Running for Normalcy, Identity Development, and the Disability Blues: An Autoethnography that Explores One Man’s Quest to Understand His Identity

A dissertation presented to
the faculty of
The Gladys W. and David H. Patton College of Education and Human Services of Ohio University

In partial fulfillment
of the requirements for the degree
Doctor of Philosophy

Cort E. Schneider
November 2010

© 2010 Cort E. Schneider. All Rights Reserved.
This dissertation titled
Autoethnography that Explores One Man’s Quest to Understand His Identity

by
CORT E. SCHNEIDER

has been approved for
the Department of Educational Studies
and The Gladys W. and David H. Patton College of Education and Human Services by

Jaylynne N. Hutchinson
Associate Professor of Cultural Studies

Renée A. Middleton
Dean, The Gladys W. and David H. Patton College of Education and Human Services
Abstract

SCHNEIDER, CORT E., Ph.D., November 2010, Curriculum and Instruction, Cultural Studies

Running for Normalcy, Identity Development, and the Disability Blues: An Autoethnography that Explores One Man’s Quest to Understand His Identity

Director of Dissertation: Jaylynne N. Hutchinson

Identity development is a difficult process for many people with disabilities. Individuals who have disabilities often struggle to come to terms with their identities. As a person with cerebral palsy, I spent most of my life struggling with my identity. I tried to reject my disability in order to fit in with the able-bodied world. However, my attempts to fit in always failed.

Then in 2004 I had an intellectual awakening that allowed me to come out as a person with disability and embrace my membership in disability culture. This autoethnographic inquiry is my attempt to understand my journey of identity development. This dissertation examines the various factors that co-created my identity. Moreover, I use Gill’s (1997) model of identity development in order to examine how the process of embracing my membership in disability culture has impacted my identity.

This dissertation posits that the process of identity development cannot be adequately encapsulated in a theoretical model. Instead, disability as a marker of social identity operates in contradictory ways. Furthermore, as a person with a disability I am constantly negotiating my existence between two cultures; the world of disability and the culture of people who are able-bodied.
Approved: _____________________________________________________________

Jaylynne N. Hutchinson

Associate Professor of Cultural Studies
Acknowledgments

There is no way that I could have completed this process without the help of many individuals. I would like to acknowledge those people for their assistance. I would like to thank my advisor, Dr. Jaylynne Hutchinson, for her hard work and diligence on this project. I would also like to thank the other members on my committee: Dr. Francis Godwyll, Dr. J.W. Smith, Dr. Dianne Gut, and Dr. Lynn Harter.

I would also like to thank my parents. Without their love and support I would not be here today.

Most of all, I need to give eternal thanks to my girlfriend. She showed love and compassion throughout this entire process. Plus, she always gave me the motivation I needed to move ahead. Most importantly, her love and support throughout has made this entire project worthwhile.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>3</td>
</tr>
<tr>
<td>Acknowledgments</td>
<td>5</td>
</tr>
<tr>
<td>List of Figures</td>
<td>10</td>
</tr>
<tr>
<td><strong>Chapter 1: Introduction</strong></td>
<td>11</td>
</tr>
<tr>
<td>Narrative Background of Study</td>
<td>11</td>
</tr>
<tr>
<td> Quest for Normalcy</td>
<td>11</td>
</tr>
<tr>
<td> A New Education in Disability</td>
<td>15</td>
</tr>
<tr>
<td> A New Calling</td>
<td>16</td>
</tr>
<tr>
<td>Identity and People with Disabilities</td>
<td>18</td>
</tr>
<tr>
<td> The Marginalization of People with Disabilities</td>
<td>18</td>
</tr>
<tr>
<td> Disability Narratives and Identity</td>
<td>22</td>
</tr>
<tr>
<td> Identity Development and People with Disabilities</td>
<td>23</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>26</td>
</tr>
<tr>
<td>Research Questions</td>
<td>27</td>
</tr>
<tr>
<td>Significance of the Study</td>
<td>27</td>
</tr>
<tr>
<td>Limitations of the Study</td>
<td>32</td>
</tr>
<tr>
<td>Delimitations of the Study</td>
<td>33</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>33</td>
</tr>
<tr>
<td>Organization of Study</td>
<td>36</td>
</tr>
<tr>
<td><strong>Chapter 2: Methodology</strong></td>
<td>38</td>
</tr>
<tr>
<td>The Organization of My Narrative</td>
<td>38</td>
</tr>
<tr>
<td>Narrative Inquiry</td>
<td>40</td>
</tr>
<tr>
<td>Autoethnography</td>
<td>43</td>
</tr>
<tr>
<td> What is Autoethnography?</td>
<td>43</td>
</tr>
<tr>
<td> Autoethnography Can be Empowering</td>
<td>45</td>
</tr>
<tr>
<td>Autoethnography and People with Disabilities</td>
<td>48</td>
</tr>
<tr>
<td>Autoethnographies and the Quest for Identity</td>
<td>51</td>
</tr>
<tr>
<td>Responses to Possible Criticisms of Autoethnography</td>
<td>52</td>
</tr>
<tr>
<td>Data Collection in an Autoethnography</td>
<td>55</td>
</tr>
</tbody>
</table>
The Struggle of Living in Two Worlds ................................................................. 141
Chapter 5: Relationships and Identity Development ........................................... 144
Identity is a Relational Endeavor ........................................................................ 144
Family and Identity .............................................................................................. 145
Identity and Family Scripts ............................................................................... 145
Idealized Social Scripts ...................................................................................... 147
The Fluid Nature of Scripts .............................................................................. 148
My Family Script ............................................................................................... 149
The Only One with a Disability ...................................................................... 150
Normalcy is the Goal ......................................................................................... 152
To Walk or Not to Walk .................................................................................. 152
Don't Play the Tiny Tim Card .......................................................................... 156
When Should I Use My Disability? ................................................................. 158
Am I Normal or Abnormal? ............................................................................ 160
Moving Beyond the Family Script ................................................................. 162
Coming Out and Shocking My Family .............................................................. 162
Able-bodied People Don't Understand Me ...................................................... 164
My Mom Attempts to Understand My Identity ............................................... 165
Romantic Relationships and People with Disabilities ....................................... 168
Romance and Identity ..................................................................................... 168
You Won't Date Until College .......................................................................... 170
A Self-fulfilling Prophecy ................................................................................ 173
Jane .................................................................................................................... 174
To Date or Not to Date ...................................................................................... 174
The Disability Date ........................................................................................... 177
Stability and Change ....................................................................................... 178
Autonomy and Connection ............................................................................. 179
Invisibility and Visibility .................................................................................. 181
Family and Interability Relationships ............................................................... 183
Jane's Mom ....................................................................................................... 183
Chapter 6: Public Discourse, Disability and Identity Development .................. 187
List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>Headline and picture of me in the Athens News</td>
<td>187</td>
</tr>
<tr>
<td>Figure 2</td>
<td>Image of Me as a poster child in the Columbus Dispatch</td>
<td>202</td>
</tr>
<tr>
<td>Figure 3</td>
<td>Article about my Involvement with the March of Dimes</td>
<td>208</td>
</tr>
<tr>
<td>Figure 4</td>
<td>Headline appeared in the Columbus Dispatch</td>
<td>221</td>
</tr>
</tbody>
</table>
Chapter 1: Introduction

Narrative Background of Study

Quest for Normalcy

It is impossible to understand my journey through life without first knowing that I am a person with a disability. I was born with cerebral palsy (CP). CP is “an umbrella term covering a group of non-progressive, but often changing motor impairment syndromes” (Reid, Lanigan, & Reddihough, 2006, p. 606). In effect, cerebral palsy impacts an individual’s movement and posture (Blair & Stanley, 1997; Cheney, 1997).

This disability occurs because of a lesion or injury to the brain (Blair & Stanley, 1997; Reid et al., 2006; Straub & Obrzut, 2009). As Straub and Obrzut (2009) explain, CP “results from brain injury before development of the brain is complete” (p. 153). This injury can occur in a variety ways. These can include: underdevelopment of the brain during the gestation period, lack of oxygen during the pregnancy or birth which causes brain damage, an accident during the birthing process, or an injury that occurs shortly after birth (Blair & Stanley, 1997; Cheney, 1997; Reid et al., 2006).

Cerebral palsy is the most common cause of physical disability in children (Martin, Rowell, Reid, Marks, & Reddihough, 2005). CP occurs in approximately 2 percent of live births (Martin et al.). Cheney (1997) maintains that about 5,000 children with moderate or severe CP are added to the population each year (p. 153).

I was born two months premature which caused my brain to be underdeveloped. Thus, I have had cerebral palsy since birth. As a result, I walk on crutches and struggle with my coordination. Even though I have a moderate type of CP, I often had not
considered myself to be a so-called “person with a disability.” I even had contempt for other people with disabilities as a child. I recall telling my father, “I hate crippled people.” Moreover, during most of my life I was on a quest for normalcy. My goal was to be normal; I constructed a life on the notion that I could be just like everybody who did not have a disability. Furthermore, I rejected the notion that my disability was a major aspect of who I was as a person.

My quest for normalcy created an interesting dichotomy in my life. On the one hand, I knew I was not normal because I had a disability. I saw myself as the byproduct of a birth defect, and I never truly felt that I fit in with the most of my peers. On the other hand, I thought that even though my disability made me abnormal, I could become normal through my actions. Therefore, I worked tirelessly to achieve what I thought was a normal life. I went to a regular public high school, lettered in two sports, and developed friendships; in short, I did the things I thought “normal” people were supposed to do.

However, despite my best efforts to attain a “normal” life I still felt as though I did not belong. I feel my perception of not belonging had something to do with how I was treated when I did things that people considered “normal.” When I played sports for example a significant number of people treated me as an inspiration. I often became irritated when people labeled me as inspirational for doing what a lot of other kids did. Because people labeled me as an inspiration for doing “normal” activities, it made me realize that I was not normal. Yet I was certain that when I went to college I would finally be able to fit in the able-bodied world. I was under the impression that going to a
new place and attending a university would mean that my disability would no longer have a major impact on my life.

I chased after normalcy in college with the same dogged determination that I had shown in my high school years. I worked at a radio station, earned two Bachelor’s degrees, covered sports, drank beer, and developed memorable friendships. However, I still felt like an outsider. Despite the fact that I enjoyed my undergraduate years immensely, I still felt that I was not “normal” enough. In my college years, I think the idea that I was not normal was in my head. When I came to Ohio University I “worked too hard” to be normal. I went out of my way to use my disability to shock and embarrass people. My thought at the time was that using my disability to shock people was a way for me to make others comfortable. As I reflect back on it, I realize that my blunt approach was what helped make me feel isolated from people who were able-bodied.

My desire for a normal life continued as I entered graduate school. While earning my first Master’s degree, I was a graduate assistant for the History department at Eastern Michigan University. Now that I was in college earning an advanced degree in a subject I love, I thought I would be normal. Striving to become a scholar and obtain a faculty position at the university level meant that I would enter the academic world, and therefore my disability would no longer be an important part of my life. I remember thinking that attempting to be a scholar meant that I would lead a life that focused on my intellect. By focusing on intellectual pursuits, I felt as though I could set aside the physical aspect of my disability. What I did not understand at the time was that my
disability impacted more than my physical being, my CP also altered my perception of the world around me. Therefore, it is impossible for me to set aside my disability.

Needless to say, despite my desire to fit in the able-bodied world, I felt I did not. I felt like a phony, that was posing as someone I was not. I considered myself a fraud because despite my best efforts to be normal and ignore my disability, I kept coming to the conclusion that other people’s perceptions of my disability were an impediment to my progress. I felt that no matter what I did, people would always see me as the “guy on crutches.” As I reflect back on it, I realize that my feelings were a mix of how other people viewed me, and how I saw myself. For most of my life, some people have not been able to see past my disability and this led me to believe that no one could look past my CP. Living with a disability became a constant reminder that people who are able-bodied did not see me as normal.

Therefore, it became apparent to me that trying to approach life as if I were not disabled was a lost cause. Because I had worked my whole life to be seen as normal and I had come to the realization that people in society would never view me as normal, I developed a lot of bitterness and anger toward my disability. I blamed my disability for making me different and not allowing me to fit in. It is safe to say that I often projected a lot of anger onto people around me. This anger was often expressed in my sarcastic sense of humor that emerged from the hurt and confusion I was feeling inside. I am sure my anger kept me from reaching my full potential. I was headed down a path that would have had me spending a lifetime being angry with myself and the rest of the world. I was angry because I thought everybody saw me as different, and I did not really understand why.
A New Education in Disability

Despite my growing anger towards my disability, I returned to Ohio University in the fall quarter of 2003 to earn another Master’s degree, this one in Education. It was at this point that the perception I had of my disability changed forever. In the summer of 2004 I enrolled in a Cultural Studies in Education course. For the final research project, the professor allowed the students to choose any topic that interested them. I chose to examine how people with disabilities are portrayed in the media. This project was the moment when I began to get a new education on disability, and I would never again see my disability as something that limited just me personally. I began to understand that having a disability involved a complex mixture of physical, social, and psychological factors that impact many people who have disabilities. Living with a disability means that many people who have disabilities are often told they are inferior, which impacts their identity.

While doing research for the class project, I came to realize that those who have disabilities are often reduced to stereotypical one-sided characters in the media. While I knew that images in the media often stereotype people from other marginalized cultures, I was amazed at the plethora of images that represent people with disabilities in a negative way. Famous characters in fiction such as, Tiny Tim, Captain Hook, and The Joker are just a few examples of the myriad of cultural images that show people with disabilities in a negative light. After studying these disturbing images, I had an epiphany. I realized that media images often depict people with disabilities as inferior to those who are able-bodied. I also came to understand the negative media images that portray people with
disabilities were part of a larger culture of ableism that stigmatizes the notion of disability.

My new awareness that Western culture often devalues people with disabilities was a moment of clarity for me. I realized the main reason I felt abnormal was because the culture in which I live does not view people with disabilities as equal members of society. Therefore, I began to feel that I did not need to work so hard to be normal, because I came to believe the society in which I live would never accept me as normal no matter how many “normal” activities and achievements I attained.

A New Calling

At this point, my goals in life changed. My primary goal would no longer be to pass as normal in order to be accepted by people who were able-bodied. I had a new calling. This new objective was to shed light on how our society treats people who have disabilities. The anger and bitterness that I held toward my own disability transformed into a passion that focused my efforts on changing society’s negative attitudes about people with disabilities.

In order to accomplish my goal of altering society’s off-putting opinion about those who have disabilities, I decided I should become a scholar so I could become a voice that could address issues of disability. In order to reach this goal, I decided to earn a Ph.D. in Cultural Studies in Education at Ohio University. Throughout the course of my doctoral program I explored literature that examined the ways in which various minority groups are often oppressed in mainstream society. I started to connect literature that explicates how people are oppressed, to my own personal experience as a person with a
disability. I came to realize that the concepts of cultural domination that were being used to explain how people are marginalized could be applied to people with disabilities. Therefore, I began to explore specific ways that people with disabilities are marginalized in American society.

As I progressed through my doctoral program I went from a person with a disability who was in a state of denial about his condition, to a person who became committed to exposing the oppression that many people with disabilities face in their everyday life. When I re-entered Ohio University, I rejected the notion that I had a disability. I felt lost – like a person without a spiritual center. However, as I began to examine the issues of discrimination that many people with disabilities encounter, I gained a spiritual center surrounding my disability. I no longer rejected my disability, but rather embraced it as a fundamental part of the person that I am. I felt like I had been “born again” as a person with a disability. I found a new calling that included an intellectual and emotional examination of who I was and how my disability impacted my perception of the world around me.

My newfound desire to understand how living with a disability has impacted my perception of the world led me to begin a deeper exploration of my inner struggle to come to terms with my disability. While reflecting on my personal battle, I started to see that my story might relate to other people with disabilities who have also labored to come to terms with their own identity. In other words, studying my own struggle with identity steered me to a broader question. I now wanted to explore whether my own struggle with personal identity was similar to the experiences of other people with disabilities.
Therefore, I sought to explore this topic in my dissertation. When deciding what might be the best way to research the question of identity as it relates to people with disabilities, I realized that my own struggle with identity could be a powerful tool that could shed light on identity development. The realization that my story could have academic value, led to the decision to employ an autoethnographic methodology in order to explore the issue of identity development as it relates to those who have disabilities.

Identity and People with Disabilities

The Marginalization of People with Disabilities

Not only have I struggled to comprehend my identity as a person who has a disability, but many other individuals with disabilities struggle with this as well. This struggle with identity occurs because people with disabilities are often marginalized by mainstream society (Berger, 2009; Cameron, 2007; Davis, 1997; Gill, 2004; Howland & Rintala, 2001; Joseph, 2010 Lawrence, 1991; Linton, 1998; Longmore, 2003). In turn, this isolation can have an impact on how many people with disabilities perceive their identity (Gill, 1997; Hahn, 1997; Hernandez, 2005; Onken & Slaten, 2000; Shakespeare, 1999). In 2001, President George W. Bush acknowledged that isolation is a fact of life for people with disabilities when he stated, “Too many Americans with disabilities remain trapped in bureaucracies of dependence, denied the tools they need to fully access their communities” (The White House New Freedom Initiative, 2001). In an effort to further understand the extent of this isolation, the Bush Administration commissioned the writing of the New Freedom Initiative that examined the various areas of society in which people with disabilities are marginalized in an attempt to understand the barriers faced by many
people with disabilities. The data compiled paints a bleak picture of the obstacles that may people with disabilities encounter in their everyday lives at the turn of the 21st century.

To start with, many people with disabilities are economically vulnerable. Over seventy percent of people with disabilities are unemployed, and over thirty-three percent of people with disabilities are considered impoverished while only twelve percent of people who do not have disabilities live in poverty (Darling, 2003; Gargiulo, 2006; Joseph, 2010; Rank, 2004; *The White House New Freedom Initiative*, 2001). Therefore, living with a disability in the United States means that a person is much more likely to face the burden of poverty than people who are able-bodied.

In addition, many people with disabilities face barriers to achieving an education. Approximately one out of five people with disabilities have less than a high school education (*The White House New Freedom Initiative*, 2001). Furthermore, Stolz (2010) states, "high school drop-out rates for disabled youth, at 28% far exceeds that of the general population" (p. 1). Moreover, those with disabilities who do graduate high school are less likely to attend college than their able-bodied peers (Darling, 2003; Joseph, 2010; Stolz, 2010). According to Stolz (2010), individuals with disabilities attend college at a rate that is half that of people who are able-bodied (p. 1).

Home ownership and access to the internet are two more areas where people with disabilities fall behind individuals who are able-bodied. Only about ten percent of people with disabilities own their own home, compared to almost seventy-one percent of their able-bodied counterparts (*The White House New Freedom Initiative*, 2001). Not only are
many people with disabilities isolated because they cannot achieve home ownership, many do not have access to technology further isolating them from mainstream society. Computer usage among individuals with disabilities is half that of people without disabilities (The White House New Freedom Initiative).

Another barrier those with disabilities encounter is isolation from the political process. Individuals with disabilities vote at a rate twenty percent less than their able-bodied counterparts. According to The White House New Freedom Initiative (2001), issues that impact people who are disabled seldom surface as major topics in local election campaigns. People with disabilities are often discouraged from voting because polling stations are often not accessible to people with disabilities (Rank, 2004).

These statistics demonstrate that many people with disabilities remain isolated from their communities. This isolation can cause many people with disabilities to develop a negative self-image (Bachman, Drainoni, & Tobias, 2004; Brunnberg, Bostrom, & Berglund, 2008; Jones & Lollar, 2008; Li & Ford, 1996). In turn, a sense of low self-esteem causes many people with disabilities to use drugs and alcohol as a way of numbing themselves to the reality of their lives (Li & Ford, 1996; Myers & Salt, 2007). For example, Bachman et al. (2004) found that people with disabilities abuse drugs and alcohol at a higher rate than the general population (p. 190). In addition, Myers and Salt (2007) demonstrate that those with disabilities are more prone to drug and alcohol addiction than their able-bodied peers. Thus, it seems clear that many people with disabilities abuse drugs as away to cope with the isolation they face in their lives (Bachman, et al., 2004; Jones & Lollar, 2008; Li & Ford, 1996; Myers & Salt, 2007).
Moreover, the feeling of isolation that many people with disabilities experience can become problematic during adolescence. For example, Jones and Lollar (2008) found that high school students with disabilities report feelings of sadness and hopelessness at a rate that is twice that of their able-bodied peers (p. 254). In addition, students with disabilities are two times more likely than their able-bodied classmates to contemplate suicide (p. 254). Consequently, during this crucial period of identity development many people with disabilities develop low self-esteem. Developing low self-esteem can make it more difficult for those individuals to find a comfortable place in their communities (Gill, 1997; Onken & Slaten, 2000).

The feeling of sadness that many people with disabilities experience during their teenage years continues as they transition into adulthood (Gill, 1997; Hernandez, 2005; Stolz, 2010). In fact, many people with disabilities do not find their life satisfying. In a Harris poll conducted in 2000, only about one-third of people with disabilities found their life to be very satisfying. In comparison, sixty-seven percent of individuals who do not have disabilities found their life to be very satisfying (Gargiulo, 2006). These numbers indicate that many adults with disabilities continue to feel isolated from mainstream society.

Thus, it seems clear that many people with disabilities encounter isolation and sadness in their everyday lives (Berger, 2004; Davis, 1997; Gill, 2004; Shaw, 1994; Russell, 1998; Wade, 1994). Moreover, there is a connection between the discrimination that many people with disabilities encounter on the one hand, and the sadness that they feel on the other. As Gill (2004) states, “oppression leads to depression” (p. 172). In other
words, the reason many people with disabilities struggle with their identity is because they live in a world that discriminates against them because they have a disability. Therefore “coming to terms” with a disability is a difficult struggle for many individuals.

**Disability Narratives and Identity**

The struggle to come to terms with a disability is evident in many personal stories that explore the lives of people with disabilities (Berger, 2009; Engel & Munger, 2003; Fries, 1997; Juette & Berger, 2008; Lewis, 2007; Mason, 2004; Rapp, 2007; Rucker, 2007). While there is still a greater need for narratives that explore disability, there are first person narratives that detail the struggle many people face to overcome the isolation associated with a disability (Johnson, 2005; Juette & Berger, 2008; Lewis, 2007; Linton, 2007; Rapp, 2007; Rucker, 2007; Smith & Sparkes, 2008a). When examining these personal narratives, there is further evidence that the isolation many people with disabilities encounter impacts their identity. Therefore, personal life stories can be an important way for scholars to better understand the connection between the discrimination that people face, and how they perceive their disability. To state it another way, Shor (1992) argues that critical awareness occurs when individuals can comprehend the connection between systemic discrimination and the everyday experiences of the individuals who encounter that oppression. Personal narratives are one tool that may help individuals gain a critical awareness about issues of disability, including questions of identity development.

One example of a personal narrative that elucidates the connection between disability and identity can be found in Lewis’ (2007) autoethnography that explores her
struggle to find a new identity after she acquired a disability. Her research demonstrates that scholars interested in issues of disability can write personal stories that explore identity. Various scholars argue that the field of disability studies needs more autoethnographies that further explicate the issue of identity as it relates to individuals with disabilities (Cameron, 2007; Couser, 2005a; Couser, 2005b; Darling, 2003; Gill, 1997; Ostrander, 2008; Shakespeare, 1999; Smith & Sparkes, 2008a, 2008b). Since there is a need for autoethnographies exploring questions of identity and disability, this autoethnography may allow me to make a contribution to the field of scholarship exploring the identity development of people who have disabilities.

**Identity Development and People with Disabilities**

In order to connect this autoethnography to the larger intellectual conversation surrounding the questions of identity and disability, this study will be academically grounded using the theory of identity development. The notion of identity development emerged in the late 1960’s when psychologists began to look at how humans develop a separate identity while also engaging in meaningful relationships with others. Erikson (1968) argues that identity development is an essential life task that most human beings undertake.

Gill (1997) builds on Erikson’s psychological development model by creating a model of identity development that examines how people with disabilities come to terms with who they are. Gill argues that the quest to obtain a unified sense of self for people with disabilities is in part a journey in which individuals will become comfortable with their group identity as individuals who are disabled. In other words, in order to become
comfortable with whom they are, people with disabilities need to come to terms with what it means to be a person with a disability in American culture (Gill; Hernandez, 2005; Ostrander, 2008; Whitney, 2006).

Since Gill (1997) first developed her theory, it has become the dominant model of identity development applied to individuals with disabilities. Some scholars have used this model to explore the ways in which individuals who receive violent spinal cord injuries deal with a new identity for themselves once they have become disabled (Hernandez, 2005; Ostrander, 2008). Still other scholars have used Gill’s model to explore identity development for people with disabilities who identify as gay or lesbian (O’Toole, 2000; Shakespeare, 1999; Whitney, 2006). Gill’s model has been an important contribution to the scholarship that examines questions surrounding identity and disability.

Despite the important contribution that Gill’s model has made to the field of disability studies, various scholars argue there is a need for more scholarship exploring identity development and people with disabilities (Cameron, 2007; Darling, 2003; Galvin, 2005; Gill, 1997; Smith & Sparkes, 2008a). Specifically, scholars argue there is a need for more personal stories of people with disabilities that demonstrate how questions of identity impact people in their everyday lives (Cameron, 2007; Darling, 2003; Do & Geist, 2000; Gill, 1997).

Exploring the ways in which identity development operates in the life of someone with a disability is one of the purposes of this autoethnography. My story can help shed light on how my identity development impacts how I perceive the world around me. It is
also my hope that by illuminating the way my own identity development has affected my worldview, I will help scholars better understand the ways in which identity development might impact the perceptions of other individuals who have disabilities.

Additionally, the process of identity formation is largely a social construct (Berger, 2009; Engle & Munger, 2003; Erickson, 1968; Ostrander). An individual’s identity is impacted by the culture in which he or she lives. People with disabilities in Western culture live in a society in which being able-bodied is seen as the goal for everyone (Davis, 1997; Linton, 1998; Thomson, 1997). Therefore, those with disabilities are often devalued because they do not meet the able-bodied standard of normalcy. This goal has become part of the culture of disability because Western society privileges a biomedical model that asserts that people with disabilities can and should be “fixed” so that they can achieve the able-bodied standard of normalcy (Berger, 2009; Consalvo, 2004; Linton, 1998; Mason, 2004; Shapiro, 1994). The problematic with the biomedical model is that it is a way of framing disability that views people with disabilities as broken because they are not able-bodied. In the biomedical model disability is viewed as a defect needing to be “fixed, cured, rehabilitated.” In addition, this model assumes that society should endeavor to “cure” those with disabilities. One can imagine the cultural message that is sent via the medical model: There is something wrong with me. I am not normal. I am broken. These are difficult messages for a person with disabilities to navigate and maintain an empowered sense of self. It is against this cultural backdrop that my life takes place.
Statement of the Problem

This autoethnographic research seeks to explore the question of identity development as it relates to people with disabilities. There is evidence to suggest that people with disabilities are often marginalized in American society (Consalvo, 2004; Davis, 1997; Fries, 1997; Joseph, 2010; Linton, 1998; Williams, 2010). Furthermore, the isolation that many people with disabilities face in their everyday lives may cause some people to have a negative sense of their self-worth. In turn, the negative perception that many people with disabilities hold of themselves may inhibit their personal identity development (Brunnberg et al., 2008; Davis, 1997; Gill, 1997; Hahn, 1997; Jones & Lollar, 2008; Li & Ford, 1996).

Therefore, the purpose of this dissertation is to utilize an autoethnographic approach in order to articulate my story using the theoretical lens of identity development in order to gain a deeper understanding of factors that can impact the self-perception of people with disabilities. This dissertation will explore the complicated nature of identity development. First, this autoethnography will illustrate the complex way in which someone with a disability might negotiate his or her existence in two different worlds; the culture of disability on the one hand, and the world of people who are able-bodied on the other. Second, this dissertation will investigate the manner in which family relationships might impact the identity of those with disabilities. Third, this autoethnographic study will explore the way in which being involved in an interability romantic relationship can impact the process of identity development. Finally, this autoethnography will examine
how being storied in public discourse may affect an individual's understanding of his or her disability.

