, and there were

not a lot of people who were in wheelchairs who had my intellectual abilities except my sister and stuff.

Being a wheelchair athlete adds an interesting element to the question of peer group. Like Margaret, those students who were not involved with wheelchair athletics have no other disabled friends and have intentionally distanced themselves from other disabled peers. Two respondents, one born with her disability and one who acquired his as a child, said that they were not friends with anyone else with a disability and had no interest in creating this type of network. Those involved with wheelchair sports through their childhoods, whether they were born with their disabilities or acquired them, describe a very strong disabled peer group and articulate the value of support from other disabled people. They were involved with athletics at a young age and continue to be today. This involvement shaped their identities as athletes which continues to be a major defining aspect of their identities.

“In-group/Out-group” language and slang

An interesting finding as related to disability culture was the use of disability-related language by respondents. Throughout their interviews, respondents used language such as “disabled”, “someone with a disability”, “in a chair”, “able-bodied” or “A.B.”. These terms were used innocuously as general descriptors.

When I asked Erin about why she uses the term able-bodied, she had never thought about it before. We discussed the implications of calling someone without a disability “able”-bodied and she took pause.

E: I say able bodied. Like is her boyfriend in a wheelchair or is he able bodied? Stuff like that. Or like AB, you know?

I: Did someone teach you that at some point or did you just like start saying it when you were younger?

E: Nobody really taught me. I just started saying it. I have heard other people in wheelchairs say it and I just kind of caught on and kept saying it. Yeah.

I: ... I don't really say able bodied. I usually say someone with or without a disability or disabled – non-disabled or whatever. Because I don't know – able bodied to me is like I feel able bodied. I mean I feel like I am healthy. If someone else is able-bodied, what am I?

E: I never thought of it that way. I get the point. I never really thought of it that way. I was just like oh, yeah, they are able bodied.

Ben, a first-year student who became disabled as a result of cancer, consistently said that he was “rendered disabled.” Ben did not say where he heard this language, but did speak much about his interactions with medical professionals throughout all of his surgeries and hospital stays. It is possible that Ben memorized this explanation as a

child. No other respondent used the term “rendered” to describe his/her situation. Ben is a student who does not have many disabled friends and is not as connected to the disability culture as other respondents.

What is more important to the discussion of disability culture than general language, is the disability slang respondents used. Through their discussion on slang, respondents identified an “in-group/out-group” dynamic for disability that mirrors that of other cultural groups. The two students who were not athletes did not use disability slang, where the athletes said that they regularly use words such as “gimp”, “crip”, and “cripple” with one another. They say that this type of language is common within their peer groups, which are predominantly comprised of athletes. Christopher uses disability slang only with close friends or fellow athletes.

Yeah. I suppose I would use insider language at a rugby tournament where I just pretty much assume most people are insiders. But outside of that, outside of my own personal disability culture, I don’t just randomly go to people in wheelchairs and call them gimps.

Ankur also expressed that he freely uses “gimp” with friends and believes the term hold no negative connotations. However, he would not use such language in a professional setting.

If I am with my really close friends, I am not afraid to use the word gimp at all.

There is no negative connotation to it when we are just hanging out, you know? I would not say that if I was in an official situation.

Erin explains how she uses the word “gimp” and how it upsets her mother.

E: I use the word “gimp” a lot.

I: To who or in what context?

E: I say it to my friends in wheelchairs. Well, I say it around my friends who aren't in wheelchairs. They think it's funny. [My friend] and I were calling ourselves gimps last year, and one of the guys that lived in our hall would not say that word. He thought it was like so wrong. By the end of the year we got him to like not call us that but use that.... My mom doesn't like that word at all. She hates it when I call myself that kind of stuff. I didn't really start it until I got here actually. Because out here I hear a lot of people calling themselves that or other people in wheelchairs do. I just kind of caught on to that. I know it sounds kind of bad but ...Hey where are you hanging out tonight? Oh, just with all my gimp friends. And she just says – I hate when you use that word.

I: Why do you think she hates it?

E: I don't know. She just thinks it is so bad I am calling myself that. I don't know why. She just doesn't like the word.

When asked, respondents uniformly said that they would not feel comfortable with non-disabled people, or “A.B.s” using that language. They were able to describe an “in-group/out-group” dynamic, similar to that of racial or ethnic cultures. Those who were “in-group” could freely use slang or derogatory language because they shared in the experience of disability, which gave them permission. Those who were “out-group” were

not able to use such language. Some students said that they would not be offended if very close able-bodied friends or family used this language, but those were the only exceptions to this rule.

Much like other cultural in-group/out-group dynamics, language is a complex issue to understand. Students discussed the rules or etiquette for using slang. During his interview, Jack and I discussed dynamics of disability slang. Jack shared that he has told non-disabled friends not to use disability slang with him because he finds it unacceptable.

J: I know if I hang out with people who have disabilities, we will mess around with each other. We will call each other cripple and the like. We will flip each other. We will hit each other – all that good stuff. But if I am hanging out with somebody who is not in a wheelchair, who is able bodied – like if it is somebody I have never hung out with before – I will tell them straight out if I am hanging out with these guys and they are in wheelchairs, they can call me crippled. They can call me whatever. That doesn't mean you can call me that. So I tell them straight out. But if it is like one of my really close friends like my friend ____ or my friend _____. I know they are just messing with me. So like that I am fine with. But if it is someone I have never really hung out with, I will just tell them straight out don't say that around me.

I: Do people do that? Like do people call you that? You know what I mean?

J: No, I just like to tell them that I don't think it is right for people to say.

I: So you do get kind of angry when there is inappropriate use of the word?

J: Yeah.

Erin said that she does use disability slang, but she admitted so almost apologetically. She describes some of the dynamics around such slang.

E: Well a lot of my friends – like kids in high school would never use this but like being around people in wheelchairs – people will call each other like gimps.

I: Do you say that?

E: Occasionally. I have kind of stopped. My mom got mad at me. But honestly I used to take that so offensively. I think if it came from somebody – it's almost like saying the "N" word I guess. If it came from somebody that didn't know me, I would be really offended. People I know I'm okay with it. But it is almost like if we don't want people to be called it, we really shouldn't be saying it.

Brian explains his comfort level with disability slang and his feelings around who is permitted to use it.

It took me a while to get into like the crippled and gimp words, and I still don't like it per se but I've become more accepting of it. And obviously it has everything to do with who's saying it. It even bothered me initially when other people in chairs would throw that around. I think crip and gimp are pretty strong, bad words that I wouldn't want an able bodied person or somebody outside of the

culture to try to use it. And that happens sometimes. And people think they are being funny but it's probably like when I come up to my buddy and I'm like - you're my favorite nigger or whatever. I'm sure it's the same kind of feeling. The person saying it thinks they can get away with it and isn't trying to hurt your feelings necessarily. I think they just think they are closer than they are. It happens most often like on our women's team. They have an able bodied boyfriend or something so they obviously have a close relationship so he might feel he has more of a license to say stuff or make jokes, but to me that still never flies. I don't care.

Respondents could not describe a process for becoming "in-group." It was more understood than formal. It went beyond simply anyone having a disability because not all disabled individuals were considered "in-group." However, it did appear as though all athletes were "in-group." Jack insinuated that disability was a vast experience and that not all disabled people could relate to one another. Betsy also said that because she does not identify herself only as disabled, she would find it difficult to automatically connect with another person who happened to also have *spina bifida* or use a wheelchair. However, both Jack and Betsy stated that their teammates were "in-group." Athletics adds an important dynamic to disability culture that all athletes in this study were able to acknowledge but not necessarily explain.

Significance of wheelchair athletics

A significant finding as related to disability culture is the positive impact wheelchair athletes makes on the lives of student athletes. The significance of athletics in the lives of the respondents emerged consistently throughout their interviews. Eight of the ten respondents are or were heavily involved in wheelchair sports and three have been involved since before college. All eight students speak repeatedly about the implications athletics has had on identity, peer group, sense of self, and involvement in college and in the community. Each of the eight students attributed their choosing to attend UA to the strong athletics programs and/or being intentionally recruited to play. When asked what has made the most impact on their college experience, the, all five wheelchair athletes answered sports and their teams.

Christopher discusses the meaning athletics has in his life and the role it played in helping him form a disability identity.

...the most helpful thing for me was getting into this whole disability community and getting on the rugby team and being surrounded by people who have had similar experiences. Because it helped me – it helped me fit in and form my identity and kind of get a more comfortable view of how I wanted to be treated in the world and how I viewed myself as being treated. I mean that helped me – to see other people. It made me consider things that I had never even thought about.

Betsy, who has been an athlete since elementary school describes the impact athletics has made throughout her life.

It wasn't necessarily at first – wanting to be an athlete. When I was younger, I never thought I was going to do sports or anything. When I got into it, I was just more active I guess. But it is really about bonds that you make and friendships and the teamwork that you do. You know a lot of sports pretty much are teamwork – well for basketball anyway. So, you get to learn like life lessons, interactions on and off the court. You learn how to cope with certain situations, how to handle and deal with people. I guess it's just the most accessible outlet out there for people with disabilities to really feel like they are going to be supported in a tight-knit community and really just kind of explore and find out what works for them.

What makes athletics unique is that it supersedes all of the findings in that it is related to culture, community, peer group, involvement, and that all athletes clearly stated that athletics supports a positive disability identity. The respondents answers indicate that they cannot discern athletics from independent concepts of “culture” or “community” seemingly because they are so entrenched in the culture of athletics. Wheelchair athletes spend the majority of their time outside of class practicing, scrimmaging, or competing. Additionally, they spend time with their teammates in a casual, social environment when they are not on the courts.

Jack describes the time commitment for basketball alone. Other sports practice separately.

I: So you play rugby and basketball. Are you involved with other stuff yet on campus or interested in becoming involved in other things?

J: Well, right now I don't have a lot of time for it. I am spending so much time between school and rugby. I'm learning rugby as much as I can and trying to keep up with school.

I: How much time do the sports – do athletics take up for you?

J: We have practice Tuesday, Thursday, Friday and Sunday morning scrimmage, and Monday, Wednesday, Friday I usually lift to stay in shape. So it takes up a fair amount of time.

Discussed earlier in this section was the significance of disability-related language and the use of disability slang within the disability community. The slang used by students was used most frequently spoken during practices or games. This language is used off the courts and outside of the gym, but is largely spoken in the athletic environment.

UA has an internationally recognized sports program and wheelchair athletes are recruited from around the world. There is an extreme sense of pride shared by these athletes. This feeling of pride is not widely found in other disability-related programs, services, or opportunities. Students would not explicitly use the word “proud” when describing their feelings about being athletes, but they spoke much about their teams, traveling for competitions, and the camaraderie they experience with other athletes.

Similar to the plight of female athletes and women's sports, the students interviewed are sensitive to the need to qualify their sports with terms like "adaptive" or "wheelchair." Wheelchair athletes are athletes. They have the same experiences as other student athletes without the immediate recognition or understanding of their sport. Several of the students referenced the 2005 film *Murderball* as a positive representation of wheelchair athletics.

Betsy, born with her disability, has been an athlete since childhood and describes her local sports team as her favorite activity growing up and attributes her many friends and positive associations with disability to it. She speaks about her frustration over the general ignorance the public has toward wheelchair sports.

People always ask us, "how do you play tennis in a wheelchair?", "how do you play basketball in a wheelchair?" And I explain the rules. It really bothers me in terms of ESPN will air poker tournaments or hot dog eating contests, and they won't air [wheelchair sports]. You have to dig on the internet to find a national wheelchair basketball game. It is just not out there. You have to do your part in getting out there so people can see this is what we really can do. I do that through my public speaking, but it is taking small steps like that. You kind of want it to get bigger...like the Paralympics on TV.