**Research Questions**

The telling of my story within this dissertation is guided by research questions that allow me to explore identity development as it relates to people with disabilities. These research questions frame my autoethnographic exploration of the relationship between disability and identity. The research questions are:

- **RQ1**: How does my identity development as a person with a disability compare with the dominant ability identity development model postulated by Gill (1997)?
- **RQ2**: What are the dialectical tensions I perceive to be present in my relationship with my partner who is able-bodied? How do I experience those dialectical tensions? How does the process of managing those dialectical tensions within our relationship alter my identity development as a person with a disability?
- **RQ3**: How am I storied in public discourse? How do the various ways that I am storied in public discourse impact my identity development as a person who has a disability?

**Significance of the Study**

I believe my autoethnographic study has significance for the following groups of people whose interests may cut across a wide array of academic disciplines. First, scholars who specifically study the link between disability and identity might find this study valuable. Although some scholars have begun to explore the relationship between disability and identity, there is a need for more research that explores this topic (Berger,
Therefore, this study might enrich the literature for scholars that explore identity development as it relates to people with disabilities.

Second, while this dissertation focuses on how my story coincides with the experiences of others who have disabilities, my autoethnography might be useful to other scholars who study different models of identity development. For example, scholars who study Racial Identity Development, or Lesbian Gay and Transgendered Identity Development might find this dissertation useful because the above models illustrate the process of identity development for individuals within marginalized groups. There is evidence that people with disabilities are marginalized by mainstream society (Axtell, 1999; Brittain, 2004; Burton & Parks, 1994; Couser, 2005a; Depauw, 1997; Frame, 2007; Taggart, McLaughlin Quinn, & Milligan, 2006). There is also support for the idea that the isolation people with disabilities face is similar to the experiences of individuals from other marginalized groups (Corker & French, 1999; Ingstad & White, 1995; Linton, 1998; Thomson, 1997; Wendell, 1996). Therefore, scholars might find it helpful to juxtapose this narrative with stories of people from other isolated groups. Scholars might discover that the quest for a complete identity undertaken by some people with disabilities is similar to the identity development of other marginalized groups.

Third, academics who are interested in studying how individuals navigate multiple cultural identities might find this autoethnography to be useful. It is evident that people with disabilities have created a unique culture with its own set of values (Albrecht, 1999; Barnes & Mercer, 2001; Burbach&Babbit, 1993; Fidduccia, 2000; Gill,
1994b; Guldin, 2000; Siebers, 2008). In fact, the values that are important in disability culture are often in conflict with the values that are significant in the mainstream culture (Gill, 1999; Linton, 1998; Longmore, 2003; Shakespeare, 1999; Tepper, 2000). Therefore, it seems that many people with disabilities often live in two conflicting worlds; culture of disability, and the world of people who are able-bodied (Albrecht, 1999; Barnes & Mercer, 2001; Gill, 1999; Guter & Killacky, 2004; Kemp, 2004; Longmore, 2003; Shakespeare, 2006). Thus, many individuals with disabilities, like numbers of other minority cultures, negotiate their multicultural existence by carefully selecting when and how they will choose to embrace their position in the minority culture on the one hand, and their place in the dominant culture on the other (Axtell, 1999; Darling, 2003; Hernandez, 2005; Ostrander, 2008; Shakespeare, 2006).

In this autoethnographic inquiry, I will explore how the process of navigating my membership in both of these worlds impacts my identity. Hence, this dissertation might be useful to academicians who wish to gain a broader understanding of how the act of negotiating a multicultural existence can effect a person's identity development. In short, this autoethnography may provide scholars with another way to view the process by which people negotiate their multicultural identities.

Fourth, scholars who investigate how people with disabilities are depicted in the media might also find this dissertation helpful. There already exists a great deal of literature that explicates images of those with disabilities in the media (Barnett & Hammond, 1999; Brittain, 2004; Consalvo, 2004; DePuaw, 1997; Goggin & Newell, 2003; Howe, 2008; Quinlan & Bates, 2009; Ross, 1997; Schwartz & Lutfiyya, 2009).
However, most studies that investigate the media and disability do so in general terms. That is to say, most of this scholarship explores how people with disabilities are stereotyped by the dominant culture (Barnett & Hammond, 1999; Consalvo, 2004; Howe, 2008; Quinlan & Bates, 2008; Ross, 2001; Sandell, Delin, Dodd, & Gay, 2005). Often the literature explains how dramatization of those stereotypes often gives people a simplistic image of people with disabilities (Gilbert & Schantz, 2009; Goggin & Newell, 2003; Quinlan & Bates, 2007; Riley, 2005).

Research in the area of media and disability rarely seeks to understand the reaction of individuals that are being portrayed in a specific media artifact. There is a need for more inquiry into how a person *feels* about being the subject of a particular media story. Examining the ways in which individuals comprehend their own mediated images might provide scholars with a unique view of how the media can impact the identity development of an individual who has a disability. This autoethnographic inquiry will demonstrate the various ways that my disability has been portrayed in the media and will elucidate the imprint those media images continue to leave on my identity. By connecting the way I have been storied in the media with the issue of personal identity development, my hope is that this dissertation will provide a fresh perspective on disability images in the media.

Fifth, educators and professionals who are interested in studying the connection between families and the identity development of people with disabilities might be interested in the issues that are examined in this autoethnography. Family is the place where people begin to construct their identities (Atwood, 1996; Berk, 2008; Byng-Hall,
Thus, in order to investigate the process of identity development for those with disabilities, it is important to explore the family's role in that process. While there is a growing body of literature that discusses the effect familial relationships can have on the process of identity development for people with disabilities, there is a need for more research that interrogates this topic (Byng-Hall, 1998; Canary, 2008b; Fitzgerald & Kirk, 2009; Gill, 2001; Green, 2003; Terry & Campbell, 2009).

Therefore, this autoethnography investigates the impact that familial relationships have on my identity development as a person with a disability. Conversely, this dissertation also illuminates how my identity development as an individual with a disability has affected my relationships with various members of my family. Hopefully, this dissertation can shed more light on the ways in which familial relationships can impact the identity development of those who have disabilities.

Sixth, scholars who study romantic relations between interability couples may find this study useful. While there is a growing body of literature that explores interability coupling, there is still a need for more research on this topic (Axtell, 1999; Chance, 2002; Davies, 2000; Fiduccia, 2000; Siebers, 2008). The scholarship that illuminates interability relationships suggests there is a need for literature that explicates the personal stories of interability couples (Davies, 2000; Gill, 1996; Guldin, 2000; Guter & Killacky, 2004; Joseph, 1991; Milligan & Neufeldt, 1998; Moin, Duvdevany, & Mazor, 2009; Ostrander, 2009; Pitzele, 1995; Tepper, 2000). Since my autoethnography
explores my own relationship and its impact on my identity, this dissertation might add to the area of scholarship that explicates romantic relationships and people with disabilities.

**Limitations of the Study**

Having discussed the potential significance of this dissertation, next some of the research limitations of this autoethnography are outlined. First, my story is one that explores the life of a person who has a physical disability. Therefore this dissertation is useful for scholars who are exploring identity development as it relates to people with physical disabilities. Because my cerebral palsy is a visible disability, my experiences may be different than someone who has a hidden disability. In addition to possible limitations as applied to people with hidden disabilities, my autoethnography may not be applicable to individuals with cognitive disabilities, as their experience may be different than someone who lives with a physical disability. Therefore, some assertions and/or conclusions of this autoethnographic study might not apply to individuals who have invisible disabilities or those with cognitive disabilities.

Second, this narrative is the story of a White, working class, college-educated, heterosexual male. I realize that as a White male who has multiple graduate degrees; my experience might differ when compared to a person who is a different race or someone who may have a different educational background from my own. In addition, one’s social class status might impact the experience of a person with a disability based upon what resources they and/or their family are able to garner. Finally, as it relates to interability romantic relationships, research exists that indicates the dynamics in same-sex couples is different than that of heterosexual couples. Therefore, the analysis within this dissertation
could be limited in contexts where race, social class, gender, and sexual orientation are significant contributing factors to a person’s identity development.

Third, autoethnography is a very personal research methodology. Some scholars may have concerns the autoethnographic approach is focused so intently on the life of the individual, that it limits the ability of a personal narrative to make academic claims that transcend the life of that specific person. Chapter Two will further outline the autoethnographic methodology employed in order to analyze my life story.

**Delimitations of the Study**

I have chosen to research this topic through an autoethnographic methodology. This delimits my research to an analysis of my story. This dissertation examines certain aspects of my story that relate to the research questions that guide this study. The goal of this study is to use my narrative in order to further develop the scholarship that deals with identity development for people who have disabilities. It is my hope this autoethnography will reveal insights that will contribute to the literature that investigates this topic.

**Definition of Terms**

In order to explore the issue of identity development as it relates to people who have disabilities, it is necessary to define and/or stipulate certain concepts and terms used in this dissertation. The definitions of terms follow in this section.

*Ableism*: The systemic discrimination of individuals with disabilities (Mason, 2004; Shaw, 1994; Wade, 1994).

*Culture*: a unique way of life (Barnes, & Mercer, 2001; Gill, 1994; Longmore, 2003; Shaw, 1994).
Disability: When the term disability is used it refers to the legal denotation of disability that is written into the Americans with Disabilities Act (ADA). The ADA defines someone with a disability “as any person who has a physical or mental condition that substantially limits one or more major life activities” (Glick, 2006).

Disability Culture: A unique way in which individuals are unified by the experience of living with a disability (Gill, 2001; Linton, 1998; Wade, 1994).

Identity Development: The process that individuals undertake in order to develop a unified identity that allows individuals to develop a continuous understanding of who they are across space and time. The process of identity development allows people to construct an independent sense of self while also being able to forge meaningful relationships with others (Erikson, 1968; Gill, 1997).

Identity Development Models: Models constructed in order to explain the various stages individuals might encounter in their quest to develop a unified identity (Darling, 2003; Gill, 1997; Ostrander, 2008). Identity development models maintain that when individuals create their own identity, they must also come to terms with a larger group identity, and that process is often fraught with struggle. These models often illuminate the identity development process of individuals within a specific group. In doing so, these models attempt to illuminate the ways in which being a member of that group creates unique challenges that may impact identity development. While identity development models are often written as a series of linear progressions that occur over time, it is important to understand that identity development models are not linear in their real life
application. People often move from one stage to another depending on the particular context.

*Interability Relationships:* are relationships in which one person has a disability and the other person is able-bodied (Braithwaite & Harter, 2000).

*Media:* The institution within society that is primarily responsible for conveying and disseminating mediated ideas to a large audience (Goggin & Newell, 2003).

*Person First Language:* Person first language asserts that when referring to those with disabilities it is preferable to put the word “person” before the word disability. Person first language is an attempt to help people who are able-bodied see individuals with disabilities as people rather than labels. Therefore, in person first Language it is better to say a “person with a disability” instead of a “disabled person”. While I recognize that it is preferable to use people first language when referring to individuals with disabilities, I do not think that it is always necessary. In my own struggle of identity development I have come to feel that it does not really matter whether someone calls me a person with a disability or a disabled person. I view person with a disability and disabled person as acceptable ways to reference my disability. Within this dissertation I will employ mainly person first language; still there are places where I do not, and that is simply my choice. It is not to offend anyone who prefers the use of person first language.

*Super Crip:* The depiction of people with disabilities in the media as heroic characters simply because they attempt to lead normal lives (Goggin, & Newell, 2003). The “super crip” depiction focuses on the inspirational nature of people with disabilities,
and tends to ignore the complexity of what it means to live with a disability on a daily basis.

**Organization of Study**

The key terms that will be used throughout this autoethnography have been defined leading to an outline of how this dissertation will be organized. The majority of the academic scholarship underpinning this dissertation will be interwoven with the personal narrative. It is my hope this approach will allow the reader to develop a clear sense of how my experiences intersect with the larger academic discourse that explores people with disabilities. My lived experience as a person with a disability is not separated from intellectual discourse, but rather my identity development continues to take place within already existing societal discourse. Therefore, constructing my story alongside a larger academic conversation is a compelling way to illustrate how I have lived my life as a person with a disability.

Even though most of the literature will be interwoven within the telling of my life story, the first two chapters will help set the stage for and organize my narrative. Chapter One introduced the reasons why I chose to explore identity development as it relates to people who have disabilities. It also outlined both the objectives and scholarly significance of this dissertation. Chapter Two explicates autoethnography which is the research methodology employed throughout this dissertation. The second chapter not only explains what an autoethnography entails, but includes a discussion of the major theories that will be used to academically ground my narrative. Included will be an explanation of how those theories apply to the analysis of my story.
Chapter Three “Identity Development: A Journey of Reflection, Transformation, and Ongoing Struggle” explores the journey of identity development that transformed me from a person who rejected my disability into a person that embraced it. Chapter Four “Living in Two Worlds and The Dialectical Nature of Disability” examines the complex way that I negotiate my existence in the culture of disability on the one hand, and the world of people who are able-bodied on the other. Chapter Five “Relationships and Identity Development” examines the way that my identity development impacts my relationships and vice versa. In particular, I scrutinize my relationships with family members and my relationship with my able-bodied girlfriend. Chapter Six “Public Discourse, Disability, and Identity Development“ explores how the ways that I am storied in public discourse impacts my identity development and vice versa. Chapter Seven “Conclusion” discusses various academic themes that have emerged in this dissertation. I also illuminate the possible implications of the research found in this dissertation.
Chapter 2: Methodology

The Organization of My Narrative

The purpose of this chapter is to explain the methodology of this autoethnography. In order to set the stage for the discussion of the methodology, I will first describe the organization of the autoethnography. Following that, the methodology of autoethnography is addressed, and how and why it is useful. This is followed with an explanation of how and why autoethnography is a relevant methodology to respond to my research questions. I will also include a reflection on how my positionality as the researcher may impact the method and analysis of this dissertation.

Because this dissertation employs an autoethnographic methodology, it does not have a chapter separating the scholarly literature from the story. This study will employ the autoethnographic approach that Carter (2002) utilized to tell her story of physical abuse. Carter argues that illuminating her personal story alongside the academic literature on spousal abuse allows the reader to look beyond the academic discourse in order to see personal impact that abuse can have on someone. I will be employing this integrative technique in order to connect my own struggle with identity to the larger academic discourse that explores the complexities of disability and identity. I will demonstrate that my story is not separate from the discourse that surrounds people with disabilities. My struggle with identity should be understood as a battle that takes place within the context of a larger cultural conversation about those who have disabilities. My life experience has been influenced by that discourse. Therefore it seems appropriate for this
autoethnography to interweave my own experiences within the larger academic
discussion that explicates issues of disability and identity.

While I am not exploring the issue of spousal abuse, Carter’s approach to
constructing an autoethnography is a useful way to construct this dissertation. The
academic literature on the issues that undergo investigation in this dissertation are
interwoven with the telling of my personal narrative. I do not believe that life is lived in
isolation from the discourse on disability, but rather, my identity is constantly being
altered by the societal discourse that surrounds people with disabilities. Therefore,
employing an autoethnographic methodology that integrates the relevant academic
literature with personal narrative is an appropriate way to tell my story that is connected
to the larger discourse that explores disability. Presenting my story alongside the
academic scholarship on disability might also add to the literature exploring the identity
development of people with disabilities.

While most of the academic scholarship will be intermingled with personal
narrative, two major theoretical approaches will underpin the analysis of the narrative.
Since these theoretical frameworks are central to the methodology that will be used to
analyze the autoethnography, these approaches will be explained in this chapter. First, I
explicate Gill’s (1997) model of identity development. Second, I discuss the concept of
dialectical theory. However, before I further illuminate these concepts, it is useful to
explain the important role that narrative inquiry can play in researching various
phenomena. It is to this discussion that I now move.
Narrative Inquiry

A recently expanding group of scholars have argued that studying personal stories can enrich understanding of any phenomenon (Brody, 1987; Clandinin, 2007; Gabb, 2008; Johnson & Golombek, 2002; Laboskey & Lyons, 2002; Phillion, He, & Connelly, 2005; Phillion, 2002). Moreover, researchers who engage in the practice of narrative inquiry contend that stories are one of the most important ways that individuals make sense of the world. As Pinnegar and Daynes (2007) state, narrative researchers “usually embrace the assumption that the story is one of if not the fundamental unit that accounts for human experience” (p. 4). Since stories are an important way that scholars can understand a particular phenomenon, narrative inquiry can be a valuable methodology that can help enrich the scholarship on a number of different topics.

Narrative inquiry is a research methodology that involves the exploration of stories in order to gain a deeper understanding of a particular issue. Clandinin and Connelly (2000) argue that narrative inquiry can be a useful research methodology when the researcher can connect personal stories to a larger body of academic literature. In short, narrative inquiry seeks to connect personal stories to a larger social discourse. As Gabb (2008) explains:

Narrativisation of experience does not simply tell a story, it constructs an account within the language, conventions and social milieu that translates experience. Life stories do not mirror life experiences; they re-present them in particular contexts in culturally intelligible formats. (p.39)
In other words, narrative inquiry allows the researcher to help make sense of a story by placing that story within a specific social context in order to help shed light on a particular issue. Thus, the process of narrativising one’s life experience not only seeks to connect those experiences to a larger social issue, but narrativisation tries to connect single events in a story to a broader narrative. As Brody (1987) states, “The concept of “story” suggests an appreciation of a narrative-mode that certain sorts of events can only be understood as part of an ongoing narrative and not as disconnect events occurring in isolation” (p. xiii). In other words, the events that are undergoing integration in narrative inquiry should be connected to the larger personal, social, and academic narratives that might apply.

For instance, this autoethnography is a form of narrative inquiry that sheds light on my perception of my experience as an individual who has cerebral palsy. Moreover, the individual events in my story are connected to the ongoing narrative that is my life. In addition, this narrative occurs within the larger discourse related to the issue of disability as a cultural identity. In short, this autoethnography is not a simple retelling of my story; instead I use various personal, cultural, and academic lenses so that my narrative can enhance the scholarship that discusses identity and people with disabilities.

Moreover, the stories in this autoethnography are based on my perceptions about important events that have occurred in my life, not on whether they are actually “true”. The question of “truth” in an autoethnography (and in many qualitative studies as well) is not the applicable question to ask in that this genre of research inquiry is not seeking “truth” in the sense of consensus of what occurred, but is seeking meaning via perception.
The stories shared in this autoethnography are used to illuminate how certain events impacted my life. By sharing these stories I am not attempting to speak for anyone but myself.

I recognize that many of the individuals referenced in these narratives do not have a chance to provide their perceptions of the events shared in these stories. Therefore, some critics of autoethnography may claim that I should use a form of member checking in order to verify the accuracy of these stories with others who were party to these events. While conducting a member check is certainly a valid way to approach others forms of qualitative research, it does not have to be a part of the autoethnographic method. In other forms of qualitative research such as a standard ethnography it may be important that the researchers represent the perceptions of the people they are researching. In that case a member check might be appropriate.

Conversely, a primary purpose of an autoethnography is for the researcher to share how they perceive the events in their life. For example, my autoethnography is an attempt to understand how events in my life shaped my identity. Thus, the stories in this autoethnography demonstrate how I perceive others and the world around me. Therefore, it is not necessary for me to engage in a member check with the individuals that are part of these stories because I am not exploring how they felt about these events. Instead I am investigating how I am impacted by these events. In short, these stories illustrate factors that are important to my identity development. Consequently, I did not do a member check with individuals that are part of my narrative. Now I will further explicate autoethnography as a specific form of narrative inquiry.
Autoethnography

What is Autoethnography?

In its simplest definition, an autoethnography is a method of research that enables the researcher to use his or her own personal experiences in order to shed light on a research topic (Ellis & Bochner, 2000). An individual who is constructing an autoethnography interprets his or her own life by using various social, cultural, and academic lenses in order to connect his or her personal experiences to a broader cultural phenomenon and to the relevant academic literature (Couser, 2005; Ellis & Bochner, 2000; Lionnet, 1989; Pratt, 1992). To explain it another way, an autoethnography allows the researcher to demonstrate the relationship between the personal and the political (Carter, 2002; Couser, 2005; Jones, 2007; Pratt, 1992; Reed-Danahay, 1997). Illustrating the relationship between the personal and the political means that an autoethnography allows the researcher to connect his or her own experiences to a larger culture whose values and norms have an effect on the experience of that individual. Connecting the personal to the political also allows individuals who construct an autoethnography to show how their story relates to other individuals in similar circumstances.

For example, this autoethnography allows me to examine my identity development as a person with a disability in a culture that devalues people with disabilities. Moreover, this autoethnography allows me to examine the interplay between my own perception of identity, and cultural norms about those who have disabilities. In addition, writing an autoethnography allows me to contrast my own identity development with the experiences of other people who have disabilities.
The definition provided above helps scholars delineate the difference between life stories and autoethnographies. As noted earlier, not all autobiographies are ethnographic. In order to be considered an autoethnography, a narrative should link the experiences of an individual to a social context that transcends the personal (Carter, 2002; Couser, 2005; Jones, 2007; Pratt, 1992; Reed-Danahay, 1997). The autoethnographic researcher should be able to demonstrate how his or her own experiences have been shaped by cultural forces that exist in society. Lionnet (1989) explains this process as “the defining of one’s subjective ethnicity as mediated through language, history, and ethnographical analysis; in short, a kind of ‘figural anthropology’ of the self” (p. 99). In turn, the autoethnographic method seeks to examine the various ways that the values of a culture impact the personal development of the author.

Furthermore, autoethnographic narratives are part of a preexisting cultural conversation. As Murray (1999) states “narratives do not, as it were, spring from the minds of individuals but are social creations” (p. 53). Hence, stories are not the narrative of one person, but rather they are a part of a larger societal discourse that transcends the life of that individual. Not only do narratives come from an already existing culture, but they also help extend the social discourse on a particular topic (Atwood, 1996; Berger, 2009; Byng-Hall, 1995; Frank, 1995; Lewis, 2007; Smith & Sparkes, 2008a).

In short, the act of telling one’s own story is a social act. That is to say, when someone shares their story they are contributing to a larger social discourse. As Roets, Goodley, and Van Hove (2007) state, “Once you let stories go, they might lead lives of their own” (p. 324). Thus, when someone shares a narrative it can become a social
artifact that will add a new perspective to the cultural conversation on a topic (Cameron; 2007; Carter; 2002; Frank, 1995; Jones, 2007; Smith & Sparkes, 2008a).

For example, my autoethnography occurs within the larger intellectual conversation that already exists about the issues of disability and identity. This story of a quest for identity has been influenced by the preexisting cultural rhetoric regarding people with disabilities. Therefore, this story should not be comprehended in isolation from that discourse, but rather considered within this broader context. Hopefully, this autoethnography will enrich the discourse surrounding the identity development of people with disabilities.

Autoethnography Can be Empowering

Since autoethnographies can give “voice” to individuals within a social context allows it to be an empowering method of inquiry. Bochner and Ellis (2000) argue that the process of writing an autoethnography can help individuals develop coherence between past events that have influenced their life, and their present identity. Other scholars have demonstrated that the retelling of stories can help individuals make sense of their identity, thereby giving them a newfound sense of empowerment (Cameron, 2007; Do & Geist, 2000; Engel & Munger, 2003; Fries, 1997; Johnson, 2005; Juette & Berger, 2008; Lewis, 2007; Mason, 2004; Rapp, 2007). When autoethnographies allow marginalized individuals to share their struggle, it can give them a newfound sense of power over the oppression they have encountered in their lives. Autoethnographies also allow individuals to give a name to the discrimination they have encountered, and naming oppression can
help empower people (Berger, 2004; Gill, 2004; Lewis, 2007; Shaw, 1994; Shor, 1992; Wade, 1994).

While writing an autoethnography can help individuals construct their identity, autoethnographies can also give voice to people who are marginalized in society. For instance, Reed-Danahay (1997) contends that a form of autoethnography that she describes as native anthropology can help people who have been oppressed by gaining an empowering discourse that describes their oppression. Native anthropology occurs when members of a marginalized group begin to tell their stories. Reed-Danahay’s conception of autoethnographic inquiry allows individuals who have often been studied by members of the dominant culture to obtain their own voice and speak for themselves.

Pratt (1992) also argues that autoethnographies can empower individuals who are from marginalized groups. Pratt contends autoethnographic inquiry can help individuals who have been oppressed understand the nature of their oppression. She asserts the process of writing a life story allows individuals to engage with the various ways they have been marginalized in a society. In addition, autoethnographies are a space where individuals explore the larger systemic forces of oppression. Therefore, Pratt contends that autoethnographies allow marginalized individuals to label the nature of their oppression. In turn, the process of labeling their oppression allows them to contest the dominant view that society may hold about their identity. Therefore, the autoethnographic method allows individuals who suffer oppression to begin to gain power over the cultural forces that collaborate to marginalize them.
Additionally, autoethnographies can help individuals illuminate personal oppression. Therefore, autoethnographic inquiry might help raise society’s critical awareness toward issues of discrimination. The autoethnographic approach to inquiry provides the researcher with a unique opportunity to illuminate how personal discrimination impacts an individual who is situated within a larger cultural context.

For example, this autoethnography provided me the opportunity to explore deeply how being a person with a disability has impacted my perception of my own identity. Hence, sharing my story through this autoethnography provides me with a method to explore my identity that would not be present if I were to have used a more traditional research methodology. In short, constructing an autoethnography allowed me to explore how I gained a critical conscience surrounding the issues of disability and identity. Shor (1992) defines critical consciousness as:

> Critical consciousness allows people to make broad connections between individual experience and social issues, between single problems and a larger social system. The critically conscious individual connects personal and social domains when studying or acting on any problem or subject matter. (pp. 126-127)

Autoethnography is one method that can help individuals identify the relationship between social systems that marginalize specific groups of people, and how members of that group deal with the discrimination they may encounter in their daily lives. Consequently, autoethnographies contribute to the discourse of discrimination by shining a light on how discrimination impacts the way in which marginalized people interact with the world around them. This may help individuals interested in studying systemic
discrimination acquire a better understanding of how individuals who are marginalized come to terms with their oppression. The next section will specifically address how autoethnography can be a research methodology that can be used to empower people with disabilities.

**Autoethnography and People with Disabilities**

Certain hegemonic narratives can dis-empower those with disabilities. Often these are stories told about people with disabilities created by those who are able-bodied (Davis, 1997; Fries, 1997; Thomson, 1997). In turn, many of these narratives frame people with disabilities as inferior to those who are able-bodied (Davis, 1997; Consalvo, 2004; Linton, 1998). Thus, many of these narratives dis-empower and marginalize people with disabilities, because many of these stories frame disability from an able-bodied perspective.

As illustrated previously, autoethnographies can create a space for individuals who are marginalized to tell their story. To have the ability to share one’s life story can be a source of empowerment (Berger, 2009; Fries, 1997; Juette & Berger, 2008; Lewis, 2007; Mason, 2004; Rapp, 2007; Rucker, 2007). The fact that autoethnographic inquiry often seeks to empower marginalized individuals makes it a useful research methodology for people who have disabilities.

There have been numerous scholars who have elucidated the systematic oppression encountered by people with disabilities (Butler & Parr, 1999; Corker & French, 1999; Davis, 1997; Engle & Munger, 2003; Gill, 2004; Goggin & Newell, 2003; Joseph, 2010; Linton, 1998; Shapiro, 1994; Shaw, 1994; Thomson, 1997; Wendell,
Many scholars have also argued that people with disabilities are often stigmatized by the “research” of people who are able-bodied (Berger, 2004; Consalvo, 2004; Davis, 1997; Frame, 2007; Gill, 2001; Linton, 1998; Wade, 1994). Moreover, historically, people with disabilities have not been afforded many opportunities to speak for themselves. Therefore, those with disabilities are under-represented in academic discourse (Butler & Parr, 1999; Consalvo, 2004; Corker & French, 1999; Davis, 1997; Linton, 1998; Shakespeare, 2006; Siebers, 2008; Wendell, 1996).