Christopher reflects back to the time directly after his injury and speaks about how athletics and the athletics community has helped him develop.

My personality has changed a lot since that day – since those times. The biggest difference for me was coming to school here – just being a part of the wheelchair rugby community, the people that I have gotten to know here, the classes that I have taken. It has just all kind of helped me re-identify and have a whole new perspective on the world and everything and how I relate to it.

Sports provide these student athletes with opportunities to travel, work-out, and compete. Beyond the gym and the games, the athletes have become friends and consider their teammates their social circle. The strong athletics at UA programs influenced all the athletes to attend this specific university and is what keeps these students involved on campus. Personally, athletics has helped students develop a positive identity around disability through social interaction, the sense of team, and role modeling. This specific finding has direct implications for institutions of higher education to help support their disabled student populations.

Conclusion

Many findings emerged throughout the interview process that provides insight into the development of a disability identity. Several of these findings were directly relatable to the experiences of other minority groups, which helps to understand disability in a larger social and political context. Findings on perspectives, culture, community, and campus support a sociopolitical construct of disability in that the interplay of the individual within society was critical. This presents a challenge to traditional ways of understanding identity development.

All students spoke about their experiences with disability and with their environments. They described their social networks, and campus involvement, as well as what frustrates or angers them regarding disability and how they feel disability positively enhances their lives. What is clear based on the rich and multidimensional experiences described by the respondents is that their disability identity is dynamic. While they have a solid understanding of their disabilities, they also respond to their environments—to physical, attitudinal, and social barriers or opportunities. Internalizing disability is what makes them able to respond to their environments, sometimes with anger, sometimes with joy, and sometimes with inaction.

In traditional identity development models, individuals do not have the permission to respond to their environments. Responding with emotion or confusion has come at the expense of their fully developed, healthy, self-actualization. These findings support a dynamic sociopolitical framework of understanding disability identity that allows individuals to have an identity that is fluid, changing, and, indeed, dynamic. Themes presented in this chapter have direct implications for institutions of higher education in the areas of practice, policy, and research related to disabled students.

REFLECTION SIX

A few weeks before I graduated with my Master's degree, I scheduled an appointment with the staff member coordinating the logistics of my hooding ceremony. We introduced ourselves and I asked her about the program for the ceremony. She explained the route to me. This route was inaccessible. When I pointed this out to her, she immediately became defensive and quipped back, "This is how I've always done it." I, heart pounding, tears in my eyes, suggested a few alternative routes that would allow all students the opportunity to process in and recess out. She would not budge. The route for commencement was set. I would have to sit on the side of the auditorium and not partake in the processional. I then took a breath, mustered up all the strength I had, and calmly and clearly said, "I am getting my Master's degree. My parents will be here. I am participating in my hooding ceremony." The woman paused; her expression and entire demeanor changed. She agreed to utilize my suggested route and then began apologizing profusely to me. She said that not only was she apologizing to me, but to all the students who graduated prior to 2003 whose hooding ceremonies she had ruined. She looked to me for forgiveness, to absolve her of her wrong-doings. I would not. I thanked her for being willing to work with me on this and she thanked me for being so assertive. Assertive? I truly did not consider my words or my actions to have been assertive. I only asked for an opportunity to participate in my own graduation. I suppose I made the mistake of expecting that a university ceremony would afford all students an equitable experience, that it would not place different values on different students. If my being "assertive" was what it took for this woman to hear me, then so be it.

After the woman thanked me once again, I left the auditorium and immediately burst into tears. Luckily my advisor's office was upstairs. I shared with him my experience and explained that what left me the most uncomfortable was how this woman interpreted me as a revolutionary for wanting to do the right thing. I said that I just wanted to forget that experience and focus on celebrating my upcoming graduation...but my advisor challenged me to go write it down.

CHAPTER FIVE

CONCLUSIONS AND IMPLICATIONS

Introduction

This research project sought to examine the disability identity development of physically disabled students and outline their developmental process. Holding that disability is a sociopolitical construct, this study paid close attention to the social and political influences that shape students' identity, the role of the disability community, and students' emotions surrounding disability, such as anger and pride. Through qualitative inquiry, this study explored the interplay between the personal experiences of physically disabled college students with their social and physical environments to better understand how disabled students acquire a disability identity.

To address the current lack of knowledge and familiarity around the disabled student population, this research sought to offer implications for higher education professionals to increase their understanding of the disability experience. This study aimed to inform student affairs practitioners, faculty, and administrators on how to create more inclusive campus environments with effective resources, programs, and services in an effort to end the marginalization of disabled students and validate their experiences. This chapter will summarize all major findings, discuss implications for practice, the institution, and future research, and introduce a multidimensional model of disability identity.

Summary of Major Findings

In essence, my findings are the title of this study. Identity is fluid and dynamic. It is about an individual interacting with and responding to his/her environment (Mead, 1934). Through their interviews, respondents reflected that idea about disability identity. Students described having to negotiate their identities across various environments and in spite of various barriers. Specifically, four major themes emerged.

Sequence of identity development: Challenging traditional stage-like models

A major finding was that students did not develop their disability identities in a stage-like process. Once students were at a place at which they understood they had a disability, they did not progress down a one-directional path. Culture, community, systems, organizations and societal dynamics all played a role in shaping self-concepts and identity development. These dynamics were articulated by students as being critical to their experiences with disability, and thusly, they did not “move through” feelings or stages and abandon related emotions or ideas.

Disability is critical to, but not does not define, identity

While all students understood they were disabled and the effects of disability on their lives, none of the students identify only as disabled. In fact, students were reluctant to state “disabled” as their primary identity and made it clear that many qualities, characteristics, and experiences defined their identities. Students expressed that this might be incongruous with how others perceive them. They said that others likely

assume that disability is the most important piece of who they are. Students resist that assumption. This contrast speaks to the common ideas, stereotypes, and conceptualizations that exist for disability in society that do not accurately represent disability for those who are disabled.

Perspectives on disability

Several themes emerged related to perspectives on disability. All students spoke about how being disabled has positively enhanced their lives. They spoke about the positive effects of wheelchair athletics, opportunities to travel and do public speaking, and their strong disabled peer groups as ways disability has enhanced their lives. An extension of this specific finding was that most students stated that disability has changed their outlooks on life and overall life philosophies. Because of their disabilities, two students expressly identified as overachievers and explained that they feel the need to prove people wrong by exceeding others' low expectations for those with disabilities. Others described how they are better able to handle challenging situations because they have already dealt with so much in their lives. Several students indicated that they handle stress better, are more outgoing, and make better decisions all because of the perspectives they developed through learning to live with disability.

Students spoke about anger and oppression as related to disability. When discussing anger, students shared similar examples of what made them angry related to disability. They mainly focused on external factors such as physical and attitudinal barriers. They did not indicate that they became angry every time someone asked them

about their disabilities or every time they encountered an inaccessible location, but such experiences were frustrating and would upset them occasionally.

Oppression was a challenging topic for students to discuss in general and almost impossible for some to relate to disability. Some students were able to speak about oppressive structures and give examples of how disabled individuals were oppressed within society, but they were reluctant to say that disabled people were an oppressed group. Perhaps due to their ages, some younger students may not have fully understood the meaning of oppression. The older students more readily stated that disabled people were oppressed in society. It is difficult to identify as a member of an oppressed group and that may be an explanation for why some were unable to make the express connection between disability and oppression.

When asked to define disability, students also struggled. A proper dictionary definition of “disability” did not match students’ personal definitions. Respondents consider their disabilities a part of their lives, one that is neutral if not positive, whereas dictionary and practical definitions of the word are extremely negative and oppressive. Students struggled when they were asked to provide a definition of disability. Some thought about disability as existing on a spectrum or continuum and explained that everyone had some level of disability. Others explained it as a difference and tried not to place a value upon the word. Similar to conceptualizing oppression, it was difficult for students to reconcile the incongruence between how they personally experienced disability and how disability is defined in society.

Disability culture

All students agreed that a disability culture exists and discussed key aspects of the culture. Students stated that UA has positively enhanced their identities, self-esteems, and daily functioning and independence through its highly accessible campus and positive conceptions of disability. Students who have spent time in rehab discussed this experience as an important aspect of disability culture. They described how rehab taught them to become independent and introduced them to disabled friends and role models. Peer group was another theme that emerged related to disability culture. All but two students had either entirely disabled peer group or one that was comprised of friends with and without disabilities. The eight students with a strong disabled peer group are athletes, those who do not have a disabled peer group are not. Choice of major and career aspirations emerged as another theme. Eight of the ten respondents had majors that were related to disability and were preparing for careers in disability-related fields such as Special Education or Rehabilitation Counseling. This finding was not congruent with the number of student athletes.

The final two findings related to culture are closely related. Students discussed disability-related language and slang. Students explained their comfort with certain terms to describe disability, like “chair user,” “able-bodied” or “disabled person.” They also discussed slang they used related to disability like “gimp,” “crip,” or “bif.” This slang was limited only to in-group usage. Only disabled individuals were permitted to use this language and the students would only use it on others with disabilities. More so, they were most likely to use this language with their fellow athletes. Students were able to

describe an etiquette related to using disability-related language that reflected in-group/out-group dynamics.

Wheelchair athletics was a significant finding related to culture. Eight of the ten respondents identified strongly as athletes. Athletics superseded many aspects of disability. Self-esteem, peer group, opportunities to compete, travel, and bond, and choosing to attend the UA were all attributed to athletics. UA has a particularly strong wheelchair athletics programs and all the athletes explained how beneficial their team and overall experience with sports is to them.

Conclusion

Students did not acquire their disability identities on a rigid, sequential path, like traditional identity development models assert. They described disability identity as multi-dimensional. Students articulated many dimensions of disability and how they were able to exist within them concurrently. For example, students could be angry and proud at the same time, and perhaps their anger was necessitated by their pride. When looking at anger, pride, oppression and community as they relate to disability, it is difficult to discern one from another. These are only some of the important aspects of the disability experience. Disability is multi-faceted and disabled individuals should not be forced to abandon their emotions or connection to community in order to develop their identities. In fact, emotions and community involvement should be embraced in order to advance disability as a sociopolitical construct and affect the systemic, institutional change that is needed.

A Multidimensional Model of Disability Identity

A new approach to identity development

As explained thus far, the experience of disability is vast and multidimensional. This study put forth a new conceptualization of disability identity—the multidimensional model of disability identity. Two major frameworks guided this research: identity is dynamic and responsive to the environment, and disability is a sociopolitical construct. Research drew upon existing identity development models and also looked to disability history, policy, and legislation for context.

The creation of this specific model does counter the rigid, stage-like progressions of previous identity development models because it allows individuals to respond to their environments and takes into account unpredictable external influences on the disability experience. Further, it allows for the potential that individuals have in shaping or influencing the environment. This model challenges the notion that individuals should “move through” their emotion. The idea that this is even possible is reflective of the American ideal of rationing and controlling emotion, an ethic that is perpetuated specifically by the current upper-middle or professional class. This ideal has infiltrated the professional world in many ways. True professionals conform or succumb to this emotionless archetype. Stoicism is rewarded over activism. Calm is rewarded over tears.

Existing identity development models reward a lack of emotion/ controlling emotion and those who conform to the prevailing ideas of success and normalcy. In identity development models such as Cross’ (1971,1991,1995) Model of Psychological Nigrescence or Cass’ (1979) Model of Homosexual Identity Formation end with stages

five and six respectively in which the individual has worked through his/her emotion and is considered healthy and balanced.

In Cross' original 1971 model, identity development ended with Stage Four: Internalization. In this stage the individual's hostility and anger subsides, s/he develops a nonracist perspective and is characterized by a calm and peaceful demeanor. Cross revisited his model in 1995 and added a fifth stage: Internalization-Commitment. This new fifth and final stage employs the energy and emotions the individual has developed in subsequent stages to be an active participant in the black community. Cross adjusted his model because it was criticized for assuming that the individual abandon all emotions and perspectives developed along his/her developmental path and become inactive by its, then, final stage. While this Cross' Model of Psychological Nigrescence was modified to correct for its originally limiting view of a complete identity, it remains stifling. It still assumes that Stage Five is a final stage of development and that identity development is predictable and linear. This model does not assert that identity is fluid or dynamic and does not allow for the interplay of individual and environment.

Similarly, Cass' model culminates with Stage Six: Identity Synthesis. In this final stage, homosexuality is viewed by the individuals as one of his/her identities and is no longer the most salient. Again, this model assumes that an individual is able to and should, in fact, downplay sexual orientation. To understand the progression of this model, one might offer that balancing one's sexual orientation would make life easier for the individual. The critical question to ask is whether it would make life easier for the individual or for the dominant group. Cass' final stage puts forth a homosexual identity

that is locked into place, always on par with or downplayed against other identities. This rigid definition, like Cross', does not allow for an individual to respond to or influence the environment. Stage Six does not seem like it would be a place for activists, artists, or even for those who become incidentally frustrated with a routine occurrence.

In 1994, D'Augelli criticized Cass' model for defining identity development through a sequential progression of stages. He contends that identity is socially constructed and can be shaped by societal and institutional factors. Much like the Multidimensional Model of Disability Identity developed through this research, D'Augelli assumes that individuals can shape and respond to their environments. D'Augelli's model is comprised of six interactive processes, not stages, involved in homosexual identity formation.

The Multidimensional Model of Disability proposed in this study values emotion and does not reward individuals for moving through it. Emotion may be the spark that ignites personal, societal or institutional change, the type of change necessary to dismantle oppressive structures around disability. Emotion produces activists, artists, and educators. Without it, the status quo would rule, and that is antithetical to the very idea of higher education.

Negotiating Identity

Once an individual either acquires or understands his/her disability, s/he may exist within various dimensions related to disability. Navigating these dimensions is dependent upon environment, mood, encountering barriers etc., as identity is fluid and

dynamic. The term negotiated disability identity is introduced to capture and describe the on-going experience of reconciling internal and external factors as well as the ability the individual has in shaping the environment.

Ignorance

Initially students are unaware of disability. Those born disabled are ignorant until they develop the consciousness to understand that not everyone is disabled. Because they live with disability from birth, they do not question themselves until they are prompted by interactions with others, or increased life experiences.

Of course not all disabled individuals were born disabled. Many acquire their disabilities through accidents, illness, or otherwise. These individuals are ignorant of disability until they become disabled. Many respondents indicated that they had no concept of disability before they became disabled in that they did not know others with disabilities, and could not accurately define it.

Questioning

Once individuals become disabled or they realize that not everyone has a disability, they begin to question. Living with disability from birth means that these individuals have never known a different reality. Understanding that disability is not a universal experience requires several incidents or encounters in which an individual is able to make comparisons. These incidents may occur when socializing, through

answering others' questions about his/her disability, or when they encounter challenges in accessing various resources or opportunities that their non-disabled peers do not.

Once individuals acquire disabilities, they begin to question what disability means to them and what impact it will make on their lives. They must learn to live with disability and that process may be difficult, both physically and psychologically. Because of a potential lack of experience with disability thus far, learning about disability is even more challenging. Questioning may begin during experience in rehab or hospitals and may continue beyond.

Negotiated identity

The term negotiated identity was chosen intentionally to describe an identity that is dynamic in that external influences trigger internal responses. Students who participated in this study spoke about how they learned to communicate needs, become advocates, and manage emotion. They described situations and opportunities that both helped and hindered a positive disability identity. Throughout all interviews, there was an emphasis on the interplay of individual and environment.

Contrary to existing models that require individuals to travel a one-directional path to optimum identity development (Cross, 1971, 1991, 1995; Cass, 1979; Schlossberg, 1977, 1995) or models that lock individuals into identity profiles (Josselson, 1971), the Multidimensional Model of Disability Identity allows individuals to live in the multiple dimensions of disability. A negotiated identity means that all experiences are valid and neutral. It is not better or worse to be an athlete, or not be an athlete, to be an

activist, or not be an activist. These experiences are often impossible to discern from one another. Additionally, one may shape the other, and they may change constantly or over time. This model allows disabled individuals to respond to and shape their environments and does not bind them into a stage or phase as they do so.

Negotiated disability identity is visually represented by overlapping, interacting spheres. The spheres represent various aspects of disability or contexts in which disability may exist. The descriptors included are not all encompassing, but serve to be representative of the disability experience. This visual represents a sense of motion. As mentioned above, it is not necessary, or sometimes even impossible, to discern one sphere from another or to strictly determine how they interact with or influence each other. Individuals negotiating disability identity are not simply reacting to their environments, they are also agents of their own development, active players within their ever-changing environments.

Ignorance

Student is either unaware that s/he is disabled because they do not yet realize not everyone has a disability or student has not yet acquired a disability

Questioning

Student begins to question his/her own situation and compare to others'. Student is beginning to learn to live with a new disability or is discovering that the disability with which s/he was born is not universal, but unique.



Figure 1: Multidimensional Model of Disability Identity

Implications

The goal of this study was to provide implications or suggestions for higher education professionals who, through the scope of their work, could influence the experiences of disabled and non-disabled students. The following implications for practice, institution, and future research are aimed at staff, administrators, and faculty. The overarching message for higher education professionals is to hold disability on par with other social groups; in practice, on an institutional level, and in research, disability must be considered a valid social justice issue. Some of the more concrete suggestions may not be possible on certain campuses due to lack of resources, but challenging existing notions of disability and looking critically at one's institution is something that all professionals can and should do to improve conditions not only for disabled students, but for the entire campus community.

Implications for practice

Paradigm shift

Based on the findings of this study, there are several implications for the practice of higher education administrators, practitioners, and faculty. Implications for practice are intended to yield university-wide change and also help to make daily interactions between disabled students and practitioners more effective and equitable. A paradigm shift is necessary in the way disabled students are viewed and embraced on college campuses; professionals must hold disability on par with other social justice issues and cultural groups. Disability should not be considered a deficit or one individual's

problem. Responsibility must shift to disabling environmental and attitudinal barriers that exist. Once professionals begin to validate disability and disabled students in the same way they do other identity groups, it will infiltrate their practice and improve the experiences of disabled students on campus.

An initial step is for professionals to begin looking critically at the institution at which they work and analyze the messages that are being sent to disabled students. There are many ways to check for inclusive messaging around disability. For example, what theories or models do units or individuals use to inform their practice with disabled students? If units are operating from a deficit model, it is critical to consider disability as a sociopolitical construct, a construct that the campus environment has a responsibility to support. Considering disability as a social construct may help professionals remember that the onus should not always be placed on the disabled student to request access and equity. Professionals should try to alleviate that stress for disabled students by creating inclusive and equitable programs, services and overall environments.

A suggestion for professionals as a way to initially assess their efforts is to look to campus cultural centers. This would require that disability is acknowledged as a cultural group. Many universities have dedicated offices or units that work specifically with certain culturally underrepresented groups. These units may have social outlets for their students, both formal and informal, that may be replicated for disabled students by disabled students. Cultural centers tend to have student governing boards or opportunities for students to program around specific issues. Examples of such initiatives

could be disability pride events, student councils to assess campus disability issues through programming, or honoraries.

Programs and services that promote positive disability identity—students as self-advocates

Higher education professionals understand the impact student involvement makes on student success and retention (Astin, 1984; Richmond, 1986). Professionals must ask themselves about involvement of disabled students on campus. Much can be done to support disabled student involvement on campus and promote a positive identity around disability in the areas of programming and services. As the respondents indicated throughout their interviews, UA helped promote a positive concept of disability that they were able to internalize. They attributed this much to the overall climate of the UA and its surrounding community, but also to the programs and services available on campus. Increased programming on college campuses for disabled students would help all students. Disabled and non-disabled students alike would learn positive ideas about disability.

In an effort to challenge the culture that exists for student involvement, I recommend, rather than having professionals develop programming opportunities for students, that students be actively involved in developing their own opportunities for involvement. This promotes a more progressive approach to student development in general, but also breaks away from the idea that disabled students need help in order to be successful (Swain, French & Cameron, 2003; Smart, 2001). Pioneers of student

development like Arthur Chickering and William Perry assert that students must be actively engaged in their experience to promote their own growth and development (McEwan, 1996; Evans, Forney & Guido-DiBrito, 1998). If students are to be considered agents of their own development, they should be active in their own needs assessments and in developing opportunities for involvement. Beyond involvement, students should also be self-advocates (McCarthy, D., 2007). Respondents all spoke about their frustrations when others felt the need to help them simply because they were disabled. If disabled students were empowered to give input and craft new paths to inclusion, education, and involvement on campus, they would dispel the myth that disabled individuals require the help of those without disabilities in order to be successful.

Due to the lack of scholarship and real, first-hand knowledge available on disabled students, higher education professionals may not be effective in creating disability-related organizations or raising involvements from disabled students. These professionals would benefit from consulting disabled students on their campuses to gain a true understanding of disability and promote their own education. It is truly disabled students who are their own best advocates.

The benefits of social and programmatic opportunities are clear for those students with and without disabilities. For students who have not had extensive experience with disability, or for those who are grappling with their disability identities, a social club may provide support or simply opportunities to network. This group could benefit incoming or transfers students with disabilities in particular who are learning to navigate the campus and university life. Increased involvement and presence of disabled students

would also serve to educate those who do not have disabilities on the disability experience.

My specific recommendation challenges the practice and dynamics of traditional student clubs and organizations and the role of the advisor. For the reasons described above, I suggest that a peer network of disabled students is created for disabled students by disabled students. These students can act as mentors or advocates for new students, can plan activities and events that they believe would benefit the campus community, and can serve as in a consultant capacity regarding access, accommodations, and policies. The needs and efforts of the group would be developed organically, out of personal need or interest. These students may also train student leaders in other organizations on how to conduct personal needs assessment or advocate for other students. The professional working with this group would not serve as a traditional “advisor” but as more of a facilitator. This model serves to put students in control of their own college experience and empowers them to advocate and create opportunities for themselves, rather than relying on professional to help them, thus challenging the traditional power dynamic that exists around disabled individuals being “saved” by the non-disabled.

Campus marketing and recruitment

University programs and services should reflect diversity of students in its membership. The strategic and deliberate recruitment of disabled students for all clubs and organizations is necessary to achieve diverse participation. Advisors, supervisors, and campus leaders should ask themselves if disabled students are represented across

student organizations. If not, it may be because disabled students do not feel empowered to pursue such options. Soliciting the feedback of disabled students regarding programs and services and their experience accessing such services is critical in meeting the needs of students. Lack of participation may indicate an overall chilly climate around disability on campus, or it may specifically have to do with marketing.

Marketing plays a key role in advertising what may or may not be an inclusive community. When looking at marketing, staff should be cognizant of where marketing is distributed, who is represented in photographs, what language is used, and where posters are physically displayed. If disabled students are not receiving information or do not see themselves represented in marketing materials, they may not feel that they are valued members of the campus community. If posters are hung so high that disabled students cannot reach them or utilize sign-up sheets, they may not be aware of various opportunities or be able to request information.