Thus, Reed-Danahay’s (1997) assertion that the autoethnographic method of research can help individuals from marginalized groups become active participants in academic discourse; can be applied to people who are disabled. In fact, numerous texts claim that scholars might benefit from more first person accounts of what it is like to live with a disability (Berger, 2004; Butler & Parr, 1999; Chance, 2002; Corker & French, 1999; Couser, 2005b; Davies, 2007; Furgeson, Furgeson, & Taylor, 1992; Galvin, 2005; Gill, 1996; Ware, 2001; Whitehead, 2006). Autoethnographies can provide scholars with a unique opportunity to explore issues that impact people with disabilities, and illuminate how living with a disability can alter certain aspects in a person’s life such as their relationships, education, employment, or identity. Demonstrating how having a disability can influence important aspects in someone’s life may help scholars understand what it means to live with a disability in our society. For example, this autoethnography provided me with a unique opportunity to use my life story in order to explore issues of identity and disability.
Furthermore, academic narratives that explore people with disabilities might enable individuals to contest the negative discourse that is part of the social rhetoric of disability. As Pratt (1992) asserts, employing the methodology of autoethnography can allow oppressed individuals to explore the discourse that oppresses them. Moreover, the field of disability studies posits that people with disabilities should be considered an oppressed minority. For instance, Davis (1997) states, “people with disabilities have been isolated, incarcerated, observed, written about, operated on, instructed, regulated, treated, institutionalized, and controlled to a degree probably unequal to that experienced by any other minority group” (p. 1). The point here is not to create a hierarchy of suffering among oppressed groups, but rather to demonstrate that people with disabilities should be viewed as a marginalized minority group. Since people with disabilities can be viewed as an oppressed minority group, autoethnographies can help scholars combat the negative discourse that many individuals with disabilities encounter.

Individuals with disabilities often encounter a dominant discourse that defines them as inferior to people who are able-bodied (Berger, 2009; Consalvo, 2004; Corker & French, 1999; Hahn, 1997; Linton, 1998; Russell, 1998; Shakespeare, 2000; Smith & Sparkes, 2005; Wendell, 1996). According to Couser, (2005a) people with disabilities can use the method of autoethnographic inquiry to define the negative discourse on their own terms. In other words, disability narratives can be more than a personal story. Autoethnographies that explore stories of disability can help contest the dominant discourse that stigmatizes disability (Berger, 2004; Couser, 2005a; 2005b; Smith & Sparkes, 2008a, 2008b; Ware, 2001; Whitehead, 2006).
Autoethnographies and the Quest for Identity

Because autoethnographic inquiry can allow individuals to contest the way the dominant discourse frames disability, it may also help some with disabilities deal with their identity. Many people with disabilities struggle with their identity because they are stigmatized by mainstream society (Axtell, 1999; Brittain, 2004; Cameron, 2007; Charmaz, 1995; Crooks, Chouinard, & Wilton, 2008; Darling, 2003; Galvin, 2005; Gill, 1997; Goffman, 1963; Hahn, 1997). Autoethnographic inquiry helps create a space where people with disabilities can explore how their identity has been shaped by hegemonic discourses that tend to stereotype people with disabilities. That act of contesting hegemonic discourse through narrative may help some people with disabilities come to terms with what it means to have a disability. Couser (2005a) hopes autoethnographies that engage disability produce “texts that explore the creation of identity within particular subcultures and texts that contest the way the author’s community is characterized from outside” (p. 128).

Not only can autoethnographies help the individuals who write them explore their own identity, but disability narratives can enhance the scholarship that explores identity development. There is a need for more scholarship that explores how issues of identity impacts people with disabilities on an everyday basis (Axtell, 1999; Cameron, 2007; Couser, 2005b; Darling, 2003; Engle & Munger, 2003; Gill, 1997; Hernandez, 2005; Ostrander, 2008; Whitney, 2006). In turn, autoethnographies can demonstrate how various factors such as someone’s education or involvement in interability relationships can influence how people understand their identity. Illuminating these factors might help
scholars understand how living with a disability interacts with how people view themselves. Thus, autoethnographies then can make a significant contribution to the literature that explores the confluence of disability and identity.

**Responses to Possible Criticisms of Autoethnography**

Possible criticisms that some scholars may have toward the academic utility of autoethnographies will now be examined. Some scholars argue that the autoethnographic method of research is too personal. That is to say, they may have concerns that autoethnographies focus too much on the individual and therefore the claims made within these narratives cannot be transferred to larger academic questions (Ellis & Bochner, 2000).

As has been previously articulated, a necessary component of autoethnographic inquiry is that it illustrates connections between the experiences of one individual and a broader cultural context. Consequently, one aspect of an autoethnography that makes it autoethnographic is its ability to connect the personal with the political (Carter, 2002; Jones, 2006; Lionnet, 1989; Pratt, 1992). If an autobiography does not attempt to connect personal experiences of the author to larger social issues, (and against the backdrop of academic literature, research questions, etc.) then that personal narrative should not be considered autoethnographic. Scholars, who claim that autoethnographies cannot make claims beyond the personal, conflate autoethnographic inquiry with other types of personal narratives that are not intended to illuminate larger social issues.

Despite their ability to illuminate an individual experience within a broad social context, some scholars still down play the academic value of autoethnographies for other
reasons. Some would diminish the scholarly importance of autoethnographic memoirs because they have concerns about the accuracy of the events shared in a memoir. They contend there is no way to verify whether the events that are written about actually occurred in the way that those events are depicted. Therefore, some scholars assert those engaged in the construction of autoethnographies are not doing social science (Ellis & Bochner, 2000). While a desire for accuracy is to be commended, a perfect recounting of facts is not the main goal of an autoethnography.

The objective of the autoethnographic method of inquiry is to gain understanding about how the events in someone’s life impact his or her current understanding of his or her position within a larger cultural context so that his or her personal story sheds light on an important issue (Cosser, 2005a, 2005b; Ellis & Boncher, 2000; Pratt, 1992). Hence, it is not as important that an autoethnography engage in a perfect retelling of a story. Instead it is more important that researchers provide an interpretation of their story connected to the larger academic discourse on an issue, because the value of an autoethnography is not simply in the events that make up the life story. Rather, the value of an autoethnography comes from the researchers’ abilities to situate their evaluation of those events within a broader academic discourse; which enables the autoethnography to enrich the scholarship on a particular topic. For example, the value of this autoethnography depends on my ability to connect my story to the larger academic discourse related to the identity development of people with disabilities.

Finally, some scholars may contend that the value of autoethnographies is limited because writing personal stories should not be considered social science. These scholars
claim that autoethnographies are too personally biased to be considered legitimate academic scholarship (Couser, 2005a, 2005b; Ellis & Bochner, 2000; Pratt, 1992). Many researchers engaged in social scientific research try to minimize the researcher’s voice in the analysis of data. Since autoethnographies use the researcher as both the object and subject of research, there is no way to limit the voice of the researcher. Consequently, some scholars are leery about recognizing autoethnographic inquiry as a legitimate research methodology because the researcher’s voice is so ubiquitous in an autoethnography.

While there is a place for research that employs traditional research methods, there also needs to be a place for the approach that is embodied in the autoethnographic methodology. Narratives can be a powerful way to explore important social issues. Many scholars argue that the telling of stories helps a society understand who they are (Atwood, 1996; Berger, 2004; 2009; Byng-Hall, 1995; 1998; Ellis & Bochner, 2000; Frank, 1995; Juette & Berger, 2008; Smith & Sparkes, 2008a; 2008b). Smith and Sparkes (2008a) explain it this way; that storytellers are always working within shared “social and cultural frameworks of interpretation.” In this regard, from the perspective of discursive psychology… the interpretive repertoire that people call upon to talk about objects and events in the world in a recognized, familiar, and relatively coherent way” (p. 218).

Through the act of telling stories, the storyteller operates within and is adding to a societal discourse. Stories help cultures process important issues. For example, this autoethnography is my attempt to process the issues of disability and identity within American culture.
Scholars interested in people with disabilities also contend that those who ignore the autoethnographic approach to research are in effect silencing people with disabilities. In fact, Jones (2007) contends that if scholars discount autoethnography as a valid research methodology then they will be missing out on scholarship that elucidates the lives of people with disabilities:

If we cannot hear the voices of those who have been marginalized, then we are not compelled to act on what they say. By not addressing this issue, researchers contribute to the muzzling of their voices, effectively and systematically, eliminating their perspective from the discourse. (Jones, 2007, p. 33)

Including a large number of perspectives in academic discourse benefits all areas of research literature. Autoethnographic inquiry is one method that can be used in order to include more voices in conversations that surround various academic disciplines. Since autoethnography can increase the number of people who can take part in academic discourse, and academic discourse benefits when more people can participate; it seems clear that autoethnography should be considered a legitimate research methodology.

**Data Collection in an Autoethnography**

Now that the autoethnographic method has been described, the next section explicates how data will be collected in this study. While constructing an autoethnography there are a number of ways that data can be gathered, relating to one's life story (Ellis & Bochner, 2000; Lewis, 1997; Pratt, 1992; Reed-Danahay, 1997). A person can use many of the same approaches to gathering data that are present in other forms of qualitative research (Ellis & Bochner, 2000; Reed-Danahay, 1997). In the
following section, three approaches will be delineated that will be used in order to gather
data for this autoethnography; document analysis, first person observation, and an
examination of different types of personal communications that have occurred between
me and other individuals.

Often people will use various documents that can help them create and analyze
their autoethnographic story (Ellis & Bochner, 2000; Lewis, 2007; Rapp, 2007). Whether
scholars examine previous medical records, media artifacts, or personal diaries, previous
documents can be a valuable tool for autoethnographic researchers. Thus, various media
artifacts that describe my experience as a person with a disability are examined. These
media artifacts help me understand how I have been depicted through various media
outlets, and how that impacts my identity development.

While examining documents is one effective way to gather data when completing
an autoethnography, first person observation is another important way to collect data for
an autoethnography (Couzer, 2005a, 2005b; Carter, 2002; Lewis, 2007). First person
observation entails the researcher remembering what they saw, heard, touched, and felt
about the important events in their life (Carter, 2002; Juette & Berger, 2008; Lewis,
2007; Pratt, 1992). Personal observation will be used as a major source in this data
collection. The key aspect to personal observation lies in the researcher’s ability to
honestly reflect on how he or she views important events contained in his or her
autoethnography (Berger, 2004; Carter, 2002; Ellis & Bochner, 2000; Lewis, 2007;
Mason, 2004). As various events in my life were explored, it was necessary to honestly
reflect about what I think I know about the events in my life. It is through this honest
reflection that I discovered new insights that relate to my identity development as a person with a disability.

In addition, interrogating my personal communications with various people is another important aspect of the data collection that is present in this dissertation. To start with, several of my emails are shared as a way to illustrate significant events that have occurred in my life. Moreover, in order to illuminate the important factors that impact my relationship with my able-bodied girlfriend Jane, I examine two presentations in which Jane and I discussed our relationship. Jane's words during these presentations provided me with a powerful way to analyze our relationship and its impact on my identity development.

**Theoretical Framework**

Now that the data collection has been described, this next section will explicate the two most significant theories that I used in order to analyze this narrative. First, I use Gill's (1997) model of identity development that explains the process for people who have disabilities. Second, I employ dialectical theory in order to demonstrate the conflicting nature of disability as a marker of social identity. I begin by examining Gill's identity development model.

**Gill’s Model of Identity Development**

Gill’s model posits that individuals with disabilities often progress through four stages of identity development. These stages are: (a). *coming to feel we belong*: integrating into society, (b). *coming home*: integrating into the disability community, (c). *coming together*: internally integrating our sameness and differentness, and (d). *coming
out: integrating how we feel with how we present ourselves. Now I will explain each stage individually.

In the first stage of identity development, the coming to feel we belong: integrating into society, people with disabilities work hard to gain access to mainstream society. In this stage, Gill argues that people with disabilities want to be seen as “normal.” To put it another way, people with disabilities want to be treated as if they do not have a disability (p. 42). Darling (2003) refers to this stage of identity development as normalization. According to Darling, individuals and families who engage in normalization simply want access to a “normal life.” Darling also points out that many people with disabilities who are engaged in normalization will try to “pass” so that they do not appear to be disabled. They may even reject their disabled identity in order to avoid being stigmatized (p. 883). While Gill (1997) does not use Darling's terminology of normalization, her explication of this stage of identity development is similar to that of Darling. In the coming to feel we belong stage of identity development, “fitting in” with people who are able-bodied is of paramount importance.

According to Gill, in order for an individual to move beyond the desire to fit in with the able-bodied world, that person must come home and embrace disability culture. Coming home allows an individual to view his or her disability with pride because that individual comes to feel that living with a disability makes him or her part of a unique culture. Thus, before discussing the way in which Gill’s model describes how the coming home process occurs for people with disabilities, I will first explore the concept of disability culture.
Disability Culture

Scholars in the field of disability studies contend that the experience of living with a disability is a unique cultural experience (Barnes & Mercer, 2001; Berger, 2009; Davis, 2001; Linton, 1998; Gill, 2001; Longmore, 2003; Shapiro, 1994; Shaw; 1994). For instance, Barnes and Mercer (2001) argue that, "Disability culture presumes a sense of common identity and interest that unite disabled people and separate them from their nondisabled counterparts" (p. 522). In other words, the construct of disability culture contends that people with various disabilities share a way of life that cannot be fully understood by those who are able-bodied (Davis, 2001; Gill, 1994b; Juette & Berger, 2008; Shakespeare, 2006; Shaw, 1994). In fact, Gill (1994b) concludes, "Nondisabled people no matter how much they love us do not know the inside experience of being disabled" (p. 47). Thus, many people with disabilities develop a way of life that is separate from the able-bodied culture.

Now that I have argued that people with disabilities have unique experiences that unite them as a culture; it is necessary to examine some of the experiences that bind people with disabilities together. To begin with, similar to the experience of other cultural minority groups, people with disabilities frequently encounter discrimination in their daily lives (Berger, 2009; Cooker & French, 1999; Consalvo, 2004; Klein & Kemp, 2004; Linton, 1997; Shaw, 1994; Wendell, 1996). Since people with disabilities live in a world that frequently marginalizes their existence, anger and frustration are a reality in the lives of many (Callahan, 1989; Klein, 2004; Rapp, 2007). Klein (2004) explains:
We are connected as a culture because of the shared indignities inflicted upon us by poor architectural planning and design and by others’ stereotypically negative assumptions about us. We are also connected by the frustration and anger that wells up once in a while when we tire of dealing with prostheses, scooters and sores-and that makes us search for understanding by someone who has been where we find ourselves. Anger, frustration and hurt are managed quite well by many of us…and poorly by all of us once in a while. (p. 197-198)

While anger and frustration is certainly one aspect of disability culture, it is only one part of the unique way of life that many people with disabilities experience. Scholars also point out that people with disabilities are unified because they all must learn to adapt to a world that was not designed for them (Davis, 1997; Gill, 1999; Linton, 1998; Longmore, 2003 Thomson, 1997). For example, Linton (1998) states, “the cultural stuff of the community is the creative response to the atypical experience, the adaptive maneuvers through a world configured for non-disabled people” (p. 5).

Gill (1999) concurs with Linton that the universal existence of adaptation among people with disabilities is a part of the disability culture, but she also stresses other values that make the culture unique. These include: (a) tolerance for people from other minority groups, (b) acceptance of interdependence as a fact of life, (c) understanding that ambiguity is a reality of human existence, and (d) use of dark humor by people with disabilities in order to make light of their minority status (p. 283).

Moreover, Longmore (2003) argues that disability culture presumes that “disability experience” is the “starting point” of the values and norms that connect the
culture (p. 222). Longmore also contends that the values that are important within disability culture are often in conflict with the standards and norms that are important in able-bodied culture. He explains:

For example, people with physical disabilities have been affirming the validity of values drawn from their own experience. Those values are markedly different from and even opposed to nondisabled majority values. They declare that they prize not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community. (p. 222)

Longmore (2003) further argues that the articulation of a disability culture is an attempt to redefine what it means to be disabled by taking an identity that has been traditionally stigmatized by mainstream society and reframing it so that people can take pride in their disabilities. Other scholars argue that disability culture frames disability not as a personal defect, but as a cultural identity of which one should be proud (Berger, 2009; Davis, 1997; Juette & Berger, 2008; Klein, 2004; Shapiro, 1994). Hence, framing disability as a cultural identity is an attempt by those with disabilities to redefine disability on their terms. For instance, Wade (1994) states:

No longer polite tin-cuppers waiting for your generous inclusion, we are more and more proud freedom fighters, taking to the stages raising our speech-impaired voices in celebration of who we are. No longer the invisible people with no definition beyond “Other”, we are more proud, we are freedom fighters, taking to the streets and to the stages, raising our gnarly fist in defiance of the narrow,
bloodless images of our complex humanity shoved down the American consciousness daily. (p. 24)

Therefore Wade argues that disability culture empowers those with disabilities because it allows individuals to contest society’s negative depiction of disability. In short, disability culture celebrates the experience of living with a disability. Hahn (1997) declares that the attempt by disability culture to redefine the notion of disability is similar to attempts made by people from other marginalized cultures:

One of the most common features of the social and political movements of the 20th century has been the effort to translate previously devalued characteristics such as skin color, age, gender and sexual orientation into a positive source of honor and respect. In other words, personal traits that had once been interpreted primarily as basis for stigma and discrimination can be redefined as a symbol of dignity and pride. (p. 33)

Similar to Hahn and Wade, Gill (1997) argues that becoming part of disability culture can help individuals view their disabilities with pride. Furthermore, Gill argues that coming home and embracing disability culture is a necessary step in the process of identity development for those with disabilities. I will now explicate Gill’s description of the coming home process.

Coming Home

In the coming home: integrating into the disability community, an individual with a disability comes in contact with a community of fellow individuals who have disabilities. Gill maintains that while individuals are often resistant to the idea of
identifying with a community of people with disabilities, that resistance is frequently overcome after an individual engages with others who have disabilities.

Once contact is made, many persons with disabilities find they enjoy the company of others “who have been there”. While continuing to value their relationships with friends and family, they recognized a connection unique to the relationships in the disability community. (p. 43)

In other words, coming home allows the person to connect with other individuals who have a disability. In turn, this connection helps fulfill a need for companionship by enabling individuals with disabilities to form relationships with other people who have faced similar obstacles in their lives. In addition, these relationships expose an individual to people who view their disability as a cultural identity. Gill concludes that exposure to people who identify themselves as part of disability culture enables the individual who has come home to obtain an understanding that living with a disability makes him or her part of a unique culture. Moreover, the importance of coming home to disability culture is evident in the stories some people with disabilities share about their lives.

For example, Smith (2008) admits that joining the National Federation of the Blind (NFB) was a major turning point in his life. Becoming a member of the NFB allowed him to connect with other individuals who were also blind. That connection with other individuals who are blind gave Smith a sense of companionship among individuals with similar experiences to his own. Rapp (2007) describes an experience that is similar to that of Smith. Rapp explains that when she became connected with a larger community of persons who have physical disabilities, she became more comfortable with
her own condition as a person who is an amputee. The stories of Smith and Rapp provide insight into the importance that coming home can have in the lives of individuals with disabilities.

**Coming Together and Coming Out**

Once individuals come home to begin embracing the culture of people with disabilities, Gill (1997) argues they will begin the process of coming together: internally integrating our sameness and differentness. In this crucial stage of identity development, those with disabilities come to accept the notion that they will live in two cultures; the world of disability, and the world of those who are able-bodied. Coming together is difficult because in order to come together, Gill concludes, one must first separate him or herself from the mainstream culture in which he or she was raised. She states, “In order to affirm our disability experience as a positive and important feature of our identities, people with disabilities have had to separate and individuate from a parent culture that fears and devalues disability” (p. 44). Gill concedes that the process of separating from mainstream culture is difficult for many people with disabilities because their ties to the able-bodied world are so deep, that extricating oneself from that culture is not easy.

Even though Gill believes that people with disabilities must at some point separate themselves from the values in mainstream culture that oppress people with disabilities, she is not advocating that those with disabilities completely separate themselves from people who are able-bodied. Thus, Gill explains that coming together is the process in which those with disabilities learn how to exist in two cultures.
Many of us have been asserting our right to maintain simultaneous links with both our parent culture and disability culture—in other words, our right to embrace our sameness part of the human family and our differences as part of the disability family. (p. 44)

Thus, *coming together* allows a person with a disability to embrace the various ways that living with a disability makes him or her different from those who are able-bodied, while also continuing to engage in personal relationships with able-bodied people. Gill concludes that the ability to move happily between the worlds of disability and non-disability is a key step in the formation of a positive self-image for individuals with disabilities. “Our growing comfort with multi-cultural ties holds the promise of healing conflicts within us as well as smoothing rifts of misunderstanding between us and people lacking disabilities” (p. 44). Hence, *coming together* enables people with disabilities to heal themselves while also bridging the gap between the worlds of disability and non-disability.

After an individual *comes together* he or she is ready to move to the final stage of identity development that Gill terms *coming out: integrating how we feel with how we present ourselves*. Once an individual *comes out* they have reached the point where they no longer feel the need to hide their disability. Gill describes these individuals in the following way, “They are persons who identify without hesitation as disabled, who have come out as no more or less than who they are” (p. 45). Gill also concludes that publicly embracing one’s cultural ties to the world of disability liberates an individual from social barriers that stigmatize disability. This freedom enables that person to explore his or her
identity in a more comprehensive manner. Gill states, “Allowing themselves to be
disabled frees them to explore their authentic selves and to reach out to others, disabled
and non-disabled” (p. 45). Gill’s assertion that individuals who publicly embrace their
disability often “reach out to others,” illustrates the fact that she does not view the
decision to come out as simply a personal choice.

For Gill, coming out is a personal decision, but that decision also has profound
political and cultural implications. To begin with, Gill believes those who openly support
the culture of disability are in the best position to provide a critique of the mainstream
culture that devalues people with disabilities. Gill also insinuates that there is a
connection between an individual’s decision to come out and his or her involvement in
the disability rights movement. Moreover, Gill is not alone in her belief that publicly
embracing one’s disability leads to an increased level of political activism on the part of
that individual. For instance, Hahn (1997) concludes that the choice to publicly embrace
one’s disability enables that individual to maintain a positive sense of self. Furthermore,
Hahn asserts that individuals with a good self-image are more likely to engage in political
activity.

This analysis seems to indicate that highest levels of political activism might be
found among disabled individuals who have been able not only to construct a
strong self-image but also to recognize social influences as the principle source of
their problems. (p. 33)

Hence, the process of identity development that includes an individual’s decision
to publicly embrace his or her disability enables an individual to understand the
connection between the cultural oppression that people with disabilities encounter as a minority group, and his or her personal struggle to accept a disability as a positive aspect of his or her identity. Thus, people with disabilities who have engaged in the process of identity development are able to obtain a critical consciousness about the various ways that able-bodied culture oppresses people with disabilities. Shor (1992) argues that an individual obtains critical consciousness when he or she is able to comprehend the connection between systemic discrimination on the one hand, and the resulting personalized oppression that people encounter in their daily lives, on the other. Therefore, it stands to reason that people who have experienced the stages that Gill (1997) describes in her model of identity development might gain a certain level of critical awareness regarding the psychological impact of the discrimination that people with disabilities encounter in their lives.

Furthermore, the notion that one’s personal journey of identity formation can lead to a newfound critical awareness can be seen in the stories that many people with disabilities share about their lives (Callahan, 1989; Lewis, 2007; Rapp, 2007). For example, Callahan (1989) explores his journey as an individual who suffered a spinal cord injury that turned him into a quadriplegic. Callahan details the ways in which acquiring a disability as an adult engenders both a physical and emotional journey. He readily admits that he used alcohol as a way to numb himself to the reality of his disability. Callahan also openly admits that it was the spiritual guidance that he received in Alcoholics Anonymous (AA) that helped him deal with his alcoholism and become more comfortable with his disability.
As he accepted his life as a person who uses a wheelchair, Callahan became an outspoken critic of the culture of ableism that is present in mainstream society. In fact, he employs a unique brand of sarcastic humor in order to shed light on the various ways that the ablest culture that exists in United States oppresses those with disabilities. In short, Callahan’s journey not only enabled him to embrace his disability, but it also transformed him into an advocate for people with disabilities.

Moreover, according to Gill (1997) not only can identity development lead to newfound personal and political awareness, the process should be viewed as a fairly linear progression. Gill describes the various stages of identity development as a set of steps that people with disabilities have to negotiate in order to develop a complete sense of self. In her view, people with disabilities move from wanting to integrate into the able-bodied world to accepting themselves as people with disabilities; she sees a coming out phase therefore as the “final step” of identity development (p. 45). Gill’s model frames the process of identity development as a set of discrete tasks in which once the first phase is completed the individual can move onto the next phase.

Gill’s model of identity development that generally examines the process as it relates to people with disabilities, provides a lens through which I can explore my own identity development. In the chapters that follow, this theoretical model will enable me to explore the various factors that most significantly impact my identity development. Furthermore, even though Gill’s linear model is a useful tool, it fails to encapsulate the complex nature of my identity development. Thus, this autoethnography demonstrates that the process of identity development is much more fluid than Gill’s linear model.
demonstrates. In fact, my narrative is replete with contradictions that cannot be adequately discussed in Gill's model. Thus, this dissertation employs the use of dialectical theory in order to shed light on these contradictions and their impact on my identity development. The next section further explains the value of a dialectical theory.

Dialectical Theory

A dialectical approach should not be understood as one theory. Instead, Baxter and Ebert (1999) describe "the dialectical approach as a family of theories rather than a single unitary theory" (p. 548). Baxter and Ebert also contend that even though dialectical scholars may have contrasting theories that describe the dialectical nature of relationships, dialectical scholars agree on two key assumptions that underlie dialectical theory. First, dialectical theorists believe "in the centrality of contradiction in relationships", and dialectical theorists also concur that contradiction plays a major role "in the change process" (p. 548).

In order to understand how contradiction works to impact change in relationships, I describe what dialectical theorists mean when they use the term “contradiction.” Baxter and Montgomery (1998) assert that dialectical theorists describe contradiction as "the dynamic interplay between unified opposites" (p. 4). Dialectical tensions are unified opposites because they are simultaneously dependent on each other, and these opposites also work to negate each other. Consequently, Frame (2007) argues that it is helpful to view "the dialectic as a continuum in which one pole cannot exist without the other" (p. 28). Hence, contradictions in the dialectical sense should not be seen as merely opposing
forces, because one key aspect of dialectical opposites is their mutual dependence on each other for their existence.

While dialectical theorists believe that dialectical tensions are "unified opposites", they also contend that dialectical opposites help create change in every relationship (Baxter & Ebert, 1999; Baxter & Montgomery, 1998; Brown, Werner, & Altman, 1998; Frame, 2007; Goldsmith, 1990). Baxter and Montgomery (1998) define change as the "difference in some phenomenon over time" (p. 7). In short, dialectical tensions alter relationships as they progress. In fact, dialectical theorists would argue that it is nearly impossible to separate the process of change from contradiction (Baxter & Ebert, 1999; Baxter & Montgomery, 1998; Braithwaite & Baxter, 1995; Frame, 2007; Goldsmith, 1990). Baxter and Montgomery (1998) explain that it "is not useful conceptually to separate change from contradiction, because it is the tension or interplay of opposites that results in ongoing fluidity for any relationship" (p. 7).

Additionally, dialectical theory not only allows scholars to understand how change occurs within relationships, it also enables scholars to look at particular phenomena in complex ways. Often dialectical opposites are portrayed as various sets of binary opposites. For example, when scholars explore the dialectic of autonomy-connection they are describing the contradiction between the human need for independence on the one hand, and the desire to form connections with other human beings on the other. However, dialectical tensions should not be seen as only binary opposites. Suter et al., (2006) argue that dialectical tensions should be studied as multivocal opposites. Conceptualizing dialectical tensions as multivocal opposites
increases the usefulness of the dialectical approach because rather than limiting contradictions to a set of bifurcated opposites; the multivocal approach enables contradictions to be viewed as a web of interconnected opposites that each impact one another. Baxter and Montgomery (1996) state:

Multivocal contradictions exist in a dynamic web of interplay among the many radiant implicated in a given A-B contradiction. It expands the conceptualization of contradiction from oversimplified binary structures like openness-closedness to more complicated meanings like the tensions between expressiveness, verbal disclosure, directness, honesty, on the one hand, and privacy regulation, deception, ambiguity, and discreteness, on the other. (p. 30)

Moreover, the dialectical tensions that are present in this autoethnography can be understood more completely by using a multivocal approach. While some contradictions are binary, many dialectical tensions are more complicated than a simple bifurcation is able to demonstrate. For example, the tension between abnormality-normality that is described in this narrative is connected to the tension between autonomy-connection. Embedded within these dialectics are questions that explore such complicated issues such as self-perception, personal space, intimacy, perceived expectations, independence, and dependence. Therefore, all of these issues are connected in such a way that a simple binary model is an incomplete way to analyze these tensions.