Implement or expand adaptive athletics programs

Respondents' positive experiences with athletics programs on campus were a resounding theme throughout their interviews. Because of the social networking, the sense of team and community, and the ability to travel and compete, athletics made a hugely positive impact in the lives of the wheelchair athletes who participated in this study. They all indicated that it was the ability to participate in wheelchair athletics that influenced their decision to attend UA and maintained their positive experience on campus.

Implementing opportunities for wheelchair athletics would be beneficial for campuses who wish to improve conditions for their disabled students. As there are only a few universities nationally who offer competitive adaptive athletics programs, it would be naïve to assume all campuses could easily create an elaborate athletics network. It may be more feasible for campuses to promote intramural or club sports for students with disabilities or connect disabled students to community sporting resources. Institutions could invite the campus to attend wheelchair sporting events and could highlight the accomplishments of wheelchair athletes as a way to educate around adaptive athletics and support its athletes.

Training for campus leaders

Training for campus leaders must be implemented to help demystify the inaccurate and antiquated notions around disability that are perpetuated throughout society and higher education. Staff, faculty, administrators, and student leaders would all benefit from training that would seek to help them better understand the realities of disability and provide resources for how to improve their interactions with disabled students. Staff have indicated that they have infrequent interactions with disabled students due to the low numbers of disabled students on campus (Kraus, 2002). Therefore, additional support and training would help to make staff more comfortable with disability.

Training topics could include information on practical models of disability and introduce the idea that, like many other identities, disability is socially constructed.

Information on the ADA, and resources on how to create an inclusive and equitable environment could also be potential training topics. Personal student accounts would add a powerful and real element to this training. Ideally, staff from a central office or students interested in social justice could present this training. The burden should not fall entirely on Disability Resources staff to lead the campus in education around disability. Empowering various members of the campus community to present such trainings would be symbolic of a campus commitment to disability advocacy and education.

Training should also include strategies for evaluation and accountability. In this climate of assessment, outcomes for all areas of practice (services, programs, advocacy, and research) should be generated so that professionals can work toward specific, measurable goals (Jones, 1996).

Implications for the institution

Gauging campus climate

Before change can be affected to improve conditions for disabled students on college campuses, higher education professionals must first gauge the climate of their institutions around disability issues. To understand climate, one must analyze physical environment, campus attitudes toward disability, resources and services available for disabled students, and representation of disabled students on campus (Wilson et al, 2000).

Assessing physical space may be as simple as working with disabled individuals or consultants to identify particularly problematic areas of campus and also highly accessible spaces. Signage is critical in the area of physical access. The university can

post clear indications of accessible entrances and routes to make navigating campus as easy as possible. When assessing physical space, the location of disability-related services also should be considered. The locations of such services send a message to the campus community about the importance of disability. For example, is the Disability Resource Center located on the margins of campus, or centrally? To request accommodations, do students need to travel a far distance or is the office in an intuitive and accessible space?

Gauging attitudes may be a more involved process as it would require surveys, focus groups, and conversations with a cross-section of campus community members. This information should then be used to inform the implementation of programming and services. This could present an important opportunity for professional development workshops for staff, faculty, and administrators as well as opportunities to engage students in dialogue around disability.

Role modeling is critical for students from underrepresented groups. The visibility of campus leaders, professors, staff or administrators, with whom they culturally identify may send the message to students that they can be successful on campus and that they are welcomed. When assessing the campus community, are disabled individuals represented? If not, climate may be precluding disabled professionals from working on campus and this may have implications for the recruitment and retention of disabled professionals on campus.

Human Resources cannot mandatorily capture information from campus employees on their disabilities, as such information is captured only upon disclosure.

The inability to capture disability information makes it impossible for universities to ascertain a definitive number of campus members with disabilities. Without such hard data, it is difficult to have comprehensive conversations around the recruitment and retention of disabled professionals. It may be prudent to work with hiring authorities such as deans, directors, and department heads, to learn how they market to disabled applicants or support them once they have arrived to campus.

Advisory council for disability issues

In an effort to keep disability on the university's diversity agenda, an advisory council for disability issues would solicit input from campus and community members about the climate around disability. This group could meet regularly to discuss needs, challenges, accomplishments, and current events related to disability on campus and provide recommendations to the administration on issues that affect the disability community. The council may also work to hold the university accountable to its disabled staff and students.

Disability Studies on campus

As discussed in chapter two, Disability Studies is a burgeoning interdisciplinary field that address the historical, social, and political dimensions of disability (+Albrecht, Seelman & Bury, 2001; Snyder, Brueggemann & Garland-Thomson, 2002). Disability Studies has followed the path of other "studies" programs such as Women's Studies, Queer Studies or Africana Studies. Currently there are approximately 30 universities in

the US, Canada, and the UK that offer Disability Studies options for students. While establishing a formal Disability Studies program may not be possible for many universities due to financial constraints or lack of resources, offering disability-related courses or incorporating disability into general education requirements may be a way to increase scholarly dialogue on disability.

Adrian Sherry (1997) discusses approaches for studying the experience of disabled individuals in large, introductory, 100-level courses. She believes that incorporating disability studies into a first-year seminar would be highly beneficial and would reach a large number of students. Sherry's primary goal is to help non-disabled students assess their personal attitudes and biases toward disabled individuals and help them develop an understanding of how these attitudes affect their behavior, thus dismantling the "us" versus "them" dichotomy.

Universal Design

A critically important implication for any institution of higher education is to strive for a universally designed campus. Universal design is "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design"

(http://www.design.ncsu.edu/cud/about_ud/about_ud.htm). The intent of universal design is to provide access to all by making products, communications, and the physical environment usable by as many people as possible at little or no extra cost. Universal design is a concept that is relevant to architecture, both in the public and private spheres,

technology, policy and education. Universal design benefits people of all ages and abilities and should not be considered a disability-specific initiative.

The beneficial effects of universal design were discussed throughout the respondents' interviews. All students spoke about how when their environments were accessible, they were not preoccupied with their disabilities. Many stated that they were only reminded of their disabilities when they were confronted with a physical or attitudinal barrier. A universally designed campus would improve the overall experiences of disabled students by increasing their access and thereby making their experience more equitable to their non-disabled counterparts.

Because it may be impossible to design something truly universally accessible to and useable by all, universal design is an ideal toward which to strive. However, creating structures and systems that are accessible by the greatest number of people would yield a campus that is highly accessible, accommodating and welcoming to its community. Beyond tangible evidence of accessibility, universal design would be symbolic of a campus that valued all members equally.

Implications for future research

Expansion of sample

A suggestion for future research on students with disabilities would be to expand this study to include additional disabilities. This study specifically focused on physically disabled students with mobility impairments. Disability is a vast experience and encompasses not only various physical disabilities, but learning, psychological, visual

and sensory disabilities. Further, even within a certain type of disability, the experiences of individuals may vary dramatically. A potential explanation for current lack of research on disability is the difficulty in drawing any overarching conclusions across experiences which encounter such individual difference. An increase in understanding of all disabilities is necessary to fully address the needs of the disabled student community.

Because disability is not a higher education-specific phenomenon, this study may be emulated with disabled individuals who are not college students. Findings may yield implications for such spheres as public institutions and services, business, policy, or media. While this study was specifically intended to inform the practice and system of higher education, disability can be explored through a different lens to put forth more universal findings.

Diversify site

It would be interesting to recreate this study on more diverse campuses. As discussed in chapter three, UA is a highly accessible campus with premiere disability facilities. Additionally, it is located in a region of the country that is accommodating to those with physical disabilities, with its flat terrain, temperate climate that rarely sees rain or snow, and its relatively new architecture. Speaking to disabled students on campuses that did not place such an emphasis on the disability experience would be sure to yield different findings.

Looking internationally at disability would provide interesting insights to the American disability experience versus the disability experience abroad. Based on

Ankur's experience having grown up in India, it is clear that international perspectives on disability vary and that the American perspective may be one of the more positive and empowered. Not only would this type of study provide a comparative perspective, it may yield specific implications for disabled international students studying in the US as well as disabled American students wishing to study abroad.

A multidimensional approach

Throughout this study, identity has been discussed as fluid, dynamic and vast. An individual is not defined only by one identity. A disabled person is not only disabled. Many characteristics and factors comprise one's identity and certain identities may be more salient at different times (Mead, 1934, Jones & McEwan, 2000, Abes, Jones & McEwan, 2007, Tatum, 1997).

Expanding this study to explore identity intersections would provide more specific information on the disability experience and its intersection with other subordinated identities. For example, potential studies could explore the intersections of disability and gender, disability and race, or disability and class. This multidimensional perspective may illuminate the intricacies and realities of the disability experience as well as help to support the notion that disability is a social group, on par with gender, race, class, and sexual orientation. This concept can be expanded beyond disability identity. Student development theorists must consider the way identities intersect when looking at identity development to better understand the complexities of individual identity development.

Implications for activism and social movements

What was lacking from all respondents' accounts was a sense of shared pride specific to the disability community. While respondents expressed being proud of their athletics or other specific accomplishments, there was no shared sense of pride for disability as a cultural group, similar to that of gay pride or black power. For as much as students identified things they wanted to see changed as related to disability, they never discussed such changes as part of a collective movement. One must acknowledge the great amount that has been accomplished in the area of disability rights and disability studies in recent history. However, these accomplishments have not necessarily motivated disabled individuals to share in a sense of pride related to disability. I believe that this theme has important implications for disability activism and understanding collective change. Perhaps that missing element of pride is impeding the much needed momentum around disability activism, particularly on college campuses.

In order to promote a positive social movement around disability, a future study should explore the perceptions disabled individuals have around pride and the external factors that continue to negatively influence societal impressions of disability. Disaggregating the disability community may be a way to examine pride in the disability community. For example, the deaf community may serve as an appropriate model, as it is an historically oppressed community of which its members are proud to be a part. Perhaps this culture being unified by language, or schools, has encourages the common belief amongst the deaf community that it is preferable to be deaf than to be hearing. A future study could explore the shared elements that serve to unify the larger disability

community and how these implications could help institutions of higher education serve as centers for social change and social justice education for disability.

Apply Multidimensional Model of Disability Identity to other identity groups

Because other identities may be conceptualized in a similar way, the Multidimensional Model of Disability Identity could be applied to other subordinated social groups. This study demonstrates serious implications for the applicability of existing stage theories on identity development to cultural groups and suggests that such rigid, one-directional models are inappropriate for explaining the experiences of cultural groups as they do not allow for the vastness, ambiguity, or dynamic nature of these experiences. Looking at identities such as race, gender and sexual orientation with a multidimensional lens, may be a more current and accurate way to understand students who identify as members of underrepresented groups and the process by which they acquire their identities.

Conclusion

This study sought to explore disability identity by engaging physically disabled colleges students in in-depth interviews about their experiences. The goal of the research was to explore the process by which disabled students acquired disability identities and provide implications that would inform higher education professionals on disability identity in an effort to validate and improve the experiences of disabled students.

What emerged was a multidimensional conceptualization of disability identity that challenges existing identity development models. This model takes into account the

vastness and scope of disability. The interplay of internal and external factors are what shape, change, and propel disability identity and this model introduces the term negotiated disability identity to encapsulate and reflect such dynamics. The reconceptualization of disability identity calls for a paradigm shift in the way disability is understood. It also has specific practical, institutional, and scholarly implications for higher education.

APPENDIX A

SUBJECT'S DISCLAIMER/INFORMED CONSENT FORM

Informed Consent

Social and political influences on student identity: disabled students' self-concepts

Introduction

You are being invited to take part in a research study. The information in this form is provided to help you decide whether or not to take part. Study personnel will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

What is the purpose of this research study?

The purpose of this study is to explore the experiences of physically disabled students to better understand how students develop a disability identity.

Understanding how students develop a disability identity can help higher education researchers, practitioners, and policymakers initiate programs and policies that better support disabled students throughout college and on-campus.

Why are you being asked to participate?

You are being invited because you have identified yourself as having a physical disability that affects your mobility.

How many people will be asked to participate in this study?

Approximately 20-30 persons will be asked to participate in this study.

What will happen during this study?

You will participate in three face-to-face interviews over a two to four week period of time. You will determine an interview date, time, and location. You will be asked a series of questions related to your background and childhood, your disability, and your current life and beliefs.

How long will I be in this study?

This study should take approximately 90-135 minutes. Each interview should take 30 to 45 minutes and the three interviews will be conducted over a two to four week period of time.

Are there any risks to me?

The interview will pose no direct risks. Although I have tried to avoid risks, you may feel that some questions I ask are stressful or upsetting. If this occurs you can stop participating immediately or choose not to answer the question.

Are there any benefits to me?

You will not receive any direct benefit from taking part in this study other than the opportunity to reflect upon your experiences with disability which may prove personally beneficial.

Potential societal benefits include:

- 1) student affairs professionals and higher education administrators who are interested in creating programs and services to support disabled students on campus;
- 2) researchers interested in expanding the discourse on disability identity;

Will there be any costs to me?

This study will cost 90-135 minutes of your time that will be separated into three segments, per your availability.

Will I be paid to participate in the study?

You will not be paid for your participation.

Will video or audio recordings be made of me during the study?

I will make an audio recording during the study so that I can be certain that your responses are recorded accurately only if you check the box below:

I give my permission for audio/video recordings to be made of me during my participation in this research study.

Will the information that is obtained from me be kept confidential?

The only persons who will know that you participated in this study will be the Principal Investigator: Amanda Kraus. Your records will be confidential. You will not be identified in any reports or publications resulting from the study. It is possible that representatives of the

Federal Government or the Human Subjects Protection Program that supports the research study will want to come to the University of Arizona to review your information. If that occurs, a copy of the information may be provided to them but your name will be removed before the information is released.

What if I am harmed by the study procedures?

There is no potential harm in the study procedures.

May I change my mind about participating?

Your participation in this study is completely voluntary. You may decide to not begin or to stop the study at any time. Your refusing to participate will have no affect on your academic standing at the University. You can discontinue your participation with no affect on your academic standing. Also any new information discovered about the research will be provided to you. This information could have an affect on your willingness to continue your participation.

Confidentiality section:

Representatives of regulatory agencies (including the University of Arizona Human Subjects Protection Program) may access your records to ensure quality of data and study conduct.

Contacts section

If you have questions concerning your rights as a research participant, have questions, complaints, or concerns about the research and cannot reach the Principal Investigator, or want to talk to someone other than the Investigator, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. (If out of state use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program via the web, please visit the following website <http://www.irb.arizona.edu/contact/>.

Who can I contact for additional information?

You can obtain further information about the research or voice concerns or complaints about the research by calling the Principal Investigator Amanda Kraus, Ph.D. Candidate at (520) 626-9714. If you have questions concerning your rights as a research participant, have general questions, concerns or complaints or would like to give input about the research and can't reach the research team, or want to talk to someone other than the

researcher, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. (If out of state use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program by email, please use the following email address <http://www.irb.arizona.edu/suggestions.php>.

Your Signature

By signing this form, I affirm that I have read the information contained in the form, that the study has been explained to me, that my questions have been answered and that I agree to take part in this study. I do not give up any of my legal rights by signing this form.

Name (Printed)

Participant's Signature

Date signed

Statement by person obtaining consent

I certify that I have explained the research study to the person who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant's satisfaction.

Name of study personnel

Study personnel Signature

Date signed

APPENDIX B
INTERVIEW QUESTIONS

Name:

E-mail:

Phone:

Gender: M F

Age:

Class: Fr So Jr Sr Sr+ Grad Prof

Program/Major:

Interview One:

1. Tell me about yourself.
 - a. Where are you from?
 - b. Family? Sisters/brothers?
 - c. Speak about community

(Do they mention disability?)
2. Describe your childhood.
 - a. School
 - b. Friends
 - c. Interests
 - d. Family

3. How did you decide to come to this institution? (Or undergraduate institution for grad students)
 - a. What influenced your decision?
 - b. Did accessibility/DRC play a role?
4. What is your major? How did you select this major?
5. Describe your transition to college?
 - a. Do you live on campus?

(Ask about graduate institutions if appropriate)
6. What kinds of things are you involved with on campus? Clubs, orgs, sports...
 - a. How did you learn about these things?
 - b. Why are you involved?
7. What were your expectations about the campus in terms of accessibility or climate for disability before arriving? Has the campus met your expectations?

Interview Two:

Begin by soliciting any more info from first interview...

1. Please talk to me about your disability.

BORN WITH:

2. What are your earliest memories of your disability?

3. How does your family perceive your disability? Treat you?

4. What was your peer group growing up?

5. What is your peer group now?

a. Has it changed since college?

6. Who shaped your conception of disability?

a. Media? Family? Doctors? Friends?

7. How do you think having a disability affected your childhood?

8. Describe medical issues growing up? How did this affect your childhood?

9. Change perceptions of you? Current?

ACQUIRED:

2. What was your perception of disability before?

3. Has your life changed since? How?
 - a. How did it change your educational path? Interests?
4. How did life change for your family?
 - a. How did/does your family handle your disability?
5. What was your peer group growing up? Has it changed? How, when?
6. Who shaped your conception of disability?
 - a. Media? Family? Doctors? Friends?
7. Please tell me about learning to deal with your new disability. What are some of your poignant memories?
8. Describe your experience in Rehab. Was this important in helping you deal with your disability?
9. Do you identify as disabled? Have you always? Describe this process for me. What helped/hindered this development?

Interview Three:

Begin by soliciting any more info from first interview...

1. When you reflect on your experiences, when did you first realize you had a disability? Why? How? Can you recall/describe going through stages in understanding/internalizing your disability?

2. When you think about your college experience, who or what made the most impact on you?

3. In terms of access, how do you communicate your needs?
 - a. When/where/how did you learn this?

4. Do you remember feeling angry? Talk about this.

5. Do you feel oppressed? When were you first aware of oppression? When did you become sensitive to disability issues?

6. How do you feel that your disability positively enhances who you are? What are things that make you proud related to your disability?

7. How often do you think about your disability?

8. How do you think others see you?

9. How do you define disability? How do you think others define disability?

10. Do you think there is a disabled culture? Describe it.

11. Do you think support from other disabled folks is important? What is your disabled community? Have you always had support from other disabled people?

12. Discuss disability language. Where did you learn? How do you use? With whom?

13. Is there anything else you would like to add?

APPENDIX C**SAMPLE E-MAIL COMMUNICATION TO STUDENTS**

Hi _____,

My name is Amanda Kraus and I am a doctoral student in Higher Education. I am currently interviewing students for my dissertation. _____ recommended that I contact you for my research.

I am researching the development of a disability identity for individuals with physical/mobility disabilities. This interest developed out of my personal experiences with disability and my desire to contribute to scholarship that will inform higher education professionals about disabled students.

I am looking to speak with students who have physical disabilities 3 times over a 1-2 week period. Each interview will be relatively short (30 minutes or so), and will cover a different area of life. I am looking to speak with students who have physical disabilities. I will do my best to accommodate your schedule. I can meet with you on nights and weekends if that would be easiest.

Also, if a student agrees to participate in the study, s/he will be entered in a drawing for a \$50 Amazon.com gift certificate.

I would be so appreciative you would consider speaking with me!

Thanks so much for your help! If you'd like, please give me a call at 626-9714 with any questions or concerns.

Take Care,

Amanda Kraus

APPENDIX D

RESPONDENT PROFILES

The following profiles provide more in depth information about each of the ten respondents:

Ankur

Ankur is a 31 year old Ph.D. candidate in Epidemiology at UA and the only international student in the sample. Born in Bombay, India, Ankur moved to the US for his Master's program at the University of Kansas. Throughout his interviews, he provided an important perspective on disability because of his experience growing in a place where disability issues were not discussed and accommodations were rarely made.

While he was not born with a disability, Ankur did grow up disabled as he developed viral encephalitis²¹ during his infancy which led to paralysis of his legs and other related complications. When asked to talk about his childhood, he said that it was “different, but not different.” For him, the most challenging part of having a disability living in India was that it was rare and almost impossible to see or advocate for accessible accommodations. He says that his family was extremely supportive and that he never remembers really feeling different, but that at school or in public places things were more difficult for him than for his peers. In India there was no “ADA”, and no one discussed or embraced disability. There were no publications or organizations dedicated to

²¹ Viral encephalitis is a rare and serious form of Encephalitis. Viral Encephalitis is a swelling of the brain as a result of a viral infection (<http://mayoclinic.com/health/encephalitis/DS00226/DSECTION=1>). While the symptoms of this form of encephalitis usually lead to mental impairment, it is possible to have physical ramifications. Ankur does not fall within any of the existing risk factor groups, so his diagnosis was extremely rare. Encephalitis is life threatening, which makes Ankur's situation more positive than most.

disability and this led to societal misunderstandings and a prevailing stigma around disability.

When Ankur moved to Kansas it was the first time in his life he had lived alone or truly functioned independently. He relied on the disability services available on campus and, by comparison to his home, felt that Kansas was extremely accessible. Once he moved to UA, he noticed a vast improvement in his quality of life and level of independence. Like many other students in this sample, Ankur was attracted to the UA not only by academics, but by the terrain and climate, Disability Resource Center, and the adaptive athletics program. He played rugby and tennis until his doctoral coursework and research became too time intensive to allow for extracurricular commitments.

Ankur spoke about how his self-esteem and self-image improved upon arriving to UA and acclimating into the disability community on campus. UA was the first place he developed friendships with other disabled people. He spoke much about the overall accessibility of UA and Tucson. The fact that there were so many people with disabilities visible on campus improved his personal ideas about disability and enhanced his own self-image.

When asked about disability-related oppression, Ankur had a unique point of view. While he said that he believed that disabled people were an oppressed group, he had to temper his responses with his international perspective, reinforcing how disability is socially and politically constructed. Because conditions in the US were so much more advanced than in India, it was difficult for Ankur to say definitively that he believed disabled Americans were truly oppressed. Ankur was able to make comparisons and point

out differences in the disability experience between the US and India which added a comparative angle to this study.

Ben

Ben was an interesting person with whom to speak. Ben survived brain cancer during his childhood. As a result of the cancer and the treatments, Ben has mobility, vision, and learning issues. He walks with orthotics and a cane, but has used a wheelchair in the past and, at some point in the future, understands that he may need to again. While Ben presents a very positive attitude toward disability, he also never identified as being disabled. He consistently said that he was “rendered” disabled, which implied to me that he had not internalized his disability.

Ben explained that he believed disability existed on a continuum. For instance, he did not consider himself as disabled as someone who used a wheelchair. Ben also compared being disabled with being dependent throughout our interviews. Depending on how much assistance one needed, from others or from orthotics etc., one would be more or less disabled. This notion is somewhat in line with disability being socially constructed. If environments were more universally designed to increase access for all, people with disabilities would be less disabled, as their access would not be limited.