Many dialectical tensions transcend the realm of interpersonal relationships. Suter et al., (2006) refer to the contradictions that go beyond personal relationships as external contradictions. Suter et al., (2006) contend individuals who are members of
marginalized groups will often experience tensions that occur outside the realm of their personal relationships because society marginalizes their identity. Thus, many people with disabilities experience external contradictions because their identities are frequently marginalized.

A dialectical theoretical approach to understanding phenomena can prove to be particularly valuable when studying questions of disability and identity. For example, Frame (2007) argues that using a dialectical approach is particularly useful for scholars who are interested in studying the lived experiences of people with disabilities. Frame contends that dialectical theory can help scholars better understand how the presence of a disability creates tension that complicates the interactions that people with disabilities engage in everyday (p. 28). This complexity often manifests itself in relationships between interability couples. Interability partners frequently have to manage the tensions that exist between connection, openness and stability on the one hand, and autonomy, closedness and change, on the other. Braithwaite and Harter (2000) argue that while dialectical tensions of autonomy-connection, openness-closedness and stability-change are present in all relationships, interability couples face a unique “balancing act” because the presence of a disability tends to complicate relationships.

I use a multivocal understanding of dialectical theory to explore the way that these contradictions impact my emotions. Within the framework of most dialectics, there exist multiple layers of conflict. For example, my maternal grandmother pushed me to be normal; while my paternal grandmother treated me as though I were abnormal. This brief example helps explicate my point. On one level, the different treatment that I received
from both grandmothers reinforced the tension in my life between normality-abnormality. However, applying a multivocal approach to understanding the conflict I felt about my relationship with both grandmothers provides an analysis that moves beyond a simple bifurcation and includes my deeper emotional contradictions. The way that my paternal grandmother treated me left me emotionally conflicted. Part of me felt that I should embrace her regardless of how she reacted to my disability, because after all, she was my grandmother. Another part of me felt little desire to get close to my grandma because of the way she viewed my disability. By employing multivocal dialectical analysis, I am able not only to explore how contradictions play out in my life on one level, but I am also able to demonstrate how those tensions such as normality-abnormality worked to create deeper emotional conflicts that also impacted my life. Those deeper emotional tensions are difficult to express by using a simple binary approach.

The application of dialectical theory allows this dissertation to illustrate the contradictory nature of disability. Dialectical tensions are a reality of my existence as a person with a disability. Understanding the way these contradictions impact my identity enables this dissertation to enhance the scholarship that explores identity development and people with disabilities.

Conclusion

Engaging in an autoethnographic method of inquiry will allow this dissertation to provide a unique look at the intersection between disability and identity. The analysis contained within this autoethnography might provide some useful insight for future scholars who wish to explore this topic. I also feel that grounding this autoethnography
through the use of Gill’s (1997) ability identity development model, and dialectical
theory assists me in responding to my research questions via the use of an
autoethnographic methodology. Now that I have explicated the methodology contained in
this dissertation, I now move to the analysis of my narrative.
Chapter 3: Identity Development: A Journey of Rejection, Transformation and Ongoing Struggle

I Hate People with Disabilities

As I have repeatedly mentioned, for much of my life my entire raison d'être was to try and be as normal as possible. Therefore, I rejected my disability as an important part of my identity. Part of my personal rejection included rejecting other individuals who had disabilities. I did not know many people with disabilities as a child, and I did not want to. I would often say, "I hate people with disabilities". Needless to say, I was not aware there was a larger culture of disability, and even if I had been aware that there was such a culture, I would not have wanted to be a part of it because it would stand in the way of being normal. My first encounter with someone who identified themselves as a part of the disability culture, illustrates my reluctance to engage with other people who were disabled.

When I was a junior in high school, I visited various colleges that I might want to attend. Numerous individuals, including my mother, encouraged me to visit Wright State University in Dayton, Ohio. Wright State has a long-standing reputation for its ability to accommodate students with disabilities, so I was strongly encouraged to check it out.

However, I had no desire to go to Wright State. To begin with, I wanted to be a radio broadcaster, and I did not feel like Wright State had a good communications program. On top of that, I did not want to go Wright State because they were well known for accommodating people with disabilities. The last thing I wanted to do was to go to a college where there was a bunch of people with disabilities. In fact, when my
mom encouraged me to go visit the school, I can remember sarcastically stating, "I don't want to go to crippled U."

Despite my misgivings about Wright State, I relented to my mother's wishes. I went to visit the campus in the fall of my junior year. I set up an appointment with a counselor in their disability services office. My dad drove me down to Dayton, and we arrived on the campus around 9 AM on a brisk fall morning. The first thing I noticed was the significant number of people who used wheelchairs on campus. I came from a small town, and was not exposed to many people who were disabled. When I first set foot on Wright State's campus, I was overwhelmed by the number of people I saw with obvious physical disabilities. It made me uncomfortable. Within the first minute of my arrival, I decided that I wanted no part of this place because it had so many handicapped people. My discomfort continued to rise as my father and I walked to the building that housed the office for students with disabilities. As I entered the office, I notified the secretary that I had an appointment to meet with someone at 9:15.

After waiting five minutes a woman appeared before me. She walked with a noticeable limp, and had a style of movement that told me she had cerebral palsy. I did not like the fact that she had a physical disability, because it reminded me that I was not normal. I became increasingly uncomfortable with her as she introduced herself. Her CP affected her ability to speak. This woman was the first person I had encountered who had trouble speaking.

Honestly, I was repulsed by this woman because of her disability. Her walk bothered me, and her speech bothered me. I can even remember thinking, I am glad that I
am not as disabled as she is. I did not even want to look at her, because her disability was so repulsive to me. Clearly, I had a negative attitude before our meeting even began. My attitude toward this woman did not improve as our meeting continued. After she introduced herself, she told my father to leave the room so that we could talk by ourselves. I was irritated that she did not ask me what I wanted; she just told my father to leave. I felt that she should have asked me what I wanted. I would have been okay talking to her alone, but I was really irritated that she did not ask me if he could leave. However, my dad did leave, and this counselor and I continued our meeting.

The very first question she asked once my dad left was, “Do you have any heroes?” I answered very quickly, "Franklin Roosevelt.” It became apparent that the counselor did not like my answer. She responded by saying, "how can your hero be a man who tried to hide his disability?" She then went on to tell me that, "FDR was not a good person to admire because he tried to hide his disability." I was blown away by her audacity. She asked me who my hero was, and I told her. Then she went on to tell me I did not make a good choice! I responded to her by saying "Of course he hid his disability; he was trying to be president in 1932." I went on to add that FDR showed a lot of courage by overcoming polio, and leading this country through the Great Depression and World War II.

The counselor again told me that I was wrong, and insisted that I should look for another hero, preferably one who openly embraces his or her disability. The counselor's arrogant response made me angry. I can remember thinking, “who is this disabled woman to tell me how I should view my heroes?” I angrily informed her that, "You can have
your heroes, and I can have mine. However, I am not going to kowtow to the wishes of
some disability counselor at Wright State University!"

Needless to say, she was not happy with my angry response, and our meeting
ended in a shouting match. I left the meeting in a huff, and I recounted for my dad what
had occurred in the office. I told him, "If she is what it means to be disabled, I do not
want to be a part of it ever." Obviously, my first encounter with a member of disability
culture only reinforced my belief that people with disabilities were needy, whiny, and
ridiculous. No wonder I wanted to be normal!

My visit to Wright State confirmed every stereotype I had about people with
disabilities. I saw myself as more normal than the people with disabilities that I witnessed
at Wright State. I thought "those people" thought too much about their disability. I felt
that they wanted everybody to celebrate their disabilities, and I had no interest in
celebrating my cerebral palsy. In fact, I was repulsed by people with disabilities. My visit
to Wright State reinforced my discomfort with people who have disabilities. It was clear
in my mind: I did not want any part of that world.

Now, as I reflect back on my visit to Wright State, I am appalled at how I used to
view people with disabilities. I mean, here I was, a person with cerebral palsy who had
used crutches for most of my life. Yet, I rejected other people with disabilities because
they were like me. How messed up was that?

Now that I have reached the point in my life where I openly embrace my
disability, it is hard for me to comprehend the way I used to feel about my disability. I
realize that I am a completely different person today because I have accepted my
disability as a legitimate part of my identity. Moreover, the person I am today would have a hard time recognizing the person I was when I visited Wright State as a 17 year-old kid.

In one sense, this autoethnography is an attempt to better understand that transformative process. I will investigate the factors that led to my transformation from a person who rejected his disability, into someone that for the most part embraces his disability. I will also explore the various factors that continue to shape my identity including: family, sexuality, and the media. In short, this autoethnographic inquiry shines a light on the complexities of disability as an indicator of social identity. First, I will examine the issue of identity as it relates to people with disabilities. Second, I will explore my own identity development as a person with a disability, and compare my own identity development to the process that Gill (1997) explicates in her theoretical model. Chapter Three will help set the stage for the analysis that will continue throughout the rest of this autoethnography.

**Disability and Stigma**

**Disability: A Stigmatized Identity**

Now that I have described the organization of this chapter, I will discuss the concept of identity in greater detail. Erickson (1968) proposed a model of development which contends that during the period of adolescence, individuals begin to develop an autonomous identity. While individuals are developing an independent sense of self, they are also embracing and/or trying on various group identities. Ideally, the process of identity development enables individuals to maintain various group identities without sacrificing their unique identity.
The process of identity formation occurs within a larger cultural context (Bruner, 1990; Engel & Munger, 2003; Gilson et al., 1997; Onken & Slaten, 2000; Siebers, 2008). As Engel and Munger (2003) state, “The creation of the self is not an isolated process but involves the society and culture in which the individual lives” (p. 41). In other words, individual identities are socially constructed within a larger cultural discourse. Bruner (1990) describes this process thus, “Self too must be treated as a construction that, so to speak, proceeds from the outside in as well from the inside out, from culture to mind as well as from mind to culture” (p. 108). In short, the process of identity formation is influenced by the culture in which an individual lives.

Thus, if a culture stigmatizes a group of people, such as those with disabilities, it may be difficult for those individuals who have been stigmatized to develop a positive sense of self. Goffman (1963) pioneered the scholarship that explores the relationship between stigma and identity. Goffman demonstrates that people with disabilities are often stigmatized because they have a disability. He further concludes that since society stigmatizes the notion of disability, people with disabilities have identities that are “spoiled” by society. Moreover, living with a “spoiled” identity causes many people with disabilities to develop a negative self-image.

Since Goffman’s groundbreaking study, scholars continue to examine the impact that the stigmatization of disability has on the process of identity formation. For instance, many scholars in the field of disability studies examine the relationship between the negative images that stigmatize disability on the one hand, and the impact that those negative images have on the self-image of people with disabilities on the other (Berger,
2009; Butler & Parr, 1999; Corker & French, 1999; Davis, 1997; Siebers, 2008; Snyder, Brueggemann, & Thomson, 1999). Many scholars contend that people with disabilities often internalize negative cultural images about disability to such an extent that they often develop a negative sense of self (Devlieger, Albrecht, & Hertz, 1997; Gilson et al., 1997; Hahn, 1997; Juette & Berger, 2008; Onken & Slaten, 2000; Siebers, 2008). Onken and Slaten (2000) explain it this way:

It is almost impossible to be disabled in U.S. society and not feel deficient for the difference. Awareness of the difference eventually translates into a devaluing comparison. People with disabilities often experience devaluation by others, which in turn leads them to devalue themselves. (p. 101)

Internalizing stigma to the extent that it negatively impacts an individual’s identity is an experience that is not limited to people with disabilities. Many scholars in the field of disability studies argue that members of other oppressed minority groups encounter the same type of hegemonic discrimination that individuals with disabilities often experience (Consalvo, 2004; Davis, 1997; Fries, 1997; Linton, 1998; Siebers, 2008; Wendell, 1996). These scholars further argue that individuals from oppressed minority groups including people with disabilities frequently internalize their oppression. For example, Hahn (1997) concludes:

The realization that stigmatizing attitudes are the principal barriers to social acceptance can be inundating because they may seem so inescapable. As a result members of disadvantaged groups including people with disabilities must constantly struggle to avoid the danger of internalizing oppression. (p. 33)
Furthermore, “the danger of internalizing oppression” occurs because individuals who have disabilities may come to believe that having a disability makes them inferior to people who are able-bodied. Hence, many people with disabilities often come to resent their disabilities (Davis, 1997; Gill, 1997; Hahn, 1997; Shakespeare, 2006). This resentment can cause people with disabilities to try and create a sense of self that does not include their disability. Unfortunately, when people try to create an identity that excludes their disability, they frequently develop a “fractured” identity.

Fractured Identities

Gill (1997) argues that people with disabilities are frequently encouraged to ignore the importance of their disability. Gill maintains that health professionals, family members, and other important mentors often convey, "That individuals should seek value in parts of his/her being that had not been impaired by the disability" (p. 43). She contends that when individuals are encouraged to focus on the parts of their bodies that are not disabled, they subconsciously begin to view their disability in a negative light. Furthermore, once individuals begin to view their conditions in a negative light, they try to downplay the importance that their disability plays in the formation their identity. Gill concludes that trying to construct an identity that ignores the impact of one's disability will cause that individual to develop a negative sense of self.

The attempt to fashion an identity that excludes important parts of the self, i.e., the disabled parts, then, results in a sense of self in conflict or a self-image riddled with significant gaps. In either case, the resulting identity is not sufficiently sound to support stable, resilient self-esteem. Without stable self-esteem, it is difficult
for the individual to sustain his/her sense of worth and entitlement to a place in
society. (pp. 43-44)

I realize now that for much of my life, my identity was “in conflict,” and I also
had “a self-image that was riddled with significant gaps.” Let me explain how this
gradual process occurred. From the time I was five years old, I was told by almost
everyone around me that I should be thankful that I had a working brain. These same
people also informed me that I should use my intellect in order to overcome my
disability. I was not told to embrace my disability; instead I was taught that I should use
the parts of my body that were not disabled in order to overcome it. Hence, I came to feel
that my disability was something that needed to be overcome. By the time I was a
teenager, I thought my disability was nothing more than a barrier to my success.
Consequently, I came to hate my disability, because I only saw it as an impediment.

This subconscious evolution that caused me to dislike my disability also caused
me to reject the notion that my cerebral palsy was an important part of my identity. I
mean how could something that I hated be an important part of my identity? I can
remember thinking to myself that I just want to be like everyone else. So I tried my best
to act like I was not disabled. In short, I tried to create an identity that did not include my
disability.

Despite my best efforts, this did not work because deep down I knew I was
disabled. I walk on crutches for God's sake, so there was no getting past the physical
reality of my disability. I was also very cognizant of the fact that people treated me
different because I had a disability.
For instance, I ran cross-country in high school in part to prove how normal I was. I thought that by playing a sport and earning a varsity letter, I would prove to myself and to others that I was not really disabled. However, I encountered able-bodied people at cross-country races who told me that I was amazing because I ran with a disability. I quickly became annoyed, because I wanted to be seen as a normal runner. Instead, I felt like people only saw me as the disabled runner. My experience during cross-country reinforced the idea that even though I was trying to be normal I was not. Consequently, I began to feel like I was putting on an act.

I tried to pretend I was normal, but in my private moments I knew I was a fraud. I knew I was pretending to be something I was not. I was trying to act like my disability had nothing to do with who I was as a person, but in my heart of hearts I knew that I could not ignore the fact that I was disabled. The realization that I could not overcome my disability only increased my unhappiness. I was frustrated because I could not conquer my disability, but I did not feel as though I could embrace it either. I had internalized the idea that I needed to work hard to overcome my disability. Therefore, I could not simply accept that it was a positive aspect of my identity. When I realized I could not overcome my disability, I felt like a failure. I felt like a failure because no matter how smart I was or how hard I worked at being normal, I never felt that way.

Since I had internalized negative assumptions about disability, I came to believe that if I did not have cerebral palsy, my life would be better. Thus, by the time I was in my late teens, my identity was fractured. While part of me felt like a fraud for trying to pretend I was normal, another part of me refused to accept the fact that I was disabled,
because to do so would mean that I had failed to become normal. I was not comfortable being disabled, nor was I comfortable trying to be normal. Therefore, just as Gill predicts, I developed a negative self-image that made it difficult for me to find a comfortable place in the world.

This problem of a self in conflict that is at the heart of my own struggles with identity can also be found in the stories that some individuals with disabilities tell about their lives. For example, Rapp (2007) who is an amputee admits that her disability gave her a negative body image. She openly acknowledges that she frequently felt anger toward her disability, because she believed that her disability made her unattractive. Therefore, Rapp claims that she spent much of her life focusing on the aspects of her identity that were not disabled. For instance, Rapp admits that when she was in school she strove to get better grades than her able-bodied peers in order to prove to herself that she was not disabled. She also concludes that her attempt to construct an identity that excluded her disability left her isolated for much of her life. Rapp contends she only developed a positive image once she decided to embrace her disability as a positive aspect of her identity.

Similar to Rapp’s experience, my self-image improved when I reached the point where I could accept my disability as a positive aspect of my identity. Sure, I still struggle to figure out what living with a disability means for my life. But, at least now I can accept the fact that my cerebral palsy is a vital part of my identity. In order to analyze my own transformation it is important to provide a theoretical lens through which my identity development can be examined. Therefore, I use Gill’s (1997) model of
identity development that explores the process of identity formation for people with disabilities. Gill’s model should be understood as a theoretical construct that delineates how the process of identity development generally occurs for those who have disabilities. Gill describes this process in very non-specific terms; hence, it is beneficial to explore how Gill’s model holds up in a real life context. My own journey of identity development provides a concrete situation in which to apply Gill’s theoretical model. Moreover, juxtaposing Gill’s model against my own experience illustrates strengths and weakness in her understanding of identity development. Therefore, it is to the personal exploration of my journey that I now move.

**My Own Identity Development**

**Struggling to Fit In**

It is safe to say that for much of my life I was in the *coming to feel we belong: integrating into society* phase of identity development. As I have mentioned before, during this stage of my identity development I wanted to be “normal.” I ran cross country and wrestled, because playing sports was one way that I could assert my normalcy in a way that everyone could see. However, playing sports was not the only way that I publicly declared my normalcy when I was in high school.

For a brief period during my senior year, I decided I was going to start walking with a cane rather than using my crutches. I opted to use a cane, because I thought that using a cane would make me less disabled than using crutches. So for two months, I stumbled around school trying to be “more normal” by using a cane. However, my balance was not good, so I fell quite frequently. I
was walking in a hallway that was crowded with students. As I was making my way to my next class, I slipped and fell hard on my knees. At the sight of me falling numerous students ran over to help me. This was embarrassing. After all, I was walking with the cane in order to be more normal, but falling in a crowded hallway made me feel like the biggest freak in the whole school.

I could get around better using crutches; crutches allowed me to be more mobile than a cane. Despite this obvious fact, I thought walking with a cane was what I was supposed to do. I felt that if I worked hard enough, I could master the operation of a cane and get rid of my crutches. Replacing my crutches by using a cane would be an affirmation that I overcame my disability and became “normal.”

I realize now that it was a fantasy to think that I could quit using crutches. In fact, after two months of struggling to use a cane, I gave up. My struggle to try and achieve normalcy is not unique. As Shapiro (1994) demonstrates, people with disabilities often feel the cultural pressure to appear normal. For example, many people with disabilities will push themselves to the point of exhaustion in order to walk on crutches, when using a wheelchair may be a more efficient mode of transportation. In short, people with disabilities often try to meet the standard of normalcy even when it may not be in their best interests to do so.

The problem was I could never live up to the standard of normalcy. Even though I tried really hard, I could never walk with a cane on a full-time basis. Ultimately, the fact that I had to give up my attempts to use a cane made me feel like a failure. I wanted to be seen as normal by others, and I felt like a failure because I could not make that happen.
Furthermore, when I was mired in the *coming to feel we belong* stage of identity development, a bifurcation within myself gradually occurred. After being exposed to the able-bodied cultural images that constantly encouraged me to overcome my disability, I internalized those messages to mean that my disability was a negative aspect in my life. Therefore, I tried my hardest to transcend my disability and become normal.

However, my attempts to meet the able-bodied standard of normalcy always failed. Therefore, I came to hate my disability even more. Ultimately, I reached a point where I was not happy being disabled, and I was not happy when I tried to be normal. Gill (1997) explains this problem further:

In this framework there are two choices. One either chooses the course of exhaustion by ceaselessly laboring to measure up to an ill-fitting standard, or one gives up and surrenders to invalidity. In either case a sound identity is impossible because integration is impossible. The self is split into 'good' and 'bad'. However diligently the individual works at self-development, there will be gaps in identity because parts of the self are disowned. (p. 43)

According to Gill, in order for me to develop a positive sense of self, I needed to move beyond my desire to fit into the able-bodied world, and embrace my disability. Fashioning a self-image that included my disability as a positive aspect of my identity would enable me to unify my non-disabled self with my disabled self. Ultimately, this unification would give me an identity without the conflicts that were preventing me from developing a positive and integrated sense of self.
While I agree that I needed to embrace my disability in order to develop a positive self-image, I take issue with the linear nature of Gill's model. For her *coming out* and embracing one's disability publicly is the most important outcome of identity development. Therefore, Gill’s model frames identity development as a series of stages that ends with an individual *coming out* and embracing his or her disability.

The “coming out” process is often the last step toward disability identity in a path that begins with a desire to find a place in society, continues with a discovery of one’s place in a community of peers, and builds to an appreciation and acceptance of one’s whole self complete with disability. (p. 45)

In my case, the process of identity development is more important than the final outcome. Since Gill’s model postulates the existence of a “final step”, it oversimplifies the process. There are often complicated questions surrounding one's choice to embrace his or her disability, and the choice to embrace one's disability or not is often an ongoing process. The decision to *come out* has real and perceived consequences in the daily lives of many people with disabilities. However, Gill's model ignores the complex way that people negotiate their identity as individuals with disabilities in everyday life.

*Coming out* is an important part of my identity development, but it is only part of the story. Identity development is an ongoing process in which I negotiate my desire to be a member of disability culture on the one hand, with my wish to be a part of the mainstream culture on the other. Consequently, an examination of the ways in which my own experience is in contrast with Gill's model will introduce complexity into this
discussion. I begin this interrogation by exploring how Gill’s theoretical conception of 

*coming home* differs from my own experience.

**I Can’t Come Home**

Gill contends the *coming home* process begins when an individual comes in contact with a community of individuals with disabilities. After initial contact is made, an individual begins to see the value in developing friendships with people who have disabilities. These friendships enable him or her to engage with other people who have had similar experiences. In turn, this gives him or her a sense of belonging and companionship (Darling, 2003; Hernandez, 2005; Ostrander, 2008; Whitney, 2006). Furthermore, this exposure to the disability community allows that individual to begin to see that his or her disability is something valuable, and it does not make him or her worthless. This realization will start that individual on a path that will eventually enable him or her to embrace his or her disability (Darling, 2003; Hernandez, 2005; Ostrander, 2008; Whitney, 2006).

While Gill's notion of *coming home* may accurately describe the experiences of some, it does not capture the full complexity of my own experience. Gill's description of *coming home* vastly oversimplifies the difficulties that some people have with the concept of embracing members of disability culture.

Gill assumes that someone who internalizes the stigma that surrounds disability will openly embrace other people with disabilities. This assumption fails because she does not take into account people who are so repulsed by their own disability that they reject others who have disabilities. Even though Gill does acknowledge that some
individuals "vigorously avoid" contact with other people who have disabilities, she mistakenly believes that mere contact with others who have with disabilities is the first step in the path to embracing the culture of disability. Thus, Gill’s model downplays the impact that internalized oppression can have on many individuals who have disabilities.

For instance, during most of my life I had internalized the cultural stigma surrounding disability to such an extent that I did not want to be around people with disabilities. (Recall my visit to Wright State University!) Moreover, congregating with individuals who have disabilities made me uncomfortable. I had absolutely no desire to be part of a larger culture of people with disabilities. I wanted to be normal, and associating with people who have disabilities was not normal. I could not come home, because contact with those who have disabilities only served to reinforce my negative attitude towards my own disability. Hence, before I could accept the notion that I was a member of disability culture, I had to overcome my own internalized oppression regarding disability.

In contrast to Gill’s model, the journey that enabled me to accept my disability did not begin when I came home; rather it began with my personal realization that disability is largely a social construction that stigmatizes people with disabilities. I recognized that I had internalized negative images regarding disability to such an extent, that I felt I was inferior because I had a disability. Once I became conscious of my own oppression, I could begin to move past it. I will now explain how that process began.
Separation and Coming Out

In the fall of 2004, I returned to Ohio University to begin a master's program in teacher education. I wanted to become a high school history teacher. However, on the way to my master's degree in Teacher Education, I took a divergent path that would fundamentally alter my life forever. This change occurred in the summer of 2005 when I decided to take a course in Cultural Studies in Education, which is a critical interdisciplinary program that focuses on the social foundations of education.

This course critically examined the connection between the way images within popular culture often stereotype people from marginalized groups on the one hand, and the negative perceptions that individuals often have about people from those groups on the other. For my final paper I chose to explore the way media images portray people with disabilities. When I began to study these images, I was stunned at the volume of negative stereotypes that were present. At this point, I began to recognize that media images often perpetuate the belief that people with disabilities are inferior to individuals who are able-bodied. I was disgusted by what I uncovered. I remember one day in class admitting, “I have spent much of my life hating my disability and after seeing the way that disability is portrayed in the media, I understand why. You cannot make up how ridiculous it is that so many images of disability are negative. No wonder I hated myself.”

Once I discovered that images within the media often perpetuate stereotypes about those with disabilities, I came to believe there was a significant hegemonic process at work that was oppressing people with disabilities. I came to this conclusion because at the time I was investigating these media images, I was reading Forgacs’s (1988) edited
volume that presented various writings of the Italian Marxist Antonio Gramsci. It was through this volume that I became aware of Gramsci's concept of hegemony. In order to understand how I came to believe that those with disabilities encounter a hegemony that devalues them, I will first explain Gramsci’s notion of hegemony.

**Hegemony**

Gramsci was the General Secretary of the Italian Communist Party, and viewed as a threat by Mussolini’s Fascist regime. In an effort to stop Gramsci's opposition to the government, he was arrested and jailed in 1926, and would spend the rest of his life in prison (Monasta, 2003). During his time in prison, he composed his now famous *Prison Notebooks*. In these *Prison Notebooks* Gramsci explored the concept of power, among other ideas. He questioned how people in power maintain control over individuals who are not in power. Gramsci also wanted to understand the reason why people who are oppressed often refuse to rise up against their oppressors.

In his *Prison Notebooks*, Gramsci argued there are two ways that people in power maintain control in society. One way this occurs is through the use of physical force or the explicit threat of physical force. For example, the military can be mobilized to crack down on citizens in order to allow the governing elites to maintain power. In addition to physical force, the ruling class in a society may use a second subtle means to control.

Gramsci argued that the elites in a society exercise a second type of control by creating a hegemonic system of beliefs that justifies the distribution of power in that society. People in power use various institutions such as the media or the schools in order to perpetuate a hegemony that benefits the ruling class. Kincheloe (2008) explicates how
hegemonies operate in society, “The key dimension of this process is the manipulation of public opinion to gain consensus. When hegemony works best the public begins to look at dominant ways of seeing the world as simply common sense” (p. 65). In other words, hegemonic beliefs or systems often become so prevalent that many people accept them as common sense. Therefore, Gramsci argued that most individuals in a society buy into the status quo without even realizing they are doing so.

For instance, many people in American society believe in the idea of the American dream. That is to say, many accept the idea that if individuals work hard they can be anything they want to be. The hegemony of the American dream promotes the idea that those who are wealthy are that way because they work hard and have earned their wealth (Kozol, 2004; Rank, 2004). In addition, the hegemony of the American dream perpetuates the idea that individuals who are poor are poor because they do not work hard (Kozol, 2004; Rank, 2004). A Gramscian perspective of the American dream would argue that this hegemonic notion benefits the ruling class, because it prevents people from questioning why a few elites control most of the wealth in America, because most people view it as “common sense” that the wealthy earned their place in society because they worked harder than people who are not wealthy.