Ben has an active social life, is involved on campus, plays music, and does rock climbing. He does not have a disabled peer group. He was a part of a support group for cancer survivors, but does not have disabled friends. He is not involved with wheelchair

athletics, although he is athletic. He does not utilize staff at the DRC as regularly as other students indicated they do.

When I tried to ask Ben why he would choose to participate in a disability-oriented study when he does not truly identify as disabled, he answered that he just likes to help people. Since our talks, I have seen Ben several times on campus and we always chat. I believe that Ben's experience with disability has been extremely shaped by the medical professionals who helped to save his life. He presented a very "hospital" perception of disability in that he used medical terminology and seemed to compartmentalize disability and not integrate it into the rest of his life.

Betsy

Betsy is an extremely outgoing, bubbly 18 year old first-year student at the UA. She was very easy to talk to and provided great insights and perspectives on disability. Betsy was born with spina bifida²². She uses a wheelchair, but has not used one for her entire life. She has used a chair since her early childhood. Betsy has had multiple orthopedic surgeries and has a shunt²³ in her brain.

From a young age, Betsy has been involved in many extracurricular activities. She was heavily involved in a disabled sports league, and a competitive choir through

²² Spina bifida is a neural tube birth defect that develops in the first month of pregnancy when the spinal column does not close completely (<http://mayoclinic.com/health/spina-bifida/DS00417>). It is the most common permanently disabling birth defect in the United States. An estimated 70,000 people in the United States are currently living with Spina Bifida (http://www.spinabifidaassociation.org/site/c.liKWL7PLlrF/b.2642297/k.5F7C/Spina_Bifida_Association.htm). The symptoms of spina bifida vary, but may include physical and or mental disabilities.

²³ A shunt is a tube that is inserted into the brain to relieve drain excess spinal fluid (<http://mayoclinic.com/health/hydrocephalus/DS00393/DSECTION=8>). A shunt system is very common for those born with spina bifida, as they often have complications with spinal cord fluid.

high school. She also does public speaking to education on the realities of living with disability. She is majoring in Communications to support her future career in public speaking and refine her speaking skills. Currently, Betsy is involved with wheelchair basketball and is extremely busy with her team commitments.

Betsy reflected on her childhood throughout her interviews. When I asked her how and when she realized what her disability meant, she spoke about not understanding for a long time that having a disability was not the norm. When Betsy was about five years old, she asked her mother when she had stopped using her braces, assuming that one day she too would outgrow the need for her orthotics. Betsy also spoke about how difficult it was and continues to be for her younger brother to see her endure painful surgeries and challenges. When he was younger he did not understand why she had to have surgeries and he did not. Her brother would become extremely upset when Betsy would need a surgery because he was afraid that she would die. Betsy had to support him through her surgeries, which helped divert her own anxieties in an effort to protect him.

Betsy is a very optimistic woman and, therefore, struggled with my questions to her around oppression and the definition of disability. She was reluctant to speak to oppression or more negative pieces of the disability experience because to her this is all she has ever known. She did not seem to want to admit that something so big and “normal” a part of her life was bad. Betsy is a self-proclaimed overachiever who is extremely committed to her team and to her family. She was very eager to speak about disability and believes that talking about her disability is the most effective way to

educate others and make change for the disability community. Her goal is to continue her public speaking to help dispel myths about disability.

Brian

Brian is a 28 year old undergraduate student at the UA. He is a returning student doubling majoring in Media Arts and Creative Writing. Brian was born and raised in New Jersey and was training to become a professional wrestler when he suffered a spinal cord injury during a match with over 200 spectators at the age of 22. He suffered a spinal cord injury²⁴ and uses a manual wheelchair.

When describing the impact disability has made in his life, Brian spoke much about how his injury helped him develop a different personality and attitude toward life. Pre-injury, Brian described himself as rowdy, immature, and without ambition. Now, Brian says that he has a new sensitivity that helps him connect with others easily. He says that he does not stress over things because he feels that he can handle any challenge that he may face. He is not scared of things because he feels that he is strong enough to conquer anything. Brian explained that he truly thought he was going to die and that now he feels like he is “playing with ‘house’ money” and feels lucky to be alive.

Brian described his experience in rehab as particularly poignant in his recovery and to his identity formation because it was there that he first met “normal” disabled

²⁴ The location of the injury on the spine determines the level of disability incurred (<http://mayoclinic.com/health/spinal-cord-injury/DS00460/DSECTION=2>). A broken spinal cord will most likely result in paralysis—the loss of nerve and muscle usage. An injury that occurs higher on the spine cord will result in more paralysis. There are several risk factors for spinal cord injury. Two particularly pertinent to Brian are his gender and the fact that he was training to be an athlete. Women account for only twenty percent of all spinal cord injuries (<http://mayoclinic.com/health/spinal-cord-injury/DS00460/DSECTION=4>).

people. In rehab he made friends and developed role models and mentors. He talked about the role of occupational therapists who helped him learn to live independently. He says that learning to drive again was extremely liberating and was a huge accomplishment during his recovery. He also shared with me the laughable instructional videos about how to have sex when you are disabled. He remembers giggling with friends during that film, but also the relief he felt knowing it would be possible.

Brian recalled one significant experience in Rehab in which he and a small group of other “quads” were sitting outside drinking beer and talking. It was at this moment that he thought to himself, “OK, this is what my life is now. This is what my peers look like.” That night stuck out for him because it was that night he felt a sense of peace with his newly acquired disability.

Each summer, Brian returns to that Rehab facility to volunteer. He enjoys the people and experience immensely and finds it rewarding to help those who have recently become disabled feel more at ease. He can relate to the feeling that life will never be the same. Brian feels that he can be a good example of how to lead a successful, fulfilling and fun life post-injury.

Brian moved to the UA to attend school and play basketball and rugby. He was connected to this university specifically through a friend he made in rehab. Brian is extremely social and spends the majority of his time either working-out, competing in games, or spending time with friends. He mentioned that he should probably be spending more time on academics, but, in accordance with his philosophy on life, was not going to stress over it.

During our interview, we discussed the movie *Murder Ball*. I had not seen the film, and shared with Brian that it had made me too uncomfortable to go to see it in the theater. The next morning, when I arrived to my office, a *Murder Ball* DVD was on my desk with a note from Brian telling me that he hoped it would help me with my research.

Christopher

My interviews with Christopher were, for me, the most challenging and the most enlightening. I knew Christopher casually from seeing him around campus and at the DRC. He agreed to let me interview him during his assistantship hours at the DRC. Christopher had acquired his spinal cord injury while rafting in rural Mexico six years ago. He swung across a creek on a rope and landed on a rock which broke his back. He waited for hours for a helicopter to take him to a bigger city where he could receive medical attention. He was then flown into the states for surgery. During his wait the thing that scared Christopher the most was that he felt no pain.

At the hospital he learned that he was now quadriplegic²⁵, but not yet how his life would truly change. He remembers feeling extremely depressed and anxious. He felt at that point like his life was over. He then discussed experiences that he had in rehab. It was rehab that introduced him to an idea of disability that was not completely negative.

Christopher is 29 years old and completing his Master's degree at the UA in Rehabilitation Counseling. He is also on the rugby team and through his major and his

²⁵ As mentioned above when discussing spinal cord injury, the implications of the disability varies according to the site of the injury. Christopher has use of his arms, with some limitations, but no use of his legs.

team, has a strong disabled network of friends. Christopher lives in a house close to campus with his girlfriend. Christopher's girlfriend does not have a disability and he explained that he was having trouble with his girlfriend's family assuming that she was in his life solely to take care of him. Her family consistently discredited their relationship. He does not need her, or anyone else, to take care of him, but has to prove this to her family time and again.

Throughout our conversations, while he seemed willing to answer my questions and was certainly supportive of my research, Christopher seemed reserved and cautious with his answers. Christopher was the one student who challenged my positionality as an insider to the disability community. When I asked him why he did not consider me an insider, he answered that it was just something he felt or sensed about me through our previous interactions. I explained this exchange in the third chapter of this paper because it was so poignant to me in the way I consider my own disability identity. Although I had been disabled from birth and he for only a few years, he still felt that my lack of connection to disabled people or culture made me an outsider.

We discussed things that make Christopher angry or frustrated related to his disability and in addition to access, which came up for every student in the study, he articulated that people staring at him or "over-helping" him was what he struggled with the most. He talked about how he believed that largely people were well-intentioned, however, the frequency with which he is asked if he needs help getting in and out of his car, or the urgency with which people will rush in front of him to open a door, were infuriating to him. When I asked him how he deals with such instances, he could not

really provide me any strategies, but more explained that he did not know. Somehow, he developed an ability to smile and move on, but that there were times when he would snap and become very angry at the person assuming he was not capable of independence. This was a dynamic that he could not fully explain, but one that I understood.

Christopher was the only student to ask me questions or challenge me on issues as they arose and subsequently he helped me reflect on my own identity development during our conversations and afterward.

Erin

Erin is a 20 year old Junior at UA. She is majoring in Family Studies with a specialization in Human Development. She plans to go into Social Work after graduation. Erin grew up in Connecticut and moved to Tucson to attend UA three years ago. She says that a combination of weather, accessibility, and the premiere wheelchair sports program are what influenced her decision to attend UA.

Born with spina bifida, Erin now uses a wheelchair. Her family has been involved with Spina Bifida Association (SBA)²⁶ since she was born. She believes that this helped her parents better understand spina bifida and provided them support and knowledge as she underwent surgeries through her childhood.

Out of all the respondents, Erin was the only one to speak about her involvement in a professional association dedicated to her disability. She reflects on this involvement

²⁶ The SBA has been in existence since 1973 and through education, advocacy, research, and service seeks to support those with spina bifida, their friends, and family (http://www.spinabifidaassociation.org/site/c.liKWL7PLLRf/b.2642991/k.DE3F/About_SBA.htm). The SBA has a large network of state and local chapters and has a presence in 125 communities across the United States.

fondly because it helped her connect with other children with disabilities as she grew up. Also, she was able to learn about different opportunities to play sports through her connections with the SBA. These opportunities were not made available to her through school, so she relied on this outside networking for information on wheelchair athletics. Erin also remembers a time that she no longer wanted to be involved in the SBA. She remembers outgrowing the organization. As she became increasingly involved with academics, friends at school, and with her athletics, she did not have the same need for formal meetings or conventions anymore. Her parents are still involved with the SBA and she believes this is because they find the support to be both comforting and empowering.

Erin's best friend is another woman with spina bifida who she met through the SBA during childhood. The two moved to UA together and are roommates—initially they lived on campus now in their own apartment. Erin plays wheelchair basketball, track, and loves to swim. Her friend group is a combination of those with and without disabilities, but she spends the majority of her time with her teammates. Interestingly, despite Erin's lifetime of involvement with the SBA and wheelchair sports, she does not identify as disabled. Perhaps because Erin has always been disabled and disability-related things are such a regular part of her life, she is unable or unwilling to extrapolate disability as her most salient identity.

Jack

Jack is an 18 year old first-year student at the UA. Jack lives on campus and is a member of the wheelchair basketball and rugby teams. He was injured almost four years ago during a sledding accident²⁷. Jack can recall every detail of his accident and shared with me, in a sort of facetious way, that he no longer likes the snow. My interviews with Jack were comfortable. It was clear that he was still learning to deal with being disabled, but he was very eager to speak with me and answer my questions. Jack presented as very shy, but we were able to speak at length about the interview questions during our meetings.

An interesting observation about Jack was that while he had many disabled friends and was extremely involved with adaptive athletics, he very often referred to disabled people as “them” and rarely as “us.” I do not believe Jack even heard himself use these pronouns and I do not believe he chose them intentionally. It appeared that Jack was in the habit of considering himself able-bodied. Because Jack has only been disabled for less than four years, he has a lifetime of memories that do not involve his wheelchair.

Jack was one of the few respondents whose major was not related to disability. He is an Ecology and Evolutionary Biology major. He discussed choosing to attend the UA because of its accessible campus, but also because of the opportunities the Sonoran Desert would present a future herpetologist. Jack’s friends at home are predominantly non-disabled, except for the few close friends he met during rehab. Here at the UA, his

²⁷ Jack is a C5-C6 incomplete quadriplegic, which means that he was injured between his fifth and sixth vertebrae and has no use of his legs.

friend group is comprised solely of others with disabilities, as he spends so much time with his teammates.

What is clear to me is that Jack's accident is still vivid in his mind and that being disabled has not fundamentally changed who he is. I believe that Jack still considers himself the same despite his accident, only now he uses a wheelchair.

Kate

Kate is a senior at the UA who is majoring in Special Education. She just celebrated her 21st birthday. Kate was also born with spina bifida. She is an athlete and has been since childhood. Kate is a member of the UA basketball and track teams. Athletics influenced her decision to attend UA. She spoke about the intense time commitment for her teams and the close bonds she shares with her teammates. Kate answered all of my questions but was a bit shyer than the others in the sample.

Kate is very close with her family back in New Jersey and her younger brother attends the UA. Her family has also been involved with the Spina Bifida Association (SBA) since she was a baby and this how they learned about local adaptive athletics opportunities. Her mom encouraged Kate to be independent by not overly accommodating her. She believes that this type of support empowered her to learn her capabilities and never make excuses for herself.

When Kate reflects on growing up with a disability, she spoke much about people staring at her. This confused her as a child because she did not understand why people were looking at her. Kate learned to cope with this by staring back at people until they

looked away. Their staring made her self-conscious and uncomfortable, so she developed a way to assert herself. This example speaks to the incongruence those born with their disabilities encounter between their own perspective and the perspectives of others.

Largely, Kate expressed that she was so used to being disabled that she did not did not consider disability her primary identity. She rarely thinks about using a wheelchair and sometimes even forgets that she does. Kate does feel that disabled people are oppressed but feels that the positive ways disability has enhanced her life are numerous and significant.

Margaret

I enjoyed my talks with Margaret. I feel that I could more personally connect with her on the way she has conceptualized disability than I was able to with other respondents. Margaret was born with osteogenesis imperfecta²⁸, more commonly referred to as Brittle Bone Disorder. She has had over twenty orthopedic surgeries and has used a power wheelchair her entire life. Margaret was adopted into a large family and also has a sister with a disability. Her sister was the only other person she knew with a disability. Margaret did not connect with the disability community throughout her life and does not connect at this point either. She cannot be an athlete, which may have limited her opportunity to connect with other disabled individuals.

²⁸ Osteogenesis imperfecta is a genetic disorder which causes individuals to have extremely weak, brittle bones (<http://www.oif.org/site/PageServer>). Those born with this condition may suffer bone breakage from something as low-impact as coughing or rolling over during sleep. There is no known cause for osteogenesis imperfecta and there are no particular risk factors or predispositions to the condition. Approximately one in 20,000 individuals are born with osteogenesis imperfecta (http://www.niams.nih.gov/Health_Info/Bone/Osteogenesis_Imperfecta/nurses_guide.asp#BasicFacts) opposed to the two in 1,000 born with spina bifida each year.

Because of her disability, Margaret has a very small frame. She appears younger than her age and this has made her work extra hard so as not to be treated like a child. The tendency to help someone with a disability is a common dynamic. This over-helping can be perceived by disabled individuals as condescending or patronizing, and I have heard it often compared to how adults treat children. Because she looks so young, Margaret is particularly sensitive to the need others have to help her. Margaret is a self-proclaimed overachiever. She is, and has always been, involved with several clubs and activities. Currently, she has a job, is planning to study abroad, and is involved with two extracurricular groups. She told me that she attributes her busy schedule to proving people wrong. Throughout her life, she has tried to prove her intelligence and independence to others. At a young age, her school district inappropriately tried to force her into a special education program despite the fact that her disability was only physical. This was one of her first memories of understanding that her life was different from that of her friends at school.

Throughout her interviews, Margaret spoke about the emphasis she places on education. She explained that the one place she feels free from disability is in the classroom. "I remember being really excited being [at school]...one thing I really think about is I never felt like I was in a wheelchair when I was in those classes....". I could understand that, as I have uttered almost that same sentiment many times. She believes that on a college campus people are less preoccupied with difference. She has been afforded many opportunities on campus to help her become independent, be social, and learn.

Margaret is an extremely optimistic and thoughtful person. She has a number of friends and is a successful student. Upon reflection during her interviews, she realized that beyond accommodations, she does not utilize DRC staff. She also has no other friends with disabilities, but could not articulate why not. She, unlike almost all of the other students I interviewed, was not connected to the disability community and she could not articulate why she would have the need for support from other disabled people in her life. The absence of athletics may be a reason that she is unclear about the role and scope of the disability community. I shared her attitude when I was her age, and even through as recently as two years ago.

Stephanie

Stephanie is a 20 year old junior at the UA. She is majoring in Family Studies and hopes eventually to go back to the same hospitals at which she had surgeries and therapy as a child to give back and work with young patients. Stephanie was also born with spina bifida and uses a wheelchair most of the time. She was one of only two students in the sample who was able to walk. Stephanie mainly used her wheelchair but at home she chooses to walk with crutches and braces. She believes that it is important to continue to exercise her muscles. She said that she did not want to lose her ability to walk.

An observation about Stephanie is that she spoke about walking like it was a skill she once possessed, like a foreign language she used to speak. She spoke about walking as though she was “rusty” and she needed to keep practicing so she would not lose the

ability altogether. When I analyzed my reaction to her describing walking, it reminded me of how I used to speak French and am now far less fluent than I once was when I studied in France and took French classes. At this point, I walk about as well as I speak French. It is not easy, but practice would improve my abilities. Stephanie discussed walking as though it was a cultural characteristic, as though there was a walking culture. Having both walked once, Stephanie and I had membership to this culture. Perhaps we connected through our perspectives on two cultures—walking and wheelchair—and the importance of retaining our cultural ties.

Stephanie has a sister who was born with cerebral palsy²⁹. Her family was involved in the Spina Bifida Association (SBA) and through their experiences never believed that disability was negative. They instilled this attitude in their children and encouraged them to think that they just had to do things in a different way. She described herself as being very stubborn when she was learning about her disability. She understood that she was disabled, but also felt just like everyone else. The fact that Stephanie's sister was also disabled added an interesting dynamic because it seems as though she felt like her disability was less severe than her sister's because she was able to be more independent.

When asked if she identified as disabled, Stephanie said that she did but that it was not her most salient identity. She wanted to be defined as more than disabled.

²⁹ Cerebral palsy refers to the inability to control one's bodily motions and functions as a result of damage to child's brain either during fetal development or early in childhood (<http://mayoclinic.com/health/cerebral-palsy/DS00302>). The effects of cerebral palsy can range from mild to severe and can affect both physical and mental capacity.

While Stephanie is an athlete and aspires to a career in which she will work with young disabled children, Stephanie says that she thinks about her disability only when she is confronted with a physical barrier.

REFERENCES

- Abes, E. S., Jones, S. R. & McEwen, M. K. (2007). Reconceptualizing the model of multiple dimensions of identity: The role of meaning-making in the construction of multiple identities. *Journal of College Student Development*, 48(1), 1-22.
- Albrecht, G.L., Seelman, K.D., Bury, M. (Eds.) (2001). *Handbooks of disability studies*. Thousand Oaks, London, New Delhi: Sage Publications.
- Americans with Disabilities Act (Pub. L. No. 101-336, codified at 42 U.S.C. § 12102 et seq.)
- Astin, A.W. (1984). Student involvement: A developmental theory for higher education. *Journal of College Student Personnel* 25, 297-308.
- Aune, B. (Fall 2000). Career and academic advising. *New Directions for Student Services* 91. 55-67.
- Barnartt, S., Schriener, K. (2001). *Handbook of Disability Studies*. In (G. L. Albrecht, K. D. Seelman & M. Bury, Eds.). Thousand Oaks, London, New Delhi: Sage Publications.
- Barnes, C. & Mercer, G. (2001). *Handbook of Disability Studies*. In (G. L. Albrecht, K. D. Seelman & M. Bury, Eds.). Thousand Oaks, London, New Delhi: Sage Publications.
- Barton, L. (1998). *The Disability Reader: Social Science Perspectives* In (T. Shakespeare, Ed.). London, New York: Cassell.

- Braddock, D.L., & Parish, S. (2001). *Handbook of Disability Studies*. In (G. L. Albrecht, K. D. Seelman & M. Bury, Eds.). Thousand Oaks, London, New Delhi: Sage Publications.
- Brisenden, S. (1998). *The Disability Reader: Social Science Perspectives* In (T. Shakespeare, Ed.). London, New York: Cassell.
- Bruyn, J. (1966). In Creswell, J.W. (2003). *Research design: Qualitative, quantitative, and mixed-methods approaches. Second edition*. Thousand Oaks, London, New Delhi: Sage Publications.
- Callero, P. (2003). The Sociology of the self. *Annual Review of Sociology*, 29. 115-133.
- Cass, V.C. (1979). Homosexual identity formation: A theoretical model. *Journal of Homosexuality*. (4)3. 219-235.
- Cass, V.C. (1984). Homosexuals identity formation: Testing a theoretical model. *Journal of Sex Research*. (20)2. 143-167.
- The Center for University Design: Environments and Products for All People. (2008). *About UD*. Retrieved February 29, 2008, from http://www.design.ncsu.edu/cud/about_ud/about_ud.htm
- Charleton, J.I. (2000). *Nothing about us without us: Disability oppression and empowerment*. Berkeley, Los Angeles, London: University of California Press.
- Chavez, A. F., Guido-DiBrito, F. & Mallory, S. L. (2003). Learning to value the "other" A framework of individual diversity development. *Journal of College Student Development*, 44(4), 453-468.

- Clandinin, D. J. & Raymond, H. (2006). Note on narrating disability. *Equity & Excellence in Education*, 39(2), 101-104.
- Cortes, C. (2000). *The children are watching: How the media teach diversity*. New York: Teachers College Press.
- Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, London, New Delhi: Sage Publications.
- Creswell, J.W. (2003). *Research design: Qualitative, quantitative, and mixed-methods approaches. Second edition*. Thousand Oaks, London, New Delhi: Sage Publications.
- Cross, W. E. (1971). Toward a psychology of black liberation: The negro-to-black conversion experience. *Black World Journal*, 20(9), 13-27.
- Cross, W.E. Jr. (2001). Cross's Nigrescence model: From theory to scale to theory. *Journal of Multicultural Counseling and Development*, 29. 174-200.
- D'Augelli, A.R.. (1997). Identity development and sexual orientation: Toward a model of lesbian, gay, and bisexual development. In *Human diversity: Perspectives on people in context*. (E.J. Trickett, R.J. Watts, D. Birman, Eds.). San Francisco: Jossey-Bass Publications. 312-333.
- Davis, L. (2001). *Handbook of Disability Studies*. In (G. L. Albrecht, K. D. Seelman & M. Bury, Eds.). Thousand Oaks, London, New Delhi: Sage Publications.
- Deaux, K., et al. (1995). Parameters of social identity. *Journal of Personality and Social Psychology*, 68(2), 280-291.