When I first encountered Gramsci’s notion of hegemony, I was fascinated by the concept. I soon recognized that there is a hegemonic belief system that devalues people with disabilities. I concluded that the negative media images I had examined were part of a larger hegemonic process that privileged the idea that people who are able-bodied represent the “norm” in society. This able-bodied hegemony perpetuates the idea that
people who are able-bodied are superior to people who have disabilities. Just as Gramsci described, people with disabilities often come to believe that they are inferior. This occurs because the hegemonic notion that those with disabilities are inferior has come to be seen as “common sense."

Furthermore, I worked so hard to overcome my own disability for most of my life, because I had accepted the hegemonic ideology that people with disabilities were inferior to people who are able-bodied. In short, Gramsci’s ideas help me recognize that my quest for normalcy was an attempt to meet the standard of normalcy that is promulgated by this able-bodied hegemony. This realization was a turning point in my identity development.

At the age of 27, I quit trying to live up to the standard of normalcy. For the first time in my life, I came to view my disability not as a personal defect, but as something that is an area of discrimination. The fact that I have cerebral palsy is not what makes me disabled; rather it is society’s negative construction of disability that turns my cerebral palsy from a condition into a disability. I gained a new awareness about my disability by recognizing that the mainstream culture devalues me because I have a disability. Such devaluation, while I was not consciously aware of it at the time, took its toll on my identity.

The realization that there is an able-bodied hegemony also allowed me to separate from the mainstream culture that stigmatizes people with disabilities. According to Gill, (1997) during the coming together: internally integrating our sameness and differentness phase of identity development people with disabilities “separate and individuate” themselves from a culture that stigmatizes their disabilities in order to develop a positive
self-image (p. 44). The separation that Gill describes was an essential part of my identity development. However, my separation occurred as the first step in my identity development, and in that way, my experience differs from the model that Gill proposes.

Gill argues that people with disabilities begin separating themselves from the mainstream culture after they have *come home* to engage with a larger culture of people with disabilities. She assumes that interaction with others who have disabilities during the *coming home* process will expose individuals to people who view disability as an issue of oppression. Furthermore, exposure to the notion that people with disabilities are oppressed, allows an individual to begin separating from mainstream culture in order to assert his or her identity as a person with a disability. Thus, Gill assumes that *coming home* is a prerequisite to the process of separation from able-bodied culture (Darling, 2003; Hernandez, 2005; Ostrander, 2008; Whitney, 2006).

My own experience illustrates a possible flaw in Gill’s assumption. I began to separate from the mainstream culture not by *coming home*, but through my own personal intellectual exploration. In fact, I had to separate from the mainstream culture before I could *come home*, because I had internalized the oppression regarding people with disabilities to such an extent that it was impossible for me to embrace others with disabilities until I transformed the way I viewed my own disability. Thus, *coming home* and supporting disability culture is an important aspect to my identity development, but I had to be in a place intellectually and emotionally that would allow me to make the choice to *come home*. Next I continue to examine how I made the choice to *come home*. 
Excitement and Frustration

When I began to embrace my disability, I felt like a kid on Christmas morning. I had so much excitement and enthusiasm that I probably drove some of my able-bodied friends a little crazy, because I was so focused on my new appreciation for my disability. Within the period of one month, my entire worldview had changed. I felt liberated and exhilarated at the possibility of being a scholar who advocates for people with disabilities. I remember telling one of my professors, “I feel like a kid in a candy store!”

Once I made the decision to become an advocate for people with disabilities, I decided that the best way for me to advocate for people with disabilities was to become an educator and scholar. Consequently, I dropped my original plan to get a Master’s degree in Teacher Education, and subsequently enrolled in the Cultural Studies in Education doctoral program at Ohio University in the fall of 2005. By this point I had been transformed from a person who spent his whole life trying to pass as normal, into a person who had come out and who had begun the process of publicly embracing his disability.

In one sense, I was excited to be out as a person with a disability, yet I also found the experience frustrating. Even though I had come out, I still felt isolated in my new doctoral program. For example, in the Cultural Studies courses we would discuss issues such as racism, classism, and sexism. However, the issue of ableism was not discussed unless I brought it up. I often felt that people only saw me as the guy who could talk about disability issues. In addition, I got the sense that certain professors would prefer that I not discuss issues of disability in class. I was frustrated because the majority of
people that I interacted with in my doctoral program were people who claimed that they cared about issues of discrimination, yet they ignored the plight of a large minority group! I would even poke fun at the notion that racism, classism, and sexism were the only types of discrimination that we were allowed to discuss in class. I would derisively refer to them as the “Holy Trinity” of diversity issues.

I was not frustrated because we talked about issues of race, class, or gender. Those are important issues. What was frustrating was only focusing only on those issues three areas where discrimination occurs when discussing diversity and social justice issues. My frustration in this regard is not unique. Scholars in the field of disability studies argue that issues relating to people with disabilities are frequently ignored in the world of academia (Davis, 1997; Gill, 2001; Linton, 1998; Shakespeare, 2006). As Gill (2001) explains, many individuals with disabilities have a difficult time understanding why many who claim to advocate for social justice do not see disability as a social justice issue.

Finally, in contrast to members of other minority communities, it is hard for disabled people to grasp their dilemma because it is often perpetuated even by the persons with whom they identify and from whom they expect affirmation rather than dismissal: family members, contemporaries, and fellow seekers of justice. (p. 366)

Thus, even though I started to come out and embraced my disability, I still felt isolated from many of my able-bodied peers. Yes, I was excited at the possibility of becoming a scholar and an advocate for people with disabilities, but there were also times
when I questioned whether I would ever fit into the able-bodied world of academia. At this point in my identity development I had not *come home* and embraced the idea that I was a member of disability culture. Therefore, even though I viewed my disability as a positive aspect of my identity development, I did not think anyone understood what I was going through. Yes, I had accepted my disability, but I was still struggling to “fit in” to the able-bodied world.

My experience with most of the able-bodied people that I interacted with during this period left me confused. I felt that in order to be part of their culture, I would have to sacrifice my disabled identity. I can remember thinking, “it has taken me 27 years to get to the point where I can acknowledge that my disability is an important part of my life, and I do not want to compromise that just so I can fit in with some liberal academics that do not care about people with disabilities.” I also felt that most of the people in my doctoral program wanted me to learn about the oppression that they face, but they did not want to learn about the oppression that I encounter.

Even though I often became frustrated at people who were able-bodied, I did want to be part of their world. I simply wanted to be part of their world without having to ignore my disability. I tried that for most of my life, and it did not work. Hence, I yearned for a connection with other scholars who understood what it is like to be disabled in the able-bodied culture of the academy. I found this connection as I began to explore scholars in the field of disabilities studies who do examine the concept of disability culture.
Coming Home and Disability Studies

Coming home has been both an intellectual and physical endeavor in my case. During the first year of my doctoral program I struggled with the fact that I was intellectually committed to issues of disability, but disability topics were not discussed in any of my courses. I did not see disability as a part of the discourse that surrounded my doctoral program. However, in Spring Quarter 2006, that would change when I enrolled in a doctoral course offered by the school of Media Arts and Studies at Ohio University. The course covered various theorists who engaged in the practice of critical cultural theory.

One day after class, the professor and I had a conversation about the course. I stated, “I am enjoying this course, but wish we covered scholars who discussed disability issues.” She responded, “We won’t cover any disability studies theorists in this course, but you should read my dissertation.” I asked her, “What exactly is disability studies?” She answered, “It’s a group of scholars who examine the oppression that people with disabilities experience from a cultural prospective. I used a few disability studies scholars in my dissertation. I think that you will find it useful.” I responded, “That sounds awesome, where can I get a copy?” She said “I have a copy in my office let me go grab it for you.”

I was excited at this professor’s interests in disability issues. I thought to myself, “Finally, I have found a professor who actually cares about disability issues.” Needless to say, I was ecstatic at the possibility of reading her dissertation. It is also fair to say, reading her dissertation was another important point in my identity development.
Consalvo’s (2004) dissertation examines the way bodies are portrayed in the movie and television franchise *Star Trek*. She argues that villains in *Star Trek* were often depicted as disabled in order to make them scarier. Consalvo also examines the way that people with disabilities are portrayed in the media in general. She argues that disability is a social construction that labels people with disabilities as deviant. Consalvo further concludes this notion is perpetuated by media images that often depict those with disabilities in a negative light.

Consalvo’s conclusions excited me. Consalvo’s assertions about the way people with disabilities are stereotyped in the media were similar to what I discovered when I examined various media depictions of people who have disabilities. Moreover, her research let me know that I was right. There is a hegemony that promulgates the notion that people with disabilities are inferior to those who are able-bodied. Consalvo’s dissertation was also important because it exposed me to the scholarship of Rosemarie Garland-Thomson and Simi Linton. I was so intrigued by Consalvo’s discussion of their ideas that I decided to read the scholarship of both Thomson and Linton.

First, I read Thomson’s (1997) book *Extraordinary Bodies: Figuring Disability in American Culture and Literature*. In this volume, Thomson interrogates the social construction of the disabled body in American culture. Thomson contends the disabled body is constructed as inferior. Thomson asserts that disability is not simply a physical fact of life, but is also a constructed category of social deviance. She explains:

I intend to counter the accepted notions of physical disability as an absolute, inferior state and a personal misfortune. Instead, I show the disability is a
representation, a cultural interpretation of physical transformation or configuration, and a comparison of bodies that structures social relations and institutions. Disability, then, is the attribution of corporeal deviance—not so much a property of bodies as a product of cultural rules about what bodies should be or do. (p. 6)

Reading this volume helped expand my knowledge about the way society labels the disabled body as deviant. It felt like another awakening to me. I was reading this book in a coffee shop, and can remember barely being able to contain my excitement. Her words so engrossed me, that I felt as though she were sitting next to me, and we were engaging in a dialogue about these issues. Her words were not just on the pages of a book, but they came alive. I can remember, thinking, ”Man, this stuff is amazing!” This was the first time I had engaged with scholarship that was written by someone who had a disability, and it was the first time that I saw my own experiences reflected in the words of a scholar. I thought, “Thank God! There is a scholar who understands what it is like to be disabled, and she has written about it quite eloquently.”

Her work appealed to me because she expanded my understanding of the role that culture plays in marginalizing disability as a social marker of identity. I also resonated with Thomson’s journey as a scholar, because it was similar to my own. For instance, she acknowledges that her academic investigation of disability was, “the consequence of a coming out process” (p. ix). She also admits that for much of her life she viewed her difference, “as a personal situation rather than as a political or social issue” (p. ix). Much like me, Thomson spent most of her life struggling to fit in with the able-bodied world.
Thomson further admits that after spending so much time “disavowing” her disability, the process that allowed her to come out and embrace it was “unsettling” (p. ix).

I felt as though I had finally found a scholar who spoke to me in ways that able-bodied scholars simply had not. I also thought, “If she eventually found her voice as a disabled scholar, then maybe I can too.” Thomson’s words gave me hope that I could be successful in the world of academia without sacrificing my disability. That realization was like having a weight lifted off my shoulders. Sure, it is still difficult for me to negotiate my disability in the able-bodied world of academia, but thanks to Thomson’s scholarship, I knew that it was possible for me to find my academic voice. Hence, reading Extraordinary Bodies was another important point in my identity development.

Once I finished reading Extraordinary Bodies, I had an increased desire to read the work of other scholars with disabilities. Next I read Linton’s (1998) volume Claiming Disability: Knowledge and Identity. In this book, Linton discusses the field of scholarship known as disability studies. She explains, “This book examines disability studies as a field of inquiry, its historical roots, present configuration, and explanatory value” (p. 2). Linton concludes that disability studies allow scholars to “think critically about disability” (p. 1). Linton also asserts that scholars engaged in the practice of disability studies can, “serve both academic discourse and social change” (p. 1). In Claiming Disability, Linton articulates various ways that disability studies can be a powerful tool for scholars and activists.

Moreover, she argues that disability is a cultural identity. She asserts, “Disabled people, across the broadest spectrum of disability, have solidified as a group” (p. 5).
Linton argues that people with various disabilities are unified because the experience of living with a disability has political and social consequences. She contends that members of disability culture are part of a large social movement. She states:

We are everywhere these days, wheeling and lopping down the street, tapping our canes, sucking on our breathing tubes, following our guide dogs, puffing and sipping on the mouth sticks that propel our motorized chairs. We may drool, hear voices, speak in staccato syllables, wear catheters to collect our urine, or live with a compromised immune system. We are bound together not by the list of our collective symptoms but by the social and political circumstances that have forged us as a group. (p. 4)

I was enthralled by Linton’s scholarship. She showed me that disability studies can play an important role in higher education. I was reading her book on a bench, and I jumped back in excitement. I remember thinking; “I can make my mark in this field. Disability Studies is the place where my work surrounding disabilities issues can be truly valued.”

After a year of feeling intellectually frustrated, I finally had a field of scholarship that spoke to me. I was thinking, okay this is why I am getting a Ph.D. I can merge my work in cultural studies with the field of disability studies. Linton’s discussion regarding the importance of disability studies helped me realize that I could get my doctorate and use it to explore the social and cultural implications of living with a disability. Linton also expressed frustration toward able-bodied academics that ignore issues related to disability. She states:
Disability Studies points to an inadequacy of entire curriculum with respect to the study of disability. The fault lines that have been exposed stretch from one end of the curriculum to the other: from cultural studies to American studies, from women’s studies to African American studies, from biology to literary criticism, from history to psychology, and from special education to philosophy. (p. 3)

Through these words, I realized I was not alone. I finally felt there were scholars who understood my journey as person with a disability. Reading *Claiming Disability* helped me *come home* as a result of my exposure to scholars in disability studies.

Furthermore, the scholarship in the field of disability studies, help to convince me that having a disability made me a member of a unique culture. Exploring these scholars made me view my disability as a cultural identity. Siebers (2008) explains the implications of recognizing one’s disability as a cultural identity, “To call disability an identity is to recognize it is not a biological or a natural property but an elastic social category both subject to social control and capable of effecting social change” (p. 4).

Consequently, even though I have been marginalized because of how others define my disability, I still have the power to define it own my own terms.

This conception of disability allows me to acknowledge the ways in which I am socially marginalized because I have a disability, while at the same time recognizing that I have the personal agency necessary to impact my own life. Berger (2009) argues that while people with disabilities often encounter systemic oppression, personal agency allows those with disabilities to act as causal agents in their own lives. Berger further asserts that if personal agency did not exist, "personal and social change could not occur"
Thus, the idea of disability was empowering because it provided me with a way to contest society's negative understanding of disability.

Even though I found my new understanding of disability to be empowering, I still did not have much contact with other people who identified themselves as members of disability culture. Therefore, I had a desire to seek friendships with other people who have disabilities. I found one such friendship with a man name R.L.

On the surface, R.L. and I do not have much in common. For one thing, he is almost 20 years older than I am. Second, R.L. is a man with a deep religious faith, and I do not consider religion to be an important aspect in my life. Third, he is a right-wing Republican who adores Ronald Reagan, and I am a left-wing Democratic who admires Franklin Roosevelt. Fourth, R.L. is black, and I am white. So the question becomes, how can two people who have so many differences become friends? The answer lies in our similar experiences as people with disabilities. It is our experience as members of the disability culture that gives us a foundation on which to build our friendship. Engaging in a friendship with R.L. allows me to have a friendship with someone who understands the inside experience of disability. It is nice to have a friendship where I do not have to explain what it is like to be disabled.

Before I began to come home to the world of disability, our friendship would not have been possible. R.L. knew me when I was an undergraduate at Ohio University. We did a couple of radio shows together. Back then we were not friends. In fact, R.L. openly admits that he did not like me. He tells me now, "You were so mean and angry I did not like you at all. You were always calling people with disabilities ‘gimps’ and stuff. I
thought to myself, man, this kid has got some issues. When you graduated from OU I did not know what happened to you, and I did not care."

Needless to say, R.L. was not a big fan of mine. He met me when I was an undergraduate, when I was stuck in the *coming to feel we belong* stage of identity development. What R.L. saw was a person with a fractured identity who was angry at the world, and he had no interest in being a part of my angry world. Thus, until I dealt with my anger, it was not possible for us to form a friendship.

After I graduated and left OU in 2000, R.L. and I did not see each other until 2006. By the time we ran into each other again, I had begun the *coming out* stage of my identity development. I was also beginning to *come home* to embrace the culture of people with disabilities. We became reacquainted at a dinner with disability rights advocate Joe Shapiro. It is fair to say, that I had significantly changed since the last time R.L. encountered me.

I had changed so much that he thought I was a different person. In the middle of our conversation he asked me, "Are you the same Cort who went here a few years back?" I responded, "Yeah, I am, and we have met before." R.L. was surprised and said, "Man, you sure have changed. When I knew you back then you were like a totally different person. It is good to see that you changed for the better." After that dinner, we have become friends. We can frequently be seen in public debating about movies, sports, and politics.

Besides my friendship with R.L., I have continued to *come home* and engage in relationships with other people who have disabilities. For example, I have had the chance
to speak at a sheltered workshop for people with disabilities in Athens County, Ohio. I must say I have thoroughly enjoyed that experience. When I speak to the consumers with disabilities at this sheltered workshop, I feel a unique bond with them. The fact that many of us have disabilities creates a comfortable atmosphere where we can all share our thoughts, fears, and desires. I relish those opportunities to engage with people with disabilities in a setting where we can communicate openly with each other.

Despite the fact that I have come home and embraced the idea that I am a member of disability culture in a general sense, I sometimes struggle to find a home in a community of people who have disabilities. As mentioned previously, the choice to embrace a community of people with disabilities is often a complex choice that has real and perceived consequences in the lives of people with disabilities. One such example follows to elucidate my point.

In 2007, I began attending meetings of the Athens City Commission On Disabilities. This commission is charged with examining issues that impact those with disabilities who live in Athens, Ohio. I began attending meetings, because I wanted to become a part of the disability rights community that is present in Athens. At first, I was excited at the possibility of tackling local issues that impact the lives of individuals who have disabilities. Despite my initial excitement, I quickly became annoyed with the people who have disabilities that serve on the commission. The committee met once a month and the committee members spent most of the time complaining about how hard it is to have a disability. While a part of me appreciates that sentiment, I did not feel that complaining was a productive use of our meeting time. I did not come to these meetings
to hear people complain. I became so frustrated that after four months I quit this committee.

I decided that I did not want to be a part of this group of people with disabilities. I felt conflicted about my choice to stop taking part in this committee. Part of me felt I should remain on the committee so that I could make a difference in my community. However, another part of me felt that this particular community of people with disabilities was too negative for my taste.

My decision to leave the commission had both real and perceived consequences for me. My choice to leave the commission meant that I might be giving up the chance to make an important difference in my community. I sometimes feel guilty for this reason. I wonder if my inability to fit in has hindered my ability to advocate for those with disabilities in my own community. Thus, part of me thinks I should simply learn to deal with people's complaining so that I can make a difference. However, another part of me admits that I just do not fit in with this group. I also realize that my desire to make a difference in this case is outweighed by my desire not to be annoyed.

Yet, the conflict that I felt once I chose to leave the Athens City Commission on Disability, illustrates the difficulty that people can have when they decide whether or not to come home. Hernandez (2005) and Ostrander (2008) demonstrate that Gill depicts the process of coming home as a fairly straightforward process in which people with disabilities find a connection with disability culture. While forging a connection with the culture has been an important part of my identity development, I would not characterize the experience as a straightforward process. Instead, coming home has been a journey that
has been fraught with both excitement and frustration. In short, I view *coming home* as an ongoing process in which I struggle with how and when I should embrace my position in disability culture. Therefore, Gill’s model fails to encapsulate the struggle that some individuals may encounter when they choose to *come home*.

In this chapter, I have explored my transformation from a person who rejected his disability, into a person who publically embraces his disability with a sense of pride. This narrative also explored my ongoing struggle to embrace my membership in disability culture. But choosing to embrace my membership in disability culture is only part of the story. Next, in Chapter Four I explore the various ways I negotiate my existence in two worlds; the culture of disability on the one hand, and the world of people who are able-bodied on the other. It is to that discussion that this autoethnography now moves.
Chapter 4: Living in Two Worlds and the Dialectical Nature of Disability

Living in Two Worlds

As a person who is disabled, I frequently negotiate my existence in two worlds: the world of people who are able-bodied, and the culture of disability. This multicultural existence is replete with opposing tensions that impact my identity. In order to understand the complex nature of my identity, it is important to interrogate these contradictions. In this chapter, I will explore how living in these two worlds is a conflicting reality that impacts my identity development. Once again, Gill's (1997) model of identity development provides a lens through which I investigate this ongoing journey. Additionally, a dialectical approach is used in order to explore how the contradictions present in my multicultural existence affect my identity.

Coming Together

Next I explicate how Gill's model frames disability as a multicultural existence. This model postulates that in the third stage of identity development people with disabilities go through a coming together stage. Gill describes coming together as the process by which people with disabilities come to accept that they are part of disability culture, while also embracing life in the world of people who are able-bodied. Gill argues that coming together allows those with disabilities to exist in two cultures. This multicultural existence enables people with disabilities to heal their fractured identities, and helps heal “rifts” an individual may have with people who are able-bodied (p. 44). Thus, Gill believes coming together is a key step in an individual’s journey to create a positive sense of self.
Hernandez (2005) argues that *coming together* enables an individual to value his or her disability (p. 119). Hernandez states, “This individual affirmation extends to a group affirmation (or group identity) which celebrates the important contributions of the disabled community” (p.119). Thus, in the *coming together* stage of identity development those with disabilities learn to celebrate their membership in disability culture, and their right to be part of the able-bodied world. Ostrander (2008) describes Gill’s explication of *coming together* in the following way:

Third, *coming together (internally integrating our sameness and differentness)* chronicles the actual integration of all aspects of self into a unified identity. This unified identity incorporates aspects of the self that make people with disabilities different from others with the aspects of their self that make them similar to others. (p. 73)

*Coming together* enables an individual to develop an integrated identity which allows him or her to develop a positive sense of self, because that individual’s identity is no longer fractured; as Whitney (2006) explains, that *coming together* is the process of, “integrating one’s whole self and abandoning the references to certain body aspects or traits as good or bad”(p. 44). Therefore, according to Gill (1997), *coming together* is a prerequisite to the *coming out* process (Hernandez, 2005; Ostrander, 2008; Whitney, 2006).

**Coming Out is the Only Way to Be Happy**

Once an individual *comes together* and reconciles his or her multicultural identity then he or she can *come out* and happily embrace his or her disability. In Gill's (1997)
model of identity development *coming out* is the final step to achieving true happiness for an individual with a disability. In fact, for Gill *coming out* is the only way that people with disabilities can be truly happy (Darling, 2003). Gill (1994) also seems to resent people who try and hide their disabilities. For instance, she states:

I have met people whose claims to disability truly annoyed me. I find it hard to embrace as brothers and sisters those folks spend their whole lives comfortably in the nondisabled world without any mention of personal disability until a disabled person challenges their authority to speak for us. (p. 46)

Gill reiterates those sentiments in a (1997) article in which she describes her encounters with people who have not *come out*. Gill says that when she attends conferences where there are other people who have disabilities, she frequently interacts with individuals who try and hide their disabilities. She concludes that those individuals are not happy because they do not openly identify themselves as disabled.

I still meet "successful" persons with disabilities who have been recognized and awarded by society for their achievements but who are privately tired and alienated. They dare not be themselves in public because they do not yet fully accept their differences and others who are different. They cannot be counted on to critique the values of the dominant culture so busy are they with meeting its standards. (p. 45)

Gill seems to argue that only those individuals who openly identify with disability culture are in a position to speak out against the discrimination that people with disabilities encounter. It seems Gill believes that people who do not come out and openly
identify themselves as disabled are not “real” members of the disability community. Gill is not alone in this view. For example, Russell (1994) argues that people with disabilities that do not identify themselves as members of disability culture are similar to African Americans who choose not to identify with Black culture. People of color who reject African American culture are often called Uncle Toms. Many Black people consider these Uncle Toms to be traitors, because Uncle Toms do not openly embrace African American culture. Russell asserts:

In the disability culture we have our Uncle Toms too—we call them Uncle Tiny Tims. They are thankful for whatever crumbs they are given by nondisabled people; they fear the stigma of associating with the rest of us. Uncle Tiny Tims are addicted to the charity—the enslavement-mode of thinking. They’re ashamed of being disabled and will not identify with our movement. You won’t hear Uncle Tiny Tims refer to themselves as “disabled”. (p. 13)

According to Gill and Russell, people who do not publicly embrace their disabilities cannot be trusted. These "Uncle Tiny Tims", are not "real" members of disability culture, and therefore should be viewed with suspicion. Conversely, people with disabilities who come out and publically embrace their membership in disability culture are the "true" allies in the disability rights movement. For example, Gill (1997) describes her encounters with people she meets at conferences who have come out. She declares:

Also at those conferences, there is usually a familiar commotion in the hallways caused by people with disabilities spontaneously stopping to exchange news,
ideas and laughter. These connections radiate energy. These parties may show some wear from years of advocacy battles but no strain from wars within. Such persons have forsaken normality in quiet healthy defiance. In disability groups and in greater society, they function with a certain down to earth grace. They are individuals who identify without hesitation as disabled. (p. 45)

Apparently, Gill believes the only way that a person with a disability can be truly happy is by choosing to openly accept their membership into disability culture. She also declares these individuals have “a certain down to earth grace,” and face the able-bodied world with a “quiet healthy defiance.” I think Gill is over simplifying people with disabilities as a group. Certainly, there are members of disability culture who are quiet and graceful. However, there are also members of disability culture who are neither quiet nor graceful.

I would consider myself a member of disability culture, but I seriously doubt anyone who knows me would say that I meet challenges with a “quiet defiance”, or that I posses a “certain down to earth grace”. I am neither quiet nor graceful. People who consider themselves members of disability culture are part of an extremely diverse group. Yes, the experience of living with a disability unites us, but it would be a mistake to assume that people with disabilities can be viewed as a monolithic group. Gill’s model of identity development fails to acknowledge this diversity. In this model, the only "successful" outcome occurs when an individual embraces his or her disability without hesitation. Yet, many individuals may never reach that point.
For example, Hernandez (2005) and Ostrander (2008) both use Gill's (1997) model of identity development to explore the identity of individuals who became disabled as the result of a violent spinal cord injury. In their separate qualitative studies, neither Hernandez (2005) nor Ostrander (2008) encountered any individuals who had *come out* as people with disabilities. Instead, these authors encountered people who frequently negotiated their disabled identities depending on the context in which they found themselves. These individuals embrace their disability when they are around others who have disabilities. Conversely, when they are with people who are able-bodied, they choose not to embrace their disabilities (Hernandez, 2005; Ostrander, 2008).

**Negotiated Identities**

Gill's (1997) model of identity development focuses too much attention on the importance of *coming out* (Darling, 2003; Hernandez, 2005; Ostrander, 2008). There are people like me who have *come out* in a general sense, but who also negotiate when and how they will embrace their disability. As Darling (2003) declares, "Some people are chameleons. They seem to be able to maintain multiple identities, or adopt whatever identity seems appropriate at a given time" (p. 887). Giles, Orbe, and Bourhis (2000) argue that these "chameleons" are living a co-cultural existence. The co-cultural theoretical approach is grounded in two assumptions. First, people with disabilities are in a cultural position “that marginalizes them in society” (p. 200). Second, people with disabilities will often undertake different communication strategies in order to negotiate how they present themselves to the able-bodied world (p. 201).
I am living a co-cultural existence. Thus, this chapter seeks to illustrate my existence as a "chameleon". I explore the different ways that I negotiate my identity as person with a disability. Sometimes I view my disability with pride, and at other times I resent it. Frequently, I am not sure whether I like my disability or resent it. In those moments I am conflicted. I explore incidents that have caused me to feel each of those emotions. Hopefully, investigating the feelings that I experience as a result of my existence between two worlds will enhance the scholars that explore identity development and people with disabilities. Next, incidents are described in which I am proud to be a person who has a disability.

**Disability Parking**

One way that I embrace my membership in disability culture is through the use of my handicapped-parking pass. When I use this pass I am proudly telling other people that I am part of disability culture. There are a couple of reasons why I have pride in my disabled parking pass.

To begin with, when I go Christmas shopping, handicapped parking is a godsend. There is nothing quite like rolling up to a crowded parking lot where people are frantically looking for an open parking space, and simply being able to park in the handicapped parking space right next to the entrance. It is moments like this that make me realize being born with a disability has its advantages!