- Dilley, P. (January-February 2005). Which way out? A typology of non-heterosexual male collegiate identities. *Journal of Higher Education*, 76(1), 56-88.
- Edwards, R. (1993). An education in interviewing. Placing the researcher and the research. In M. C., Renzetti & R. Lee. *Researching in sensitive topics* (pp.181-196). Newbury Park, London, New Delhi: Sage Publications.
- Erikson, E.H. (1959). *Identity and the life cycle*. New York, London: W.W. Norton & Company.
- Ethier, K. A. & Deaux, K. (1994). Negotiating social identity when context changes: maintaining identification and responding to threat. *Journal of Personality and Social Psychology*, 67(2), 243-251.
- Evans, N.J., Forney, D.S., & Guido-DeBrito, F. (1998). *Student development in college: Theory, research, and practice*. San Francisco: Jossey-Bass.
- Fetterman, D. M. (1998). *Qualitative Inquiry and Research Design* In (J. W. Creswell, Comp.). Thousand Oaks, London, New Delhi: Sage Publications.
- Fine, M., & Asch, A. (1988). Disability beyond stigma: Social interaction, discrimination and activism. *Journal of Social Issues*, 44, 3-21.
- Fougeyrollas, P. & Beauregard, L. (2001). *Handbook of Disability Studies*. In (G. L. Albrecht, K. D. Seelman & M. Bury, Eds.). Thousand Oaks, London, New Delhi: Sage Publications.

- Gordon, B. O. & Rosenblum, K. E. (2001). Bringing disability into the sociological frame: a comparison of disability with race, sex, and sexual orientation statuses. *Disability & Society, 16*(1), 5-19.
- Gotwals, J. K., Dunn, J. G. & Wayment, H. A. (2003). An examination of perfectionism and self-esteem in intercollegiate athletes. *Journal of Sport Behavior, 26*(1), 17-22.
- Haller, B., Dorries, B. & Rahn, J. (2006). Media labeling versus the US disability community identity: a study of shifting cultural language. *Disability & Society, 21*(1), 61-75.
- Hernandez, B. (2005). A voice in the chorus: Perspectives of young men of color on their disabilities, identities, and peer-mentors. *Disability & Society, 20*(2), 117-133.
- Hockenberry, J. (1995). *Moving Violations: A Memoir*. New York: Hyperion.
- Hopwood, N. (2004). Research design and methods of data collection and analysis: Researching students' conceptions in a multiple-method case study. *Journal of Geography in Higher Education, 28*(2), 347-353.
- House, J.G. (n.d.). *Conditions Spinal Cord Injury Statistics*. Retrieved February 21, 2008, from <http://www.disaboom.com/Health/spinalcordinjury/spinal-cord-injury-statistics.aspx>
- Howard-Hamilton, M. F. & Cooper, D. L. (2003). Theoretical frameworks of identity development: Foundational theories. *ASHE-ERIC Higher Education Report, 29*(6), 9-17.

- Jones, S.R. (1996). Toward inclusive theory: disability as social construct. *NASPA Journal* 33(4). 347-354.
- Jones, S. R. & McEwen, M. K. (2000). A conceptual model of multiple dimensions of identity. *Journal of College Student Development*, 41(4), 405-413.
- Josselson, R. (1987). *Finding herself: Pathways to identity development in women*. San Francisco, London: Jossey-Bass Publishers.
- Josselson, R. (1996). *Revising herself: The story of women's identity from college to midlife*. New York, Oxford: Oxford University Press.
- Kraus, A. (2002). *How student services professionals view and support students with disabilities*. Unpublished manuscript.
- Kraus, A., (2005). *The effects of university wheelchair athletics on a student's personal concept of disability: Examining the experiences of wheelchair athletes at a large, public, university*. Unpublished manuscript.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York, Long: New York University Press.
- Ludwig, J. (personal communication, October 23, 2007)
- Mayo Clinic Staff of Mayo Foundation for Medical Education and Research. (2007). *Encephalitis*. Retrieved February 4, 2008, from <http://mayoclinic.com/health/encephalitis/DS00226/DSECTION=1>
- Mayo Clinic Staff of Mayo Foundation for Medical Education and Research. (2007). *Hydrocephalus*. Retrieved February 4, 2008, from <http://mayoclinic.com/health/hydrocephalus/DS00393/DSECTION=8>

Mayo Clinic Staff of Mayo Foundation for Medical Education and Research. (2007).

Spina bifida. Retrieved February 4, 2008, from

<http://mayoclinic.com/health/spina-bifida/DS00417>

Mayo Clinic Staff of Mayo Foundation for Medical Education and Research. (2007).

Spinal Cord Injury. Retrieved February 4, 2008, from

<http://mayoclinic.com/health/spinal-cord-injury/DS00460/DSECTION=2>

Mayo Clinic Staff of Mayo Foundation for Medical Education and Research. (2007).

Cerebral palsy. Retrieved February 4, 2008, from

<http://mayoclinic.com/health/cerebral-palsy/DS00302>

McCarthy, D. (2007). Teaching self-advocacy to students with disabilities. *About*

Campus, 12(5), 10-16.

McEwan, M. K. (1996). *Student services: A handbook for the profession* (3rd ed.). In (S.

R. Komives & D. B. Woodard, Eds.). San Francisco: Jossey-Bass.

Mead, G.H. (1934). *Mind, self, & society: From the standpoint of a social behaviorist*.

Chicago, London: The University of Chicago Press.

Mehra, B. (2001). Research or Personal Quest? Dilemmas in Studying My Own Kind. In

Merchant, B. & Willis, A. (Eds.), *Multiple and Intersecting Identities in*

Qualitative Research. Mahwah: Lawrence Erlbaum Publishers.

Merriam-Webster Online. (n.d.). *disability*. Retrieved November 7, 2007, from

<http://www.merriam-webster.com/dictionary/disability>

Merriam-Webster Online. (n.d.). *disability*. Retrieved November 7, 2007, from

<http://www.merriam-webster.com/dictionary/disabled>

National Institute of Arthritis and Musculoskeletal and Skin Diseases. (n.d.).

Osteogenesis imperfecta. Retrieved February 4, 2008, from

http://www.niams.nih.gov/Health_Info/Bone/Osteogenesis_Imperfecta/nurses_guide.asp#BasicFacts

National Institute on Disability and Rehabilitation Research. (1988). *Chartbook on Work and Disability in the United States: An InfoUse Report*. Washington, DC: US Government Printing Office

Olkin, R. (2002). Could You Hold the Door for Me? Including Disability in Diversity. *Cultural Diversity and Ethnic Minority Psychology*, 8 (2), 130-137.

Osteogenesis Imperfecta Foundation. (2008, February 25). Retrieved February 4, 2008, from <http://www.oif.org/site/PageServer>

Oxford English Dictionary. (1989). *Disability*. Retrieved September 20, 2007, from http://dictionary.oed.com/cgi/entry/50064804?single=1&query_type=word&queryword=disability&first=1&max_to_show=10

Pascarella, E.T., & Terenzini, P.T. (1991). *How college affects students: Findings and insights from 20 years of research*. San Francisco: Jossey-Bass.

Rankin, S. R. (2004). Campus climate for lesbian, gay, bisexual, and transgender people. *Diversity Factor*, (Winter), 18-23.

Rankin, S. R. (2005). Campus climates for sexual minorities. *New Directions for Student Services*, (Fall), 17-23.

- Reynolds, A. L. & Pope, R. L. (1991). The complexities of diversity: Exploring multiple oppressions. *Journal of Counseling and Development*, 70(September/October), 174-180.
- Rhoads, R. A. (1995). The college campus climate for gay students. *Education Digest*, 61(1), 57-61.
- Richardson, T.J., (1990). In Creswell, J.W. (2003). *Research design: Qualitative, quantitative, and mixed-methods approaches. Second edition.* Thousand Oaks, London, New Delhi: Sage Publications.
- Richmond, J. (1986). The importance of student involvement: A dialogue with Alexander Astin. *Journal of Counseling and Development*, 65. 92-95.
- Robinson, T.L. (1999). The intersections of dominant discourses across race, gender, and other identities. *Journal of Counseling and Development* (77). 73-79.
- Ross, K. (1997). But where's me in it? Disability, broadcasting and the audience. *Media, Culture & Society*, (19), 669-677.
- Scott, S. S., McGuire, J. M. & Shaw, S. F. (2003). Universal design for instruction: A new paradigm for adult instruction in postsecondary education. *Remedial and Special Education*, 24(6), 369-379
- Schlossberg, N. (1977) The case for counseling adults. In *Counseling Adults*. (N.K. Schlossberg, A.D. Entine, Eds.) Monterey: Brooks/Cole Publishing Company.

- Seidman, I. (1998). *Interviewing as qualitative research: A guide for researchers in education and the social sciences Second edition..* New York, London: Teachers College Press.
- Smart, J. (2001). *Disability, society, and the individual.* Gaithersburg: Aspen Publishers, Inc.
- Spina Bifida Association. (2008). Retrieved February 4, 2008, from http://www.spinabifidaassociation.org/site/c.liKWL7PLLRf/b.2642297/k.5F7C/S_pina_Bifida_Association.htm
- Strauss, A. (Personal communication, October 18, 2003).
- Swain, J., & French, S. (2000). Towards an Affirmation Model of Disability. *Disability and Society, (15)4.* 569-582.
- Swain, J., French, S., & Cameron, C. Controversial Issues in a Disabling Society. Open University Press. 2003.
- Switzer, J. Disabled Rights: American Disability Policy and the Fight for Equality. Georgetown University Press. 2003.
- Tatum, B. D. (1997). *Why Are All the Black Kids Sitting Together in the Cafeteria and Other CONversations About Race.* New York, NY: Basic Books.
- The University of Arizona Disability Resource Center. (2008). *Disability Studies Courses.* Retrieved February 4, 2008, from <http://drc.arizona.edu/disabilitystudies/courses/index.html>
- Tinto, V. (2000). Looking at the university through different lenses. *About Campus, January-February, 2-3.*

- U. S. Census Bureau. *2000 Census of Population and Housing, Demographic Profile*. (n.d.). Retrieved November 6, 2007, from http://www.fedstats.gov/qf/meta/long_POP905200.htm
- U. S. Census Bureau. *American FactFinder*. (n.d.). Retrieved February 13, 2008, from http://factfinder.census.gov/servlet/DTTable?_bm=y&-state=dt&-ds_name=ACS_2006_EST_G00_&-mt_name=ACS_2006_EST_G2000_B18004&-redoLog=true&-_caller=geoselect&-geo_id=01000US&-format=&-_lang=en
- US Paralympics. (2008). *About US Paralympics*. Retrieved February 7, 2008, from <http://www.usolympicteam.com/paralympics/about.html>
- US Paralympics. (2008). *US Paralympics Network*. Retrieved February 5, 2008, from <http://www.usparalympics.org/>
- Vernon, A. (1998). *The Disability Reader: Social Science Perspectives* In (T. Shakespeare, Ed.). London, New York: Cassell.
- Waldo, C. R. (1998). Out on campus: Sexual orientation and academic climate in a university context. *American Journal of Community Psychology*, 26(5), 745-775.
- Weber, L. (1998). A conceptual framework for understanding race, class, gender, and sexuality. *Psychology of Women Quarterly*, 22(22), 13-32.
- Wertz, F.J. (2005). Phenomenological research methods for counseling psychology. *Journal of Counseling Psychology*, 52(2), 167-177.
- Williams, G. (2001). *Handbook of Disability Studies*. In (G. L. Albrecht, K. D. Seelman & M. Bury, Eds.). Thousand Oaks, London, New Delhi: Sage Publications.