However, my disability-parking pass means more to me than special parking privileges. It represents part of my own struggle. There was a point in my life where I refused to get a handicapped-parking pass, because I did not want to admit that I was
disabled. When I was in the *coming to feel I belong* stage of identity development, it was impossible for me to intellectually reach a point where I could openly embrace my disability. Therefore, I could not make myself get a handicapped-parking pass. Now that I have *come out* as a person with a disability, I am excited to use my disability blue hangtag. When I use the pass, I often reflect on my journey as a person with a disability. As silly as it may seem, I view my disability-parking pass as a symbol of cultural pride, because it represents my struggle to intellectually and emotionally accept my membership in disability culture. While using a handicapped-parking pass gives me a sense of cultural pride, I also cherish the opportunities that I have to bridge the gap between the world of people who are able-bodied, and the culture of disability.

**Bridging the Gap as a Scholar**

The opportunity to bridge the gap between these two worlds as a scholar can be a wonderful and rewarding experience. Living in both the culture of disability and the world of people who are able-bodied provides me a unique perspective as a scholar. I think that I understand these two worlds. Consequently, as a scholar I try to provide some insight on various issues that impact people with disabilities in a way that will benefit those who are able-bodied. I am often asked to speak on issues of disability, and I do so because I believe that I have a unique perspective. I am very open about my ongoing journey as a person with a disability.

My success at reaching various audiences varies. Sometimes people are informed by my perspective and other times they are not. My lectures excite some, and others are indifferent. There are also times when I emotionally impact someone.
I had a surprising impact during a lecture I conducted in a graduate level special education course at Ohio University. My lecture covered two major topics; the history of the Ugly Laws in the United States, and issues of identity. My lecture had a profound effect on the professor who taught the course. She shared her reaction in the following email:

Hi Cort:

As the dust is settling on this quarter I wanted to tell you that your presentation on Ugly Laws was a success and that students in their written reviews of this course continue to mention them as another piece of evidence that we continue to need attitude adjustment!

However, what I found MOST compelling was your discourse about your dissertation work. The very moving reflection on letting your mother know that you didn't need to be fixed really moved me—not only for your growth in understanding and accepting yourself but for all of us who need to hear a few other messages: 1) we need not try and fix our students—just facilitate them accepting themselves! and 2) we need to ALL accept who we are. Thanks for the moving moments and lesson! (M. Green personal communication, March 13, 2010)

I was stunned by the e-mail because this professor is not the type of person who I would expect to be moved by a discussion on anything. I have spoken in her class on many occasions, and this was the first time she informed me that she was emotionally impacted by my discussion. Her email made me realize that my existence as a scholar
who is living in two worlds is a valuable experience. It is rewarding to know that my experience has the capability to touch another scholar. This makes me feel that my ongoing journey of identity development is a worthwhile quest.

Moments like the one I just described make me proud of my disability. However, the experience is not always a rewarding one. Sometimes there are moments that make me resent my disability. I will move to a discussion of the frustrations that I encounter because I have a disability.

**Frustration and Disability**

**Falling at a Job Interview**

Living with a disability is an experience that is full of dialectical tensions that can be frustrating. One such tension exists between the physical limitations of the body, and the way that those limitations are framed by society (Berger, 2009; Consalvo, 2004; Davis, 1997; Linton, 1998; Titchkosky, 2003; Wendell, 1996). Therefore, it is possible for an individual to live in a situation where his or her disability has been socially constructed in a positive way, yet he or she may still become frustrated by the limitations of a disabled body (Engel & Munger, 2003; Fries, 1997; Gill, 1999; Klein, 2004; Siebers, 2008; Titchkosky, 2003). For example, even though I have come out and often proudly identify myself as disabled; there are moments when the physical reality of my condition makes me curse my disability.

When I fall at an inopportune time and draw unwanted attention to myself, I sometimes wish I were not disabled. I remember one particular incident. It was in the middle of February on a snowy day, and I was with my girlfriend who drove me to a job
interview at the University of Toledo, located in Toledo, Ohio. We arrived on campus an hour before my interview. I was nervous and excited about this opportunity. Then disaster struck. While walking in the student union building before my interview, I lost my balance on a slippery, wet, and dirty floor and fell. Here I am in a brand-new suit ten minutes before my interview, and my pants are covered in dirt. I pick myself up off the floor, and my girlfriend frantically tries to wipe the dirt off my pants. People were staring at both of us as if we were from another planet. I was so irritated that I cursed myself and my disability. This was not exactly the way I wanted to prepare for my job interview. I thought, my disability can go to Hell. Even though I generally accept my disability as a vital part of who I am, in moments like this I would rather not have a disability.

Thus, my identity development is impacted by the dialectical conflict between how disability is socially constructed by society, and the corporeal reality of the impairment (Shakespeare, 2006; Siebers, 2008; Thomas & Smith, 2009). Consequently, even though I have overcome the negative socially constructed attitudes that I once felt toward disability, I sometimes feel frustrations due to the limitations of my disabled body. I cannot escape the physical reality of my body. Therefore, it is important to acknowledge that this tension may impact the lives of people with disabilities. As Thomas and Smith (2009) conclude:

It could be argued that if we are to begin to explain disabled people’s experiences in all areas of social life then we need to recognize the many complex interdependencies that exist between their experience of impairment and disability. In other words, since disability and impairment are experienced
differentially as interdependent aspects of disabled people’s lives that continually interplay with each other they cannot, and should not be easily separated. (pp. 11-12)

Smith and Thomas use disability to refer to the way that society socially constructs impairment as a category of difference. Conversely they use impairment to describe the physical reality of a particular condition. They argue that in order to gain a broader understanding of people with disabilities, scholars should explore the way this dialectic impacts those with disabilities.

Gill's (1997) model of identity development fails to consider this contradiction. This model only focuses on the socially constructed nature of disability. In so doing, it ignores the impact that the physical reality of an impairment might have on someone's identity. Hopefully, this autoethnography demonstrates that scholars who are interested in the topic identity and disability may benefit by exploring the tension that has been described above.

**Comprehensive Exams: a Socially Constructed Barrier**

While my identity is partly shaped by the nature of my cerebral palsy, it is also affected by the way my disability is socially constructed by society. Frequently, society exacerbates my physical limitations because it creates socially constructed barriers that hinder my ability to take part in mainstream society. Many people with disabilities encounter socially constructed barriers in their everyday lives (Butler & Parr, 1999; Corker & French, 1999; Do & Geist, 2000; Goggin & Newell, 2003; Juette & Berger, 2008; Klein & Kemp, 2004).
In order to illustrate this, Goggin and Newell (2003) describe an imaginary world in which people with disabilities are the “norm”. This fictional society has been settled entirely by individuals who use wheelchairs. These wheelchair users design “a social system to suit themselves” (p. 20). This society has its own unique design and building codes. Now imagine that at some point a few able-bodied people come to live in this society. These able-bodied people don’t fit in because “they are constantly knocking their heads on door lintels, and require constant medical intervention and control” (p. 20). These able-bodied people become isolated because the wheelchair users label them as deviant. In this society, able-bodied struggle to find employment, and they are often denied the opportunity to engage in meaningful relationships with the people who use wheelchairs. In such a world, the physically impaired wheelchair users would be able-bodied, while the so-called able-bodied would become the disabled (p. 20).

Just like Goggin and Newell's imaginary world, this society erects barriers that exclude those with disabilities. Sometimes these socially constructed impediments do not impact me in a significant way, but there have also been instances when these barriers have drastically impacted my identity. I will now describe one that had a major impact on my identity development.

I began the month of March in 2007 with a high level of excitement. I was finished with the coursework in my doctoral program, and was ready to complete my comprehensive exams. I was confident in my preparation, and felt I would not have any difficulty passing these exams. Since I have a disability that makes it difficult for me to type or write I needed an accommodation in order to complete my exams.
After some discussion between the professors who were testing me, it was decided that I would talk into a tape recorder during all four exams. Then, my recorded answers would be transcribed into written form. It was also decided that Ohio University’s Office of Disability Services would provide the transcriptionist. Then after my responses were transcribed, I would work with someone for two hours, who would help me edit the answers. The edited answers would then be given to each professor who tested me. At the time, this seemed like a reasonable way for me to complete my exams. However, the accommodation turned into a debacle.

The Office of Disability Services did not do a good job finding a qualified transcriptionist. First, the director of the office insisted she could do the transcription herself. I was not so sure. In fact, I asked her, “Are you sure you can do this? There are four exams, and each is four hours in length.” Despite my concern, she stated, “I can do it I promise.” I was not convinced that she could, but did not feel like I had much of a choice so I said, “Ok.”

However, my fears came true. The director soon found that she could not transcribe my questions. After the first day of transcribing my questions, she called me and said, “Cort, I can’t do this it is overwhelming. There is no way I can transcribe your questions.” I responded, “uhh, ok.” She then added, “I don’t know what to do now. What should we do so that we can fix this problem?” I became furious. I fired back, “I don’t know.” She then asked, “What do you think we should do?” At this point I was so mad, I could barely see straight. I could visualize my future dissipating because of this person’s incompetence. I answered, “I don’t fucking know. It’s not my job. You were supposed to
find the transcriptionist not me. I should not have to worry about this.” She actually responded very nicely to my anger. She said, "Cort I am really sorry. This is my fault, but I'm just not sure what to do now." I responded, "I am sorry that I cussed at you. That was inappropriate on my part." She answered, "It is no problem at all. I understand your frustration. The question is what do we do now?"

So here I am on the phone with the director of Disability Services at Ohio University, and it becomes clear to me that she does not know what she is doing. This was a terrifying realization. I tried to compose myself so that I could solve the problem. I asked, "Can you hire somebody to do this? There are law firms all over town. So there has to be somebody that can do a transcription." The director responded, "Yeah we could do that, or maybe a secretary in one of the offices can do it for free." I can remember thinking, “We have already had one near disaster and she wants a secretary to do it.” Since it was my academic future on the line, I wanted a professional. So I told her, "Can't the office pay a professional to do it." She responded "Yes we can do that, but I would have no idea who to hire."

I am sitting on the phone listening to the director and trying to remain calm. I was not succeeding. I remember thinking, “I am in the middle of an Abbott and Costello routine from Hell.” Then I thought, “No, this can't be happening. This has got to be a joke.” In truth, I was totally befuddled. I had no idea how to respond. I did not know what to say next.

I answered the director, "Look, I have no idea who can provide this service, but there has to be someone who can do this. It is important to me that you find someone
good to transcribe my exams." She responded, "I will do my best to find someone who can do this. I will ask around." Our conversation ended politely, and I hung up the phone.

The moment after I hung up the phone, I had a feeling that this accommodation was going to turn into a complete disaster. I just did not see how this could possibly end well. Unfortunately, my instincts turned out to be right. The person the office found to transcribe my exams was an individual from a temporary employment agency. This person had never transcribed anything before. This helped make my accommodation a debacle.

The process went from bad to worse. As mentioned before, when the exams were in written form, I was supposed to work with someone for two hours in order to help me edit my exams. My advisor agreed to find someone to help edit my exams. She chose a Japanese student. The student was very nice, and willing to help. However, English was a second language for this student. When my advisor informed me that she picked this student to help me, I had concerns. English was this student's second language, and I was concerned that there would be communication issues between this student and me.

My advisor did ask me if I wanted to work with this student. I was not comfortable working with a student who might have language issues, but I did not feel I could be honest with my advisor about it. From my point of view, I was in a no-win situation. I did not feel comfortable working with this student. However, I was concerned that if I shared the truth with my advisor, she would think I was being culturally biased. I did not want to offend my advisor by telling her that I did not approve of her choice. Thus, I failed to express my discomfort with the situation.
By this point, I was extremely frustrated with the whole process. First, the Office of Disability Services turned the process of finding a transcriptionist into a fiasco. Second, my advisor picked someone to help edit who did not speak English as her first language. I felt as though my comprehensive exams were turning into a massive train wreck. I began to fear the worst. Unfortunately, my fears were realized once I examined the first transcribed answer. This is a sample of what I encountered:

As John Kosovo points out in two foot of Landmark books, he’s written voluminously but in his two landmark books *There’s a Savage Inequality In Education And The Poor*. That’s his first book written in the 80’s where he did a various case studies of different schools probably the one that always tings out into my mind is the one at East Saint Louis and he did a case study of rich schools verses poor schools and what he discovered was. If you are rich you got to a much better school. In 2004 he came out with this book *Shame of a Nation* which is really kind of an update to *Savage Inequalities* but it also looks at this poverty aspect in regards to how it plays out in terms of no child left behind, so how does poverty impact education, well what happens. Well, if you are poor. Hold on, I have to back up. I have to back up. No I guess I’ll, I guess I’ll move. Yeah I’ll move forward. I’ll move forward never mind and so what we see if that if you are poor your education will suffer. If you for example, go to an inner city school to New York that Kosovo talks about greatly chances are you will be you will go to school buildings that are not up to code. For example, *A Shame of A Nation* John Kosovo talks about more
than one school that the windows were so bad in these poor schools, the windows was so bad in these poor schools that the teacher wouldn’t even clean the windows because if they did the windows would fall out and break.

(Schneider, 2007, p. 4)

When I saw the transcribed exams, my heart sank. There were four exams, and each exam was approximately sixty pages in length. Similar to the section above, they were incomprehensible. There was plenty of blame for everyone involved.

First, I did a horrible job of dictating my answers. I had never dictated for transcription, and my inexperience showed. I had used a tape recorder during exams before, but for those exams I just simply talked. I did not worry about sentence structure or anything. I just said whatever popped into my head. Unfortunately, I used that approach during my comprehensive exams, and as you can see, it did not work.

Second, as I pursued over each exam I noticed that the transcriber misspelled all of the authors that I cited. There were also quite a few words that were misspelled. In short, the transcribed answers were a mess. I attempted to correct as much as I could in the two hour time frame I was allotted. Unfortunately, after two hours of feeling overwhelmed and struggling to overcome a significant language barrier, I only corrected three pages. Keep in mind I had 240 pages of this mess to get through! I felt hopeless.

I was certain this debacle of an accommodation was going to cause me to get kicked out of my doctoral program. I can remember thinking, “All my goals and dreams of getting a Ph.D. are gone. Why did I have to be born with this stupid disability? Fuck
this! Fuck trying to be a part of this able-bodied world! This stupid accommodation has wrecked everything!”

I wanted to quit. My frustration boiled over into a massive feeling of anger and contempt. I had contempt because I did not do a better job dictating the answers. I had contempt for my disability, because it was the reason that I needed this stupid accommodation in the first place. I had contempt for Ohio University's Office of Disability Services since they were no help at all. I had contempt for my advisor for picking someone to help me edit who did not speak English very well. In fact, I had contempt for the whole able-bodied world at this point.

Luckily, I ran into one of my committee members who pulled me into her office, and let me vent. She gave me ten minutes to unload my anger, which I did. Then she said, “What can I do to help fix the problem?” Looking back, if I had not run into that professor, I might have quit. But after this meeting, I was determined to not let this setback ruin my chances of getting a doctorate.

Hence, I found my advisor and explained the situation. I explained that there was no way that my comprehensive exams were ready to be turned in. She said, “Ok, what should we do?” I said, “Maybe my committee members could listen to the tapes, since the transcriptions are so screwed up.” She responded, “That won’t really work. You need a written document for your comps, and besides the people on your committee are visual people. They will want to see a document.” I was taken aback by the comment that the people on my committee are visual people. I remember thinking; “One of my committee members is totally blind. I don’t think he is a visual person.” Her comment made me
wonder if she really empathized with my situation. I was not sure if she really understood what it is like to be in my position.

My advisor then suggested, “Maybe you could take the transcribed answers home for two weeks, rewrite them, and then turn them in.” That seemed like a reasonable solution so I said, “Sure, I can do that.” She replied, “We will have you rewrite your comps at home then. Now remember since these were in house exams, you cannot add new information. You are rewriting them, not adding new information.” This comment angered me greatly. I was thinking, “Really, you think I am going to cheat. My accommodation got totally screwed up, and now you are reminding me not to cheat!”

At this point I was seething with anger. I saw my advisor as just another clueless able-bodied person who did not understand what is like to be a person with a disability. I wanted her to empathize with me. She is a self-proclaimed seeker of social justice, so I expected her to be upset that I had to be put through this ordeal. Yet, she seemed interested in preserving the process, instead of understanding the stress I was feeling. I wanted her to be a strong advocate for my welfare, and instead she seemed detached. I felt betrayed. Hence, I directed all of my anger and frustration about the failure of this process toward my advisor. In my mind, she represented everything that was wrong with able-bodied liberals that claim they care about discrimination, except when it comes to the discrimination that people with disabilities encounter.

Even though I rewrote my comprehensive exams and passed them without any additional issues, my anger continued to impact the relationship between my advisor and me. For a significant period after my comprehensive exams our relationship was strained
on good days, and downright contentious on bad ones. I felt that she did not appreciate my scholarship, and would prefer not to work with me. This made the process of working with her difficult to put it mildly.

Finally, a year and a half after my comprehensive exams, we confronted these issues. We had a “come to Jesus meeting” in her office. During this meeting, we openly expressed our frustrations with each other. This meeting was an honest and emotional exchange. After this meeting, I realized that she did want to work with me, and that we could work together. This come to Jesus meeting gave both her and me a new found respect for one another. Since then we have worked together effectively.

It has now been over three years since I completed my comprehensive exams, and I have gained a healthy distance from the events surrounding my failed accommodation. As I reflect back, I realize the system that was supposed to provide me with a reasonable accommodation failed. There are various people to blame for the disaster that became my comprehensive exams. Certainly, Ohio University’s Office of Disability Services deserves some blame for its inability to find a quality transcriber. My advisor probably deserves some blame for not being more empathetic to the stress I was experiencing. Finally, I deserve most of the blame.

I was not comfortable with the accommodation from the start. However, I did not clearly explicate my discomfort. I also was not comfortable editing my exams with someone who did not speak English as their first language, but I was not honest with my advisor about my concerns. I did not advocate for myself very well. I accepted an
accommodation I felt would not work, because I did not advocate for myself. I should have never agreed to use an accommodation I had never practiced.

Finally, my frustration and anger toward the process was misdirected. I mistakenly blamed my advisor for the whole process. She became a representation of everything that I came to resent about people who are able-bodied. In truth, she was overwhelmed with the failed accommodation process just as I was. She did not have any experience dealing with something like this. Perhaps, she could have been more understanding of my situation, but I did not treat her very fairly. The mistakes she made occurred because she was not sure what to do. She had no experience dealing with a botched accommodation of this magnitude.

Furthermore, I unfairly expected her to understand my frustration. I now realize that it is really difficult for someone who is able-bodied to understand the frustration of an accommodation gone wrong. This is cultural experience that is unique to people with disabilities (Gill, 1999; Klein, 2004; Linton, 1998). In addition, I did not handle my frustration well. My inability to handle frustration is not unique among those with disabilities. As Klein (2004) states, “Anger, frustration, and hurt are managed quite well by many of us…and poorly by all of us once in a while” (pp. 197-198). Clearly I did not handle my anger and frustration well.

Moreover, the conflict that occurred between my advisor and me was largely a problem with cross-cultural communication. My advisor interpreted the failed accommodation from the perspective of an able-bodied person. Conversely, I viewed the situation as a member of disability culture. While my advisor viewed the problem as a
mistake by Ohio University's Office of Disability Services, I viewed it as a symptom of a larger problem. It was an example of the way that able-bodied society creates barriers that marginalizes people with disabilities. For me, this experience was evidence that the able-bodied world does not care about those with disabilities, and I was frustrated that my advisor did not understand that.

However, I have come to realize that my perspective on the issue was different from hers, because she cannot understand the inside experience of a person with a disability. I failed to take into consideration that her perspective might be different than mine because she is able-bodied. Therefore, it is difficult for her to understand what I felt. Moreover, she wanted what was best for me as her student. Thus, in order for her and me to move beyond this conflict, we had to communicate in a manner that would bridge the gap between two cultures.

This experience demonstrates the difficulty people encounter when they are trying to move between the world of disability and the world of people who are able-bodied. This event had a significant impact on my identity. As I mentioned previously, this experience made me resent my disability. I also resented many people who were able-bodied. This event caused me to question my place in able-bodied society. I began to wonder whether earning a Ph.D. was worth this amount of stress.

Even though I have moved beyond my anger, this story demonstrates the way in which a socially constructed barrier can impact identity development. By the time this occurred, I had already come out as a person with a disability. Therefore, according to Gill's (1997) model, my identity development should have been complete. Yet, a socially-
constructed barrier made me question everything I thought I knew about my identity. Since Gill's model postulates *coming out* as the last stage in the process of identity development, it fails to encapsulate the struggle with identity that occurred because of a failed accommodation. Consequently, scholars who study identity and people with disabilities may benefit by investigating the way that socially constructed barriers may impact the identity development of people who have disabilities.

So far I have demonstrated that living with a disability can make me proud. I have also shown how living with a disability can be frustrating. Now, I explore some ways I am conflicted about my identity as a person with a disability. It is to this discussion that I now move.

**To Disclose or Not to Disclose**

While there are times when I am proud to assert my membership in disability culture, there are also times when I am hesitant to do so. For example, in December of 2007, I began compiling a resume and cover letter so I could start applying for jobs. I decided to hire a professional to help me create a resume and cover letter so that I can ensure I would be putting my best foot forward.

When it came time for me to write my cover letter, I was conflicted about whether I should disclose my disability. I was torn. I thought mentioning the fact that I have a disability might help, because I was applying for jobs in various fields related to people with disabilities. Thus, I thought mentioning my disability would demonstrate that I have personal experience that might help me on the job. I was also afraid that potential
employers might feel that I was using my disability in order to get a job. Moreover, I was concerned that some employers might not hire me because I have a disability.

Since I was not sure whether to disclose or not I asked the resume professional that I hired. Her response illustrates my quandary. Her first answer follows:

Hi Cort:

I posted to my e-list of colleagues (professional resume writers across the country) regarding mentioning your disability in the cover letter as I was truly torn (and I know you had mentioned previously about never knowing whether to mention it or not). Their overwhelming response was that if you are able to do the job you are applying for, there is no need to mention the disability. Here are a couple excerpts from their responses to me:

I have a brother-in-law who is deaf from birth and is married to a woman who is deaf. He works at the large Central Post Office that hires a lot of folks with disabilities. His opinion of this situation is IF the person is capable of working with others with disabilities and many disabled folks aren't (according to him) putting it on his resume or cover letter is not a good idea. He doesn't think much of using their disability to obtain employment. He is an EOE officer.

I agree with Steve and his brother…having worked as a job placement officer for my community college for students with disabilities and as the founder of our county’s Mayors’ Committee for the Employment of Persons with Disabilities, my experience taught me that “using” the disability in any way usually backfired. The person with a disability, like any other candidate, wouldn’t apply
(or shouldn’t) for a position for which he or she is not qualified or capable of doing competently.

I was really torn on this because we're not using it per se other than to show your intimate knowledge and experience with this. Your situation is a bit different in that you are applying for a position working with individuals with disabilities. But I think I'd rather err on the side of caution and not mention it. What do you think?

(M, Kassler, personal communication, December 11, 2007)

This e-mail demonstrates the complexity of living with a disability. On the one hand, this resume professional thought that my experience as a person with a disability might be beneficial. On the other hand, she was concerned that people who are deciding whether to hire me might think that I am using my disability in order to get a job. She was so conflicted about this issue, she reflected on it some more. After further thought, she decided that I should include my disability in a cover letter. She sent me this e-mail to explain her reasoning:

Hi Cort:

There's been some additional discussion about your situation on my e-list and several are now leaning toward mentioning your disability due to the nature of the position for which you're applying. I'm toying with the idea of adding it back in. Your thoughts??Here are a couple postings I've received today:

I can see the points of the others who wrote in about this, but I agree with Bill as well. My earlier comment in favor of using the 'disability' to his advantage would work well in this case given the target audience...don't you think? If he were
applying for a job as a manager of a cell phone company, or any other type of management, or job for that matter, I would definitely leave off the disability in all areas--cover letter and resume.

Melissa,

You know, the more and more I think about it the answer would be a resounding “Yes.” Here’s why: In our e-list discussion so far, we haven’t really talked about who the reader is. In this case, the “reader” is a university and would be by definition far more politically correct and sensitive than any other employer – other than perhaps a church. Since the employer will be very sensitive to the situation, I’d exploit it as quickly as possible. Let me know what you think! (M. Kassler, December 12, 2007)

In the second e-mail there are people claiming that I should disclose my disability, because universities might take the politically correct position and hire me because I have a disability. These e-mails left me more confused than ever. Should I just openly embrace my disabled identity and always disclose it my cover letter? Conversely, should I never mention my disability? Or should I mention my disability when it might help me get a job, and leave it off when it might be a deterrent? I am still not sure how to handle this situation. Therefore, I mention my disability when I think it might help me, and I leave it off when it might hurt. In short, my choice to embrace my disability depends upon a particular context.

Not only am I conflicted asserting my disabled identity when I apply for jobs, but I am also ambivalent about declaring it during job interviews. I am never certain when or
how, or if I should embrace my disability in that situation. I will provide an example to illustrate my point.

In May of 2008, I was very excited to be a finalist for a potential job at Virginia Tech University. This job would give me the opportunity to work in a disability services office at a large University. I was one of the two candidates being considered for this position. Consequently, I traveled to Virginia Tech for an on-campus interview. The on-campus interview would be a jam-packed eight-hour day. During this gauntlet, I would meet with various groups on campus.

I entered my on-campus interview with hope and excitement. The day began with a meeting between the four members of the hiring committee and me. This meeting took place at a restaurant that was located in a hotel. During this part of the interview, we were supposed to have breakfast. This particular restaurant had a buffet. Consequently, each person went through the buffet line and carried a tray with their food on it. Since I walk with crutches, it is impossible for me to carry a tray with food on it. No one asked me if I needed assistance. In fact, everyone got food, and I remained seated. At this point, I was not exactly sure what to do. Should I ask someone to carry a tray for me, or should I wait until someone offers?

I did not want to focus on the fact that I had a disability. I was hopeful that the committee would not think my disability would prevent me from being able to do the job. Therefore, I wanted to minimize my disability whenever possible. However, five minutes into my on-campus interview my disability put me in an awkward position. I did not know how to proceed. I decided to wait until someone asked if I needed help.
Unfortunately, the members of the hiring committee returned to the table, and began eating breakfast. Still, no one noticed that I did not have a plate of food. The interview began and everyone except me was eating. Now I really did not know what to do. I did not want to make anyone uncomfortable by pointing out they did not accommodate my disability. I felt awkward. The interview continued for about five minutes before the director of the office of disability services noticed I did not have a plate. Then he said, "Man I'm sorry I didn't even consider the fact that you're not able to carry your own tray would you like me to get you one?" Once the director spoke, the other members of the committee sheepishly apologized. I responded, "Don't worry about it. It's no big deal." The director of disability services hurriedly got me a plate and returned to the table, and everyone felt really uncomfortable because this had occurred.

Members of the committee felt embarrassed and I could tell. I mean, here I was, a person applying for a job in the office of disability services. Yet, they had failed to accommodate me, a person with a disability. No one mentioned this out loud, but the irony of the whole situation was not lost on me. I was frustrated, because everyone was uncomfortable. Sure we moved on, but I was irritated because the incident caused the members of the hiring committee embarrassment. This was not the first impression that I wanted to make. The rest of my on-campus interview was completed without any further embarrassing incidents. However, my experience at breakfast left some nagging doubts in my mind.

I did not get the job, and I wondered if the gaffe during breakfast had something to do with it. I am not saying that I did not get the job, because of this, but I wondered if I
should have handled the incident differently. Should I have asked to help with my tray? Should I have made a joke in order to ease the tension? Did they intentionally not bring me a tray in order to see how I would react? I wondered if this incident was some kind of test in order to see how strongly I would advocate for myself, because I would have to be an advocate for people with disabilities if I was hired.

As I reflect back on this experience at Virginia Tech, I have come to realize that it demonstrates the contradictory impact that my disability has in my life. On the one hand, my disability was a positive influence. I applied for the job in the first place because of my experience as a person with a disability. In addition, my experience as a person with a disability helped me impress the hiring committee. More than one person told me that they were excited about my candidacy because I was a person with a disability. My disability was at least part of the reason that I was among the final two candidates.

On the other hand, the incident that occurred at breakfast during my on-campus interview, demonstrates a negative way that my disability may have influenced the process. Certainly in that instance, my disability helped create a situation that caused everyone discomfort. It created an awkward moment that put more pressure on me during the interview process. Therefore in this instance, my disability was a negative influence on the process.

Furthermore, it is my belief that in order to understand my identity development as someone who lives with an obvious physical disability, it is necessary to explore the way in which my identity as a person with a disability operates in these contradictory ways. As Siebers (2008) explains, “As a marker of social identity disability sometimes
works in contradictory ways” (p. 4). In other words, my identity as a person with a
disability is full of ambivalence and contradiction.

**The Struggle of Living in Two Worlds**

My struggle to decide whether or not to embrace my disability is an ongoing
struggle. I often feel that I should assert my membership in disability culture more than I
do. Since I believe that I am a member of disability culture, part of me feels that I should
always acknowledge my disability. Conversely, I also consider myself part of the able-
bodied world. Thus, I sometimes feel pressure not to assert my disabled identity so that I
can fit in better with the able-bodied world. I am constantly making choices when and
how I declare my membership in these two contrasting worlds. Consequently, most of the
time I am in what Gill (1997) calls the *coming together* phase of identity development.
That is to say, I am trying to assert my membership in disability culture, while I also
assert my right to be a part of the able-bodied world.

Hence, my identity development cannot be understood as a simple dichotomy. My
existence is not either/or. That is to say, I did not think that I should have to choose
between these two worlds. Therefore, sometimes I will embrace my disability, and
sometimes I will not. Darling (2003) describes individuals like me who negotiate our
identities in the following way:

In some cases, these identity shifts simply reflect ambivalence, or the inability or
unwillingness to choose between competing norms. Thus, some disabled
individuals who have access to full inclusion in society may choose normalization
in interacting with individuals without disabilities, but may reject the norms of "fitting in" to society when interacting with their disabled peers. (pp. 887-888)

In my own journey of identity development I am unwilling to choose between the world of people with disabilities and the culture of those who are able-bodied. Since I have made the conscious choice to come together and live in both cultures I am caught in two worlds that often have a different set of values (Linton, 1998; Longmore, 2003; Shakespeare, 2006; Siebers, 2008). Therefore, it would be a mistake to judge my identity development based upon whether I chose to openly embrace disability culture without hesitation. Hence, scholars such as Gill (1997) and Russell (1994) who assume that an individual should identify without hesitation as a member of disability culture, ignore people like me who negotiate their identities.

Thus, in order to understand my identity development, it is important to understand how my identity is shaped by a dialectical interaction of various factors. Some of these tensions are individual while some of the tensions are structural (Berger, 2009; Shakespeare, 2006; Siebers, 2008). Consequently, my identity is shaped in part by intrinsic and extrinsic factors. As Shakespeare (2006) explains:

The experience of a disabled person results from a relationship between factors intrinsic to the individual, and extrinsic factors arising from the context in which she finds herself. Among the intrinsic factors are issues such as: that nature and severity of her impairment, her own attitude to it, her personal qualities and abilities, and her personality. Among the contextual factors are: the attitudes and reactions of others, the extent to which the environment is enabling or disabling,
and wider cultural, social, and economic issues relevant to disability in that society. (p. 55)

Therefore, as I continue the exploration of my identity development as a person with a disability, it is important to keep in mind the dialectical nature of disability. As a person with a disability that is living between two worlds, I constantly manage tensions that arise between intrinsic factors that I can control, and extrinsic factors that I cannot. Moreover, managing those tensions impacts my identity development. Perhaps, nowhere is the impact of these tensions more evident than in my close personal relationships with people who are able-bodied. Consequently, in Chapter Five I explore the role these relationships can have on identity development. It is to this interrogation that I now move.
Chapter 5: Relationships and Identity Development

Identity is a Relational Endeavor

In Chapter Four, I examined my existence, and the complex ways that I navigate my identity. In Chapter Five I discuss my identity as a relational endeavor, and investigate the connection between relationships and my identity. My personal relationships have an impact on my identity development, and conversely, my identity development affects my relationships (Baxter & Ebert, 1999; Baxter, & Montgomery, 1996; Braithwaite & Harter, 2000; Fiduccia, 2007; Frame, 2000; Guter & Killacky, 2004; Tepper, 1999).

Braithwaite and Harter (2000) conclude, “Relationships are central to happiness and present people with some of the greatest challenges in life” (p. 17). Braithwaite and Harter also assert, “Like people everywhere, persons who are disabled live their lives in a web of personal relationships” (p. 18). I bring my identity as a person with a disability into all my personal relationships, and my disability affects everyone with whom I relate (p. 18).

In order to understand my identity development, it is necessary to interrogate my personal relationships. While there are a number of relationships that I could examine, my relationships with able-bodied family members, and my able-bodied girlfriend Jane, have had the most significant impact on my identity. Thus, in this chapter I begin by exploring my familial relationships, and then I move to an examination of my relationship with Jane. Investigating these relationships elucidates the ways in which my identity development is a relational endeavor. I begin by exploring my familial...
relationships, because family is the place where the process of identity construction begins.

**Family and Identity**

**Identity and Family Scripts**

My family was the first group of able-bodied individuals with whom I had a meaningful relationship. I did not select a relationship with these people; these relationships began as an “accident” of birth. Scholars argue that relationships with family members are significant in the process of identity formation for all individuals, including those with disabilities (Barlow et al., 2006; Bellin & Rice, 2009; Canary, 2008a; Davies, 2007). For instance, Canary (2008a) states, “it is commonly recognized that family interactions are crucial in children's sense of self and social skills; children with disabilities are no different in this regard than children without disabilities” (p. 440). The family is the first place where people begin to create their identities (Atwood, 1996; Byng-Hall, 1995; Canary, 2008; Davies, 2007). As Atwood (1996) explains, identity “is built upon the foundation of family identity” (p. 9).

Moreover, families create scripts that help shape an individual’s identity. Before I can illuminate the concept of family scripts, it is important to discuss the concept of scripts in general. Atwood describes a script as a “devise for guiding action and for understanding it” (p. 13). To state it another way, scripts help people decide how they should behave in various social contexts. As Simon and Gagnon (1984) explain, “Scripts are a metaphor for conceptualizing the production of behavior within social life. Most of social life most of the time must operate under the guidance of an operating syntax, much
as language is a precondition for speech” (p. 53). In other words, scripts help people attach meaning to their actions. Atwood (1996) concludes:

Individuals’ meaning systems determine the content of their scripts. A person attempts to match his or her experiences with the available meanings and scripts. In this way, the person learns the language and the appropriate behaviors for his or her gender, age and culture. (p. 12)

Scripts operate on cultural, family, and personal levels (Atwood, 1996; Simon & Gagnon, 1984). Scripts are a reality in socially constructed systems. Moreover, individual families create their own scripts. Byng-Hall (1995) defines a family script as:

The families’ shared expectations of how family roles are performed within various contexts. The term "expectations" implies anticipation of what is to be done and said within family relationships, as well as family pressures to perform the roles as expected. (p. 4)

Family scripts are valuable because they help families maintain a stable environment in which all members of the family can function. Terry and Campbell (2009) conclude, "Family scripts are valuable for ensuring stability and continuity; their stabilizing effect is reinforced by being embedded in the belief systems and practices which are shared with extended family, the community and the culture" (p. 22). Thus, families do not create their scripts in isolation. Instead, they construct scripts that are part of the cultural milieu in which they live.
Idealized Social Scripts

Society often creates dominant scripts that help facilitate "proper" behavior. These dominant scripts are often idealized constructs; for example, "the good son or daughter", "the happy marriage", or the "perfect husband" (Atwood, 1996). Frequently individuals struggle to meet the standards embedded in these dominant scripts. As Atwood explains:

They are embedded in social institutions, and as such are internalized by individuals. The overriding, dominant scripts receive most attention because of their primacy and potency among people’s options. It is against the dominant social scripts that people attempt to match or reject their own personal social scripts. But this match is never perfect, and what occurs is often far from ideal. (p. 13)

When an individual falls short of these idealized expectations, he or she may develop a negative self-image. He or she may also choose to reinterpret reality in order to make his or her life “fit” these expectations (Atwood, 1996; Byng-Hall, 1995; Terry & Campbell, 2009). For example, I frequently tried to meet the standards of a "super crip" script. The super crip construct assumes that an individual should work hard to overcome his or her disability (Berger, 2009; DePauw, 1997; Fitzgerald & Kirk, 2009; Goggin & Newell, 2003; Smith & Sparkes, 2005). As a child, I subconsciously internalized the idea that I was a super crip. As a result, I worked hard in order to overcome my disability so that I could lead a normal life.

By the time I was nine years old, I convinced myself that if I worked hard enough I could walk without crutches. I was an avid Pete Rose fan. I admired his work ethic on
the field, and I told my mom, "If I work as hard as Pete Rose does, I'll walk someday" (Pearl, 1987, p. 1A). That statement seems completely ridiculous to me now, but when I was nine, it made sense to me. I wanted to be normal. However, I could never achieve the standard of normalcy I set for myself.

By the time I was 18, I realized that walking without crutches on a full-time basis was a fantasy. This realization made me feel like a failure. I felt bad about myself, and resented my disability. I viewed my inability to walk as my personal failure.

As I reflect on my feelings now, I recognize that I was attempting to fit into a socially-constructed script. I internalized the idea that walking without crutches was normal. Therefore, I tried to convince myself that I could make myself normal through hard work. My failure to make myself normal contributed to my negative self-image. This example demonstrates that certain "scripts" have had a powerful impact on my identity as a person with a disability.

**The Fluid Nature of Scripts**

While scripts are a powerful influence on the process of identity development, it would be a mistake to assume that an individual's response to dominant scripts is consistent. As Atwood (1996) states, "Although some persons follow the dominant scripts, this is not an automatic process" (p. 15). Engagement with scripts is a social act, and therefore an individual's response to scripts is a fluid process (Atwood, 1996; Byng-Hall, 1995; Terry & Campbell, 2009). Individuals may swallow a dominant script in its entirety, or they may embrace only certain aspects of a script. In addition, as an individual matures, he or she may choose to reject certain dominant scripts. For example,
when I was in the phase of identity development that Gill (1997) terms *coming to feel we belong*, I tried to meet the expectations of the super crip construct. However, when I began the process of *coming out*, I rejected the expectations of normalcy that are embedded in that script. Consequently, I no longer felt like a failure because I could not walk without crutches. I realized that I no longer had to be normal, and I could be successful not in spite of my disability, but because of it.

The personal transformation that allowed me to *come out* also gave me alternative scripts (Atwood, 1996; Byng-Hall, 1995; Terry & Campbell, 2009). These alternative scripts enabled me to see the value in my identity as a person with a disability. Thus, *coming out* helped me move beyond the dominant scripts that negatively affected my identity. As I move through life, my engagement with various scripts will inevitably change. I will reject some scripts, and embrace others. Moreover, as I embrace certain scripts and reject others, my relationships will also change. For instance, as I exclude those dominant scripts that my family members still embrace, my relationships with family members may change.

**My Family Script**

In order to understand my identity development, it is important for me to scrutinize the way in which my family constructed a script regarding my disability. It is necessary for me to explore the impact my family’s script had on my identity as a child. I also investigate how my continuing identity development has changed the way in which I view my family's script.
Before I can interrogate the ways that my family's "script" impacted my identity, it is necessary to briefly describe my family. My parents both come from small towns outside of Columbus, Ohio. My father was a union pipefitter. My mother was a stay at home mom who also held various jobs outside of the home in order to help our family make ends meet. My parents worked hard to make sure that my brothers and I lived a comfortable lifestyle. My parents instilled in us the value of hard work and education. Thus, it is not a surprise that all three of us have earned college degrees.

I was the youngest of three boys. The oldest brother, Billy, is four years my senior. Billy always liked to challenge me. If we were talking about sports, movies, or politics he thought it was his duty as the oldest brother to push my buttons. My other brother, Tim is a year younger than Billy. Tim was much quieter than Billy. While Billy was hyper, Tim was calm.

My brothers and I all played sports in high school. Billy played football, while Tim played football and baseball. I ran cross country and wrestled. Sports were a significant part of our lives growing up. From the time I was five years old, I can remember attending my brothers’ little league sporting events. Conversely, my brothers participated in my little league wheelchair basketball games. Playing sports was something that my brothers and I had in common. Going to practices and games became part of the rhythm of our family life.

The Only One with a Disability

I was the only family member who had an obvious physical disability. This is a reality that I share with many other people who have obvious physical disabilities. More
often than not, people with physical disabilities are the only members of their families who have an obvious disability (Beck, 2006; Canary, 2008b; Conway & Meyer, 2008; Fitzgerald, & Kirk, 2009; Mason, 2004). This reality makes the experience of growing up disabled different from the experience of growing up as a member of other groups who have minority status. For example, if an individual is an African American, chances are they would be raised by an African American family. African American children will have role models who can help guide them through the difficult experience of being Black in American society. Most people with obvious physical disabilities are born into families in which they are the only person with a disability. Therefore, individuals like me do not have any family role models that know what it is like to be disabled (Mason, 2004; Shakespeare, 1999; Sherry, 2004).

Hence, families tend to raise their children with disabilities in accordance with the values and norms of the able-bodied world (Mason, 2004; Nemeth, 2000; Shakespeare, 1999; Sherry, 2004). As Nemeth (2000) asserts, these able-bodied values and norms "can be very limiting" for people with disabilities (p. 38). Families may view a disability as a roadblock to a normal life. Therefore, they may create a script that pushes the disabled family member to be as close to able-bodied as possible (Atwood, 1996; Byng-Hall, 1995; Darling, 2003; Gill, 1997; Mason, 2004). In her qualitative study of working women who have disabilities, Mason (2004) discovered that many disabled women often feel pressure from family members to meet an able-bodied standard of normalcy. She states:
Some had to overcome undue pressure from parents to be "normal". One woman had to fight her parents' opposition to her using a wheelchair, even though it provided her with greater freedom and mobility. They felt she was "giving up".

(p. 8)

Normalcy is the Goal

To Walk or Not to Walk

I now provide an example from my experience in order to demonstrate how families can pressure people with disabilities to be normal. At various points in my childhood, I used a wheelchair, walker, and crutches in public. At home, I would crawl around on my knees. By the time I was eight years old, I had become pretty adept at crawling, and could move around my house quite quickly.

My parents did not like the fact that I crawled around on the floor. They felt I should walk with a cane when I was inside. So they purchased a cane for me to use inside the house. Moreover, if I crawled, my mom would ask, "Where is your cane? You should not crawl. You need to walk in order to strengthen your legs." My dad would sometimes get frustrated and would say, "Stop being lazy. Use your cane and walk. You are not a dog." His message was clear to me; people walk and animals crawl. Thus, in order to be treated as a person I would have to make the effort to walk with my cane.

My parents inculcated in me the notion that if I did not make the effort to walk with a cane in our house, I was being lazy. They believed it was important for me to walk. They wanted me to be as strong and as mobile as I could be. They pushed me to
walk with a cane because they loved me, and they thought walking was better for me than crawling.

By encouraging me to walk with a cane, my parents were creating a family script that told me that I should try to be as normal as possible. I should try to walk at all times, because walking is what "normal people" do. Scolding me when I did not use a cane was a not-so-subtle way of telling me that crawling was abnormal. To my parents, I had the ability to walk, so choosing not to was just plain lazy. Crawling was taking the easy way out, and that was unacceptable.

Even though my parents scolded me, I would still crawl despite their admonishment. I was not intentionally trying to disobey my parents. It was just so much easier to crawl than it was to walk. Walking took a great deal of effort and concentration. Walking did not come naturally to me, but crawling did. Crawling was also faster than walking. Therefore, I chose to crawl because it was easier than walking. I liked to crawl, because I did not have to think about it, I could just do it.

Even though I frequently chose to crawl, I felt conflicted about my choice. I would think, “I should walk with my cane so I don't look like a dog because I am crawling on the floor.” Sometimes I would even tell myself, “Okay, I'm going to start using my cane all the time when I am inside.” I would then use my cane extensively for a couple of days, but ultimately I would revert back to crawling. I would feel guilty about it, but would do it anyway. I could never consistently make myself use a cane inside. Then, I would feel guilty and think, man, I need to have more willpower. I can do this. I just have to want to do this.” I would also think; “If I want to walk on my own someday, I
need to work harder. I need to practice walking so that someday I can walk on my own without any crutches.”

I never really understood why even though I felt that I should walk with a cane, I did not do it. I was choosing to be disabled by crawling, and I felt bad because I was making that choice. Yet, I could never get to a place where I would walk all the time. I thought it was simply a matter of making the choice to walk or crawl.

However, as I reflect on this from a scholarly perspective, I realize that it is not that simple. My choice to crawl instead of using a cane was not a simple either/or choice. Instead, it was a decision that was replete with multivocal contradictions. As discussed in Chapter Two, multivocal contradictions are opposites that expand the concept of dialectical tensions beyond a binary structure (Baxter & Montgomery, 1996; Suter et al., 2006).

There was tension between the rhetoric of our family's script, and the physical reality of my impairment. This script encouraged me to walk whenever possible because that is what normal people do. However, my cerebral palsy made it difficult for me to walk without a great deal of concentration and effort. Therefore, I often chose to crawl because it came easy to me, whereas walking did not. Our family script encouraged me to walk at all times, but the physical reality of my cerebral palsy made walking difficult. While there was a tension between the rhetoric of our family script, and the physical reality of my impairment, there was also a conflict between my parents and me. My parents wanted me to walk, but I chose to crawl. This tension was a conflict between their
feeling that I should walk on the one hand, and my desire to make things easier for myself on the other.

Moreover, even though neither I, nor my family was aware of it at the time, there was a tension between the world of people who are able-bodied, and the culture of people with disabilities. This conflict occurred because my parents were promoting the norms and values of the able-bodied culture. Conversely, my decision to crawl was a decision based on my reality as a person with a disability. Part of the unique way of life that binds people with disabilities together is the fact that people with disabilities must frequently adapt to a world that is designed for the able-bodied (Gill, 1999; Linton, 1998; Longmore, 2003; Siebers, 2008). Linton describes this phenomenon as "a creative response to atypical experience" (p. 5). Even though I did not realize it at the time, my decision to crawl was a response to the experience of being disabled in an able-bodied household. Yes, I wanted to be seen as normal, but my decision to crawl illustrates the way in which my reality was different from my able-bodied parents. I chose to crawl despite my internal misgivings, because it worked for me.

Conversely, my parents’ perspective came from their experience as members of able-bodied culture. For them, my decision to crawl was not an adaptation. Instead, it was a sign of failure, because I was choosing to be abnormal. This example illustrates that my reality as a person with a disability was coming into conflict with their experience as individuals who were able-bodied.

Not only was their cross-cultural tension in this instance, there was also a tension underneath the surface of my family script between the power of the script itself, and my
ability to resist that script. Disability as a unique lived experience is often fraught with the tension between social factors that marginalize a person's disability, and an individual's ability to act as a causal agent in their own life (Berger, 2009; Juette, & Berger, 2008; Shakespeare, 2006). My family’s script presumed that I needed to overcome my disability in order to lead a normal life. Therefore, my parents did not want me to act disabled. Yet, my decision to crawl instead of using a cane demonstrates that I had some power to resist my family's script. The family script did have an impact on me, but, at least on a subconscious level, I resisted my family's standard of normalcy in this case. This demonstrates that while family scripts have a powerful influence in the lives of many, it would be a mistake to assume that individuals do not have the ability to resist those scripts.

**Don't Play the Tiny Tim Card**

Encouraging me to walk was one way that my parents promoted a script of normalcy. They also promoted this script by telling me that I should not use my disability in order to get special treatment. I now provide an example to explain.

My Dad and I went to the local IGA supermarket in our hometown of Johnstown, Ohio. Johnstown is a fairly small town about a half-hour northeast of Columbus. The IGA supermarket was a stereotypical small-town grocery store where everybody knew everybody else. Every time we went into the store, the store's owner, Bob Reed, would stop and talk to my Dad and me. I would use this to my advantage. When Bob would stop to say "hi" I would make the most pathetic looking face I could muster. This was my
attempt to get sympathy from Bob, because every time he felt sorry for me, he gave me candy. I did not care too much about the sympathy; I just wanted the candy!

One day when I was six, Bob stopped to say “hi” just as he always did. I proceeded to make my pathetic face just as I did on every visit. Finally, my Dad had enough. He told Bob, "Don't give him any candy. He is taking advantage of you." Needless to say, I left the store without any candy.

When we left the store, my dad let me have it. In a stern tone he said, "Stop playing the Tiny Tim Card! You cannot use your disability in order to manipulate people. You are not special just because you are disabled. You are just like anyone else, now start acting like it. I expect more from you. Are we clear?" I understood that tone in my dad's voice. He meant business. I knew that I had crossed a line that was unacceptable. This incident truly impacted me. I had learned my lesson, and I would no longer try to use my disability in order to get sympathy. In fact, this incident affected me to such an extent, that I came to believe it was wrong to use my disability to get anything.

My dad's reaction left a lasting imprint on how I saw my disability. I have always been close to my dad, and have tried very hard to live up to his expectations. Therefore, when he said he expected more from me, I felt like I needed to meet his standards. After this incident, I vowed that I would never use my disability in order to get special treatment again. In one sense, this personal vow was positive, because I no longer used my disability in order to manipulate people. In another sense, this promise was unrealistic, because sometimes as a person with a disability I needed special treatment.
There was a contradiction between the promise that I would not “use my disability,” and the reality that I did need help with certain tasks because of my disability. I knew that using my disability in order to get free candy was inappropriate behavior, and I knew better than to play the “Tiny Tim Card.” Yet, I was not clear on the difference between playing the “Tiny Tim Card,” and asking for help because I really needed it. I knew that “using my disability” in order to get candy was wrong, but wondered whether “using my disability” in order to obtain a handicapped parking pass was also wrong. I was never quite sure when it was okay to use my disability to get help that I needed. This made it difficult to ask for help, because I was never sure if I really needed it, or even deserved it.

**When Should I Use My Disability?**

On one level, I wish that my dad had explained the difference between "using my disability" in an inappropriate way, and "using my disability" in a proper context. I was not clear on the difference, because he sent mixed signals to me. For example, when I was eligible to qualify for a Social Security entitlement under the Supplemental Security Income (SSI) program; my dad was excited. He said, “This is great, play the disability card and get all of the free money that you can.” At the time, I remember feeling guilty because I was applying for a welfare program. I can remember thinking, man; I should not be getting welfare. It is wrong that I get free money from the government because I have a disability. Furthermore, I had been taught by my dad that I was not supposed to use my disability in order to get special treatment. However, when I qualified for SSI payments, he thought “using my disability” was okay. I was shocked that my dad, a man who lectured me for using my disability in order to get free candy, was excited that I was
going to get free money from the government. This contradiction did not make sense to me.

However, I have come to realize that this contradiction demonstrates the complexities of living with a disability. As discussed in Chapter Four, it is not clear whether people with disabilities should disclose their disability when applying for jobs. The struggle to decide whether to disclose a disability when applying for jobs illustrates the complexity of "using one's disability". Sometimes it is deemed inappropriate to "use a disability" while at other times it is acceptable to "use a disability".

Therefore, as I reflect back on why my dad never clearly stated the difference between playing the “Tiny Tim Card”, and special treatment that was acceptable; this is a confusing topic. Moreover, my dad probably did not realize that I internalized the incident that occurred at Bob Reed's grocery store to such an extent that I would not know when it was okay to ask for help in other situations. I never shared my confusion with him. So, how would he know? In addition, from his perspective there is a clear difference between manipulating a store owner in order to get candy, and applying for welfare. It probably never occurred to my dad that he needed to explain the distinction to me.

This also illustrates the complexity of family scripts. Part of my family's script was that I was not allowed to use my disability in order to get special treatment. In 2007, my brother Tim and I had a conversation about our childhood, and he shared the following thought, "I think one of the reasons that you are successful now, is because no one in our family let you play the crippled card in order to get special treatment." It was
part of our family discourse that I was not allowed to use my disability. However, in reality, there were times like when I applied for Social Security, that I was encouraged by everyone in my family to play the disability card so to speak.

**Am I Normal or Abnormal?**

This contradiction illustrates the tension that was present in my identity. On the one hand, I viewed myself as normal. I wanted to be just like everyone else. On the other hand, I always saw myself as different from everyone around me. There has always been this tension between abnormality-normality present in my identity. As I examine my family's rhetoric about my disability, I realize this tension also existed in our family script. The reality of my disability meant that it was impossible for my family to create a script in which I was completely normal. In my family’s script, normalcy was the dominant theme, but there were also contradictions that reinforced the idea that I was not normal.

It was also difficult for me to live up to the standard of normalcy that I subconsciously internalized. My parents encouraged me to be normal because they wanted me to believe that I could accomplish anything; whether it was academically, athletically, or otherwise. My brother Tim described it this way, “We saw you as normal. You were good at school. You played sports. Basically you did everything growing up that Billy and I did. You weren’t really any different.”

Even though my family saw me as normal, I never felt that way. I always believed that I fell short of the standard of normalcy they created. However, as I reflect on it now, I do not think my family ever felt that I was not “normal” enough. Everyone in my family
is proud of my accomplishments. They never said I was not normal enough. Yet, I internalized my family’s script of normalcy to such an extent that when I failed to achieve that standard of normalcy, I felt like a failure.

The problem was my reality did not fit the idealized version of my family’s script. I was trying to live up to an impossible standard. My experience is not unique in this regard. Many individuals internalize idealized versions of a family script, and then fail to meet its impossible standard (Atwood, 1996; Byng-Hall, 1995; Terry & Campbell, 1995). In such a case, a person with a disability may develop a negative self-image, because he or she cannot meet the perceived standard of normalcy (Atwood, 1996; Byng-Hall, 1995; Gill, 1997; Mason, 2004; Shaw, 1994).

Moreover, I did not share my feelings; I simply tried harder to overcome my disability. I was in the stage of identity development that Gill describes as coming to feel we belong, and I did not consider sharing my feelings of failure with my family. Being normal was what I thought everyone expected of me. It never crossed my mind to say, “Hey I can’t do this. I can’t be normal. I will always be different. That is just the way it is.”

My family viewed me as successful because in their eyes I “overcame” my disability and lived a “normal” life. For example, when I graduated from Ohio University as an undergraduate my Mom stated, “I am so proud of you. You have worked hard. You never let your disability stop you. You set a goal, and overcame your disability to achieve it, and now you have two degrees.” Part of my Mom’s comment was simply the pride that most mothers have when their children accomplish something, but she was also proud
because graduating from college validated that I was “normal”. In other words, it validated the family script.

Moving Beyond the Family Script

Coming Out and Shocking My Family

The process of coming out and embracing my disability was a shock to my family. However, I did not realize how much until I had a conversation with my brother Billy. We were in the kitchen of my parent’s newly built house near Mount Vernon, Ohio. I was seated in a chair at the far end of the kitchen table, and Billy was standing with his face towards me with his back leaning against the kitchen sink. We were discussing my research, and all of a sudden Billy asked, “How come you’re so militant about your disability now?”

As I mentioned previously, Billy likes to challenge me; so I am used to him asking provocative questions. However, I was stunned at this question. I had come out and began to openly assert my disabled identity, but I did not consider myself militant. So I asked, "What do you mean when you say I am more militant now?’’

He responded, “Well you talk about your disability a lot now, and you never used to talk about it. When we were kids it was no big deal that you had a disability, so why does it matter now?” I was stunned by his assertion that my disability was no big deal. I sat back in my chair and firmly answered, “When we were kids I tried to minimize my disability. I tried to fit in and pretend like my disability did not matter, but truthfully it has always been a big deal. It’s just now I am openly acknowledging that my disability is an important part of who I am.”
I think this response shocked my brother because he insisted, “You are not that disabled, so why does it matter? I don’t see you as disabled. I mean in my job as a nurse I have seen people with a lot worse disabilities than yours. Your cerebral palsy is fairly mild.”

I fired back, “Yes, my CP is mild compared to others, but that misses the issue. The issue is not that I have the most severe type of CP; the issue is that as a person who travels through life with an obvious physical disability I am stigmatized by society. Therefore my disability makes me a minority. I don’t see myself as militant simply because I am proud to say I have a disability.”

Billy responded, “I hear what you are saying, I just don’t think your disability is a big deal.” I answered, “I understand that you feel that way. I guess we will have to agree to disagree.” At that point, we decided to switch topics and discuss something else.

This conversation was another turning point for me, because it opened my eyes to the fact that my family views my disability differently than I do. At first, I was stunned that Billy had trouble understanding my disability. Shortly after this exchange, I shared my shock with one of my professors. I said, “I am shocked that my brother does not understand how important embracing my disability has been for me. I feel like I am happier and less militant than I have ever been.” Furthermore, I was frustrated because I felt that my brother should have understood. I would think, “Man why doesn’t he get it. It’s irritating. I wish he understood.

As I reflect on the incident now, I realize that Billy was trying to understand my changing perspective. Growing up, I always tried to live up to the standard of normalcy
that was part of our family script. After I *came out* I began to openly assert that I was not normal. In short, I began to openly reject the family’s script. Our conversation was Billy's attempt to understand why I have changed my perspective. I am sure my choice to embrace my disability was a shock, because I began questioning my family’s perception of my disability.

### Able-bodied People Don't Understand Me

I have come to believe that while he loves me, Billy does not understand my experience as a person who has an obvious disability. He sees my disability as a minor part of who I am. Conversely, I think my disability is a significant part of my identity. My experience in that regard is not unique. Frequently, people with disabilities encounter family members who try to minimize their disabilities (Gill, 1997; Linton, 1998; Mason, 2004; Shapiro, 1994;). As Shapiro (1994) explains, “Nondisabled Americans do not understand disabled ones” (p. 3). Shapiro further argues that many people with disabilities encounter a “clash” between their reality as disabled people on the one hand, and “the understanding of their lives” by people without disabilities on the other (pp.3-4). In fact, it is often the able-bodied people who are closest to individuals with disabilities who do not understand the reality of living with a disability.

Mason (2004) illustrates that when people choose to openly embrace their disabilities it can create tension between those individuals and their able-bodied family members. In one example, Mason interviewed a woman named Debbie who was born with cerebral palsy. When Debbie began to embrace disability culture she no longer felt the need to live up to her family’s standard of normalcy. Debbie even felt animosity
towards her mother because Debbie's mother always pushed her to be normal. Debbie also felt that her family did not understand her choice to embrace disability culture.

My experience is similar to Debbie’s, because I also reached a point where I no longer felt compelled to live up to my family’s standard of normalcy. I also rejected my family script. Furthermore, there is a tension between my family and me because of that choice. This is because it is difficult for my able-bodied family members to move beyond the script they have constructed about my disability. This is a common experience for many people with disabilities (Atwood, 1996; Byng-Hall, 1995; Mason, 2004; Terry & Campbell, 2009). When someone begins to embrace a disability, it alters the way that he or she will interact with family members. In turn, this change can be scary for some able-bodied family members. I now provide an example from my own experience in order to illustrate this point.

**My Mom Attempts to Understand My Identity**

In the summer of 2008, my mother came to Ohio University for a short visit. We ordered lunch from Kentucky Fried Chicken and visited with one another. While enjoying our chicken, potato wedges, and biscuits, we began discussing my research. My mom asked, "How is your dissertation going?" I responded, "Fine. It is fun for me to compare how I used to view my disability with how I view it now. It is such a relief not to have to live up to being normal. Realizing that I was never going to be normal was like having a weight lifted off my shoulders." Mom looked at me with shock. She responded, "You are normal. You may walk on crutches, but you are living a normal life."
I was biting into a piece of grilled chicken. As I chewed my food I can remember thinking, she doesn't get it. I told her, "Mom I am not normal, because people treat me different because I have a disability. I also walk on crutches, and that is not normal. But you know what? That's okay. I don't have to be normal."

She took in my words, and I could tell that she was having trouble processing what I was saying. All of a sudden, she got a serious look on her face, and said, "When you were growing up we treated you normally, because we wanted you to have a normal life. And now look at you. You are in grad school, you live on your own, and you have a girlfriend. That is normal to me."

My mother's words hung in the air. There was a feeling of tension in the room. I gathered my thoughts and responded, "Mom, it's okay that I don't feel normal. I have a disability, and that gives me a different perspective on the world around me." I pondered what to say next, and then continued, "One of the reasons that I am writing this dissertation is to let people know that they do not have to overcome their disabilities. They don't have to struggle to fit in to a standard they can never live up to. I know that you see me as normal. I get that, but I want you to understand that I don't consider myself normal. And I'm okay with that."

Mom slowly munched on a biscuit while she took in my words. A look of concern came over her face as she said, "I guess I'm afraid to read your dissertation. I'm afraid if I read what you have to say about our family and your disability it will change our relationship. I see you as normal, but you see yourself as abnormal because of your disability. I don't understand that."
I looked Mom in the eyes and tried to assure her, "Mom you do not have to be scared. I love and respect you, and I am grateful for the way you and dad raised me. I will always be your son. It is okay that you and I see my disability differently." She responded, "I know we see it differently, and that is what scares me. I know as you continue to explore your disability that our relationship will change."

As I reflect back on this conversation, I am struck by Mom's assertion that she was afraid because she couldn't really understand the way I view my disability. Initially, I was frustrated by her unwillingness to accept the fact that I am not normal. I can remember thinking, “Man; I wish she understood where I am coming from.” I wanted her to embrace the idea that I am not normal, but she seemed unable or unwilling to do so. This frustrated me to no end. I wanted to scream at the top my lungs, "Get over it! I am not normal, and that is that!"

However, as I examine this exchange between us from a scholastic perspective, I recognize the complexity of this issue. From my mom's point of view, she is afraid of losing the relationship we have. Thus, when I tell her that I am not normal, it illustrates that my disability is part of a world that she cannot understand, and she thinks this will cause us to lose part of our relationship.

This example demonstrates a difficult way in which I have to negotiate my identity. I need to assert my membership in disability culture without devaluing the able-bodied people who I love. I also need to be cognizant that my mother is afraid my engagement with disability culture will somehow devalue our relationship. Hence, I often
pick and choose when and how I will embrace my disability when she is present. I also
need to accept that my family may not understand my choice to embrace my disability.
This negotiation is the reality of trying to live in both the world of the able-bodied and
the culture of disability. I need to accept that even though I have been able to move
beyond our family script, not everyone in the family will reach that point. Moreover,
even though my family may not completely understand my identity as a person with a
disability, they still love and support me completely, and that love and support is all I can
ask for.

**Romantic Relationships and People with Disabilities**

**Romance and Identity**

While my relationships with family members greatly impact my identity
development, my relationship with my able-bodied girlfriend Jane also significantly
affects my identity. Therefore, it is important for me to further explore this relationship. It
is to that examination that I now move.

I am exploring my romantic relationship with Jane because the ability to engage
in romantic relationships is an important influence on identity for all people, including
those who have disabilities (Axtell, 1999; Davies, 2000; Moin, Duvdevany, & Mazor,
2009; Ostrander, 2009; Tepper, 1999). The search for a romantic partner is an important
quest in the lives of many people with disabilities (Axtell, 1999; Davies, 2000; Howland,
2001; Fiduccia, 2000; Shuttleworth, 2000). As Gill (1996) explains:

Establishing intimate relationships is a goal that is often highlighted in the stories
that women with disabilities tell about our lives. In this respect we differ little
from men with disabilities or women without disabilities. The quest for the
“right” partner is unmistakably embedded in the American dream that touches us
all. (p.183)

Therefore, in order to understand the identity development of people with
disabilities, it is important to examine their ability to engage in romantic relationships.
Unfortunately, the sexual desires of people with disabilities are often ignored by people
who are able-bodied (Axtell, 1999; Davies, 2000; Gill, 1996; Howland & Rintala, 2001;
stereotypes oppressing disabled people is the myth that they do not experience sexual
feelings or that they do not want to have sex” (p.138). Therefore, by exploring my
relationship with Jane I am not only interrogating a relationship that has a significant
influence on my identity development, but I am also contesting the notion that people
with disabilities are not sexual beings.

Issues related to romance and sexuality are difficult for many people with
disabilities to confront (Fiduccia, 2000; Guldin, 2000; Howland & Rintala, 2001; Joseph,
1991; Ostrander, 2009; Shuttleworth, 2000). As Shakespeare (2000) concludes:

Talking about sex and love relates to acceptance in a very basic level--both
acceptance of one’s self, and acceptance by significant others—and forces people
to confront things which are very threatening given the abusive and isolated lives
of many disabled people. (p. 160)

For instance, until I met Jane, I had not had much luck in the romance department.
I did not date when I was in high school. When I was teenager my inability to
successfully date was a major source of my unhappiness. My experience is not unique in this regard. People with disabilities often do not have the opportunity to date during adolescence. This inability to date frequently has a negative impact on the self-image of those with disabilities (Berger, 2009; Chance, 2002; Engle & Munger, 2003; Mason, 2004; Rapp, 2007).

**You Won’t Date Until College**

My mother understood that my disability might make it harder for me to date. Therefore when I was 12 years old she sat me down and we talked about dating. She said, “Look, I know you are starting to become interested in girls. Here is the thing. Girls at this age are not very secure, so most girls probably won’t want to date you because of the fact that you are disabled.”

As I was listening, I was not sure what to make of what she was saying. My whole life, my mom instilled in me the idea that I was normal. Yet, here she was telling me that I would probably not be able to date because I had a disability. I can remember thinking, “Man this sucks.”

I sat there in silence trying to figure out what this meant as my mom continued to dispense her advice, “You may not be able to date girls while you are in school, but when you get to college it will be different. College girls will look past your disability.” I sat there shocked, and then I asked, “You mean I will have to wait until college before girls will want to date me.” Mom responded, “Yes, but it’s not about you, it’s because girls at your age can’t really see past your disability, but when you get older it will be different.”
I was not sure what to think. Here I was 12 years old, and my mom was telling me I have to wait until I graduate from high school before girls can look past my disability. I remember thinking, man, “I must really be a freak if no girl is going to want to date me until I graduate from high school.” Needless to say, my mother's attempt to prepare me for the harsh reality of dating did not do much for my self-esteem.

Because of this conversation I went into the dating world assuming that people were automatically going to reject me because I had a disability. Furthermore, when a girl would reject me, I would say, "She is just shallow. She is only refusing to go out with me because I am disabled." One of the reasons I never dated in high school was because I automatically assumed girls could not look past my disability. I expected girls to reject me. Moreover, I always assumed it was because of my disability, and not because of my attitude or disposition. I always blamed the girls who rejected me for being shallow.

Truthfully, girls rejected me as a teenager not because I was disabled, but because I did not have any self-confidence. I was angry and bitter. Who wants to date a guy with low self-esteem that is always angry? Furthermore, a lack of self-confidence is a common problem for many people who have disabilities. For example, Shakespeare (2000) states:

If you feel good about yourself and project that self-assurance it is far more likely, whatever you look like, that others will take you seriously and see you as a potential partner. Yet disabled people, systematically devalued and excluded by modern Western societies, are often not in the right place to begin that task of self-love and self worth. (p. 161)
Thus, even though my mom was trying to prepare me for the harsh realities of being a teenager with a disability, our discussion only contributed to my negative self-image. In fact, when I first began to reflect on this discussion I was angry at my mom. I thought, how could she tell me this? I mean, to tell your child that girls are not going to date you is not a good idea. How can she not see that? However, now I have taken a more nuanced stance.

Yes, it was very difficult to hear my mom's advice about dating. But, it was just as difficult for my mother to say it, as it was for me to hear it. In a recent phone conversation my mother explained, "I had to talk to you, because I felt that things would be difficult for you when it came to dating. But I did not know what to say. What do you say to your son who has a disability? I did not want you to feel bad about yourself. I wanted to tell you that if girls didn't date you, it was not the end of the world. I also wanted you to know that things would get better."

I listened to my mother's words, and a new awareness came over me. I asked, "How did this conversation make you feel." She very quickly responded, "It was the hardest thing I've ever had to do as a mother.” As I processed her words, I understood the difficult position that my mother was in. I had no right to be angry with her.

Yes, the conversation had a negative impact on my self-image, and perhaps my mom could have taken a different approach, but I admire the fact that my mom had the courage to have the conversation with me in the first place. She felt that she needed to address the issue, and she did it the best way that she knew how to at the time. As her son, the fact she confronted the issue with compassion and courage is all I can ask for.
A Self-fulfilling Prophecy

Mom's words did become a self-fulfilling prophecy. I never dated in high school. I felt like a loser because I did not have a girlfriend and many of my able-bodied peers did. My teenage years were a very lonely and isolating time. I was too ashamed to attend high school dances, so I never went to homecoming or prom. Ultimately, I blamed my disability for my unhappiness.

After I graduated high school, I expected things to change. When I got to Ohio University as a freshman I expected dating to become easier. Mom told me that when I got to college, I would find a girl who would date me. Yet, dating during my college years remained frustrating. I was able to go on dates with various women, and I even had sexual relations with a few. However, I wanted more than just sex and a few dates. I wanted to be in a committed relationship with a woman. Despite my best efforts, I could never find someone who was willing to be my partner.

Again, I blamed my disability. I remember thinking, sure some women will sleep with me, but they do not want a serious relationship with someone who is disabled. I wish I could find someone who could look past my disability. I wanted to date a woman who saw me as normal. From the time I entered college at the age of 18, until I came out as a person with a disability at the age of 27, I struggled to find a woman who would take me seriously as a potential partner.

During this period, I thought my disability was the reason that I could not have a long-term romantic relationship. Conversely, I now realize that women did not want to be with me because I was not sure who I was. I wanted women to ignore my disability even
though I could not. I also thought being in a romantic relationship would make me happy, but now I know that I needed to become happy before I could become involved in a serious relationship. I was not comfortable with my disability, which made it impossible for women to be comfortable with my disability. What I now understand is in order for me to be involved in a serious committed relationship; I needed to be comfortable with my disability.

Jane

To Date or Not to Date

It was not until I began to embrace my disability that I found Jane. I met her in January 2006, after I began my coming out process. Since I started to embrace my disability, I no longer wanted a woman who would ignore my disability; instead I wanted a partner who would understand that my disability is a vital part of who I am as a person. Thus, coming out enabled me to be comfortable with who I was, which in turn allowed me to become involved in a serious relationship.

During the past four years, Jane and I have engaged in a cross-cultural relationship. Since Jane is able-bodied, and I have a disability, she and I have to negotiate our existence in two separate worlds; the culture of people who are able-bodied, and the culture of people who are disabled. Engaging in a cross-cultural relationship impacts our identities. In February 2008, and October 2009, Jane and I conducted joint presentations that explored the way we negotiate the cultural differences in our relationship. During these talks, Jane spoke with deep passion and profound insight. Her words illuminate our
relationship and its impact on my identity. Hence, I use Jane's words in order to interrogate our relationship.

We met on the social networking site Facebook. I was attracted to her picture, and the fact that she claimed to be a singer on her profile. I thought she was cute, and she seemed interesting, so I sent her a message. I said, “I promise I am not a weird stalker. You seem interesting, and I would like to get to know you. If you are interested, write me back.” She did, and we began communicating over the Internet. Then after a short while, we began talking to each other on the telephone. From the beginning of our relationship, I told Jane that I had an obvious physical disability, and I used crutches.

Our early conversations seemed to go well, but Jane was not sure whether or not she wanted to date someone who had a disability. During a presentation in 2008 she explained:

When Cort told me he had cerebral palsy, I did not know what to think. I didn't really know what cerebral palsy was. I never really thought that I would ever date someone who had a disability. But Cort was a nice guy so I decided to keep talking to him. (J. Hoyt, personal communication, February 14, 2008)

A couple of weeks after we began to talk on the phone Jane and I decided to meet in person. I was excited and nervous at the same time. Despite the fact that I had disclosed my disability, I was not sure how Jane would react when she saw me. Intellectually knowing that someone has a disability is one thing, but physically seeing how that disability impacts someone is another. I remember thinking; I hope she does not get freaked out when she sees me on crutches. While Jane was not completely freaked out
by my crutches, she does openly admit, that the first thing she noticed was my disability, “When I first saw him, my eyes went right to his legs. I could not help but notice how small his legs were.” (J. Hoyt, personal communication, February 14, 2008).

Moreover, once we went up to my dorm room Jane was not sure what to think. She explains, “His room was really messy and I did not know whether that was because of his disability, or because he was a slob” (J. Hoyt, personal communication, October 12, 2009). I thought that Jane was gorgeous, and I was attracted to her personality, but I could tell that she was not sure about me. She admits, “I was attracted to him, but I was not sure about the whole thing. It was a little overwhelming” (J. Hoyt, personal communication, October 12, 2009).

Initially, she was not sure she wanted to be in a relationship with someone who had a disability, and she shared her uncertainty with her friends and family, “I talked to my mom, dad, and friends. I told them that I was not sure I could date someone who had a disability” (J. Hoyt, personal communication, February 14, 2008). Jane made her feelings clear to me. In order to be with me she wanted to know more about my disability. She wanted to learn what exactly my limitations were. She admits she had a lot of questions:

Would his disability get worse as he got older? How able is he to do things? What exactly is cerebral palsy? Is it hereditary? What would sex be like? I just had a bunch of thoughts swirling around in my head. (J. Hoyt, personal communication, February 14, 2008)
The Disability Date

Jane’s uncertainty about becoming involved in a relationship with someone who has a disability is a common feeling for people who are able-bodied (Fiduccia, 2000; Guldin, 2000; Howland & Rintala, 2001; Joseph, 1991; Ostrander, 2009; Shuttleworth, 2000). Therefore, in order for our relationship to progress, I had to address Jane’s questions about my disability. This meant that I had to disclose very personal information early on in our relationship. Braithwaite and Harter (2000) argue that the issue of disclosure is a particularly complex problem for people with disabilities. Braithwaite and Harter contend the process of disclosure is a dialectical tension between openness-closedness. In other words, as a person who has a disability there is pressure to be open about your disability on the one hand, and a desire to maintain privacy on the other.

This tension is very significant in Jane and my relationship. I knew I had to be open with Jane, but I was also thinking, I don’t want to disclose too much about my disability, because that might scare her away. However, I decided that I would tell Jane whatever she wanted to know. So on our third date, we had what I call a “disability date.” On this date, Jane could ask me whatever she wanted about my disability. No topic was too personal or off limits. I think this disability date did establish a level of openness and trust between us. That does not mean that our relationship has not had its ups and downs, but we know that we can be open and honest with each other. While the disability date did create an atmosphere of openness in our relationship, talking about these personal topics added a level of intensity to our relationship. Jane states:
Talking about these topics was good because it opened our relationship up, but it also put our relationship on fast forward. I mean I was asking Cort what his disability would mean if we got married. We were talking about marriage and kids on our third date. It made our relationship very serious very early. (J. Hoyt, personal communication, October 12, 2009)

The disability date created a situation where we felt that we were in a serious committed relationship from the start of our relationship. We were just getting to know each other, and we have already talked about marriage and kids, and various ways that my disability might impact our future. This made our relationship intense.

**Stability and Change**

While there was a tension between openness-closedness, there was also a tension between stability-change. Braithwaite and Harter (2000) describe the dialect of stability-change as the “comfort of stability in relationships” on the one hand, and the “freshness of uncertainty” on the other (p. 29). From the start, Jane and I were trying to figure out the impact of this dynamic. One reason this tension is so significant is because I am not sure how my cerebral palsy may impact me differently as I age. As Jane states:

I wonder what it will be like as our relationship progresses. What will happen when we have kids? I wonder to myself, what will our relationship be like when Cort becomes less mobile? I not only wonder what the impact will be on me, but also I am curious how Cort will react to his disability when his body changes and he becomes less able to do what he does now. (J. Hoyt, personal communication, October 12, 2009)
Jane’s words demonstrate that below the surface of our everyday interaction there is always a level of uncertainty about our future. While I realize that every relationship has a certain amount of uncertainty, we experience this reality in a more pronounced way because of my disability. All we can do to deal with this uncertainty is love each other, and continue to meet the changes in our relationship with compassion and honesty. I may not know what changes my disability will bring, but I know I want Jane by my side as I deal with those changes.

**Autonomy and Connection**

While there is a dialectical tension between stability-change within our relationship, Jane and I must also negotiate the tension between autonomy-connection. Braithwaite and Harter (2000) argue that the dialect of autonomy-connection is “perhaps the most salient for the relationships between persons who are disabled and those who are not, as all parties seek to manage the need to be simultaneously independent and dependent on one another” (p. 21). Jane and I have had to manage this tension from the start of our relationship. Part of Jane’s uncertainty about whether or not she wanted to date me, occurred because she was unsure how independent I could be. She states, “I did not know what he could do and not do for himself, I was afraid that I might have to do everything for him” (J. Hoyt, personal communication, February 14, 2008).

Jane’s concern is a common one among many able-bodied people who decide to engage in romantic relationships with people who are disabled. Often able-bodied partners fear their disabled partner will be dependent on them (Berger, 2009; Gill, 1996; Juette & Berger, 2008; Mason, 2004; Nemeth, 2000). Furthermore, Nemeth (2000)
indicates that able-bodied women often feel an “added sense of responsibility” for their disabled partners (p. 43). These women often express “uncertainty about what their own rights are within the relationship” (p. 44). For example, Jane admits that it took her a while to get past the idea that she had to do everything for me. She asserts:

For a long time I felt like I had to do everything for him. I felt that I needed to help him all the time. It was exhausting. Cort would tell me you don’t have to do this, you’re my girlfriend not my caregiver. However, even though he would tell me I did not always need to help him, I still felt that I should. Finally, I got to a point where I realized that it was not my job to do everything for him, and Cort is independent and can do a lot of things for himself. (J. Hoyt, personal communication, February 14, 2008)

I did not want Jane to think of me as a burden. So I tried to be as independent as I could. I wanted Jane to see that even though my disability is an important part of who I am, it does not make me helpless. After a while, she began to realize that I may need help with certain tasks, but there are many things I can do on my own.

In addition, we manage the dialect of autonomy-connection by moving beyond able-bodied notions of independence and dependence. In able-bodied culture, the construct of personal independence is extremely important. Consequently, people with disabilities are often seen as unfit partners because they need assistance with basic everyday tasks that able-bodied people can complete for themselves (Berger, 2009; Gill, 1999; Linton, 1998; Longmore, 2003; Mason, 2004; Siebers, 2008). In opposition to able-bodied culture, disability culture embraces the idea that interdependence is a fact of
life for everyone (Gill, 1999; Juette & Berger, 2008; Klein, 2004; Linton, 1998; Longmore, 2003). Jane explains the important role that the value of interdependence plays in our relationship. She concludes:

We no longer see each other as independent or dependent. We both know that we are interdependent on one another. We take care of each other; neither of us does more than the other. We just do different things for each other. We know that both of us are going to need help with different things at different times. (J. Hoyt, personal communication, October 12, 2009)

Jane and I manage the tension between autonomy-connection by rejecting able-bodied notions of independence. We both see interdependence as a necessary part of life. Therefore, we can help each other, and still maintain our autonomous identities. Hence, we don't feel burdened by our relationship. We simply try to accept and support one another whenever we can.

**Invisibility and Visibility**

Now that I have explored the way in which the dialect of autonomy-connection impacts my relationship with Jane, I examine the way in which we manage the tension between invisibility-visibility. Up until this point, I have investigated the dialects of openness-closedness, stability-change, and autonomy-connection. Various scholars have previously examined the way these three dialectics impact relationships (Baxter & Ebert, 1999; Baxter & Montgomery, 1998; Braithwaite & Harter, 2000; Goldsmith, 1990; Frame, 2007). There is little doubt that these three dialectical tensions have a significant impact on interability romantic relationships. However, in my exploration of my
relationship with Jane I have discovered another important dialectic that has a significant impact on our relationship.

The dialectic between invisibility-visibility describes the desire to be seen on the one hand, while also having a desire to go unnoticed on the other. Interability couples are often subject to the gaze of others. Frequently when Jane and I go out in public people tend to stare at us. As Jane states, "It gets annoying sometimes when we go out somewhere and people stare because he is on crutches. Sometimes it really bothers me, and I wish that we could blend in like any other couple (J. Hoyt, personal communication, October, 12, 2009). Our experience is not unique in this regard. Being stared at is a reality that is experienced by many people who have disabilities (Callahan, 1989; Fries, 1997; Rapp, 2007; Shapiro, 1994). It happens to me so much that most of the time I do not even notice it anymore.

However, being stared at is a relatively new experience for Jane. After four years, she is still trying to get used to it. Another aspect embedded within the dynamic between invisibility-visibility is the fact that sometimes people only focus on me, and they fail to acknowledge Jane's presences. She explains how this makes her feel:

For example, when we exercise together people focus their attention on Cort, and it's almost like I'm not even there. And I am like, hey what about me? I am working out too. Why do you think he is inspirational? What am I chopped liver? (J. Hoyt, personal communication, October 12, 2009)

Jane is expressing frustration because she is being ignored, and she wants people to notice her. She admits, "I like being the center of attention so sometimes it's frustrating
when people only focus on Cort because he has a disability" (J. Hoyt, personal
communication, February, 14, 2008). Jane wants to be noticed on her own terms, she
does not want to be invisible because she is dating someone who has a disability.
As our relationship progresses, we will continually manage our desire to blend in with
our desire to be noticed. This discussion surrounding the dialect of invisibility-visibility
merely scratches the surface of the complexities surrounding this dynamic. Therefore,
scholars who are interested in the topic of interability romantic relationships should
continue to investigate the dialect between invisibility-visibility.

**Family and Interability Relationships**

**Jane's Mom**

Now that I have explored various dialectal tensions that effect Jane and my
relationship, it is important for me to briefly discuss the impact that Jane's family has on
our relationship. Frequently, able-bodied partners are told by various family members
that dating a person who has a disability will be a burden. For example, Smith (2009)
states, “Family members and friends may freely express doubt and concern of
nondisabled/disabled intimate relationships” (p. 3). Moreover, Smith also contends that it
is difficult for interability couples to “escape the prevailing beliefs about care, burden,
and dependency” (p. 3). Gill (1996) argues that the family members of able-bodied
people who are involved in interability relationships will often assume the able-bodied
partner is the "giver" (p. 187). Family members may also feel that the person who is able-
bodied will be "throwing their life away" by choosing to date someone that has a
disability (p. 187).
Jane's mother was initially concerned that my disability would be a burden on Jane. Jane admits that it was difficult to listen to her mother's concerns. She states, "My mom kept warning me that if I dated Cort I would have to take care of him for the rest of my life. It was frustrating because for a long time my mother was so focused on Cort's disability that she could not see that he also takes care of me" (J. Hoyt, personal communication, February 14, 2008).

Not only did her mom share her concern openly with Jane, but she also made it obvious to me. For instance, we went to Jane's mom's home for a weekend visit. Her mom made the following statement, "Jane's ex-boyfriend was really good with his hands. He was good to have around the house because he could always fix things." I thought Jane's mom was letting me know that I was not suitable for her daughter.

This made me very angry. I remember thinking, who is this woman? She is really ignorant and rude. Needless to say, Jane's mom and I did not get off to a good start. I did not like her, and I do not think she liked me. I thought that Jane's mom was just another able-bodied person who did not get it. I was very quick to judge her, and I did so harshly. Looking back, I realize that I did not treat Jane's mom fairly. I wanted her mom to instantly accept my disability, and the fact that I was dating her daughter. Now I see that my expectations were unrealistic. After all, it took me 27 years to accept my own disability so how could I expect her mom to be okay with it after two days.

Unfortunately, Jane was in between her mom and me. She explains how this made her feel:
It's tough because I felt like I was stuck between my boyfriend and my parents. I wanted my parents to acknowledge that my love for Cort was real. I also needed Cort to be patient. I wanted him to understand that my mom just needed time to get used to the idea that he had a disability. (J. Hoyt, personal communication, February 14, 2008)

I was not convinced that Jane's mom would ever accept the fact that I had a disability. After dating for six months Jane and I broke up, and one reason was her mom. I felt that her mom would never see me as a potential partner for Jane, so I wondered if our relationship was a dead end. Luckily, Jane and I worked through our issues, and got back together. Since we have been back together, I have come to see that I was wrong about her mom.

Jane's mom has moved past her initial discomfort about my disability. She now sees me as a capable person and a good boyfriend to her daughter. She has said, "You have been a really good influence on my daughter, and I am glad that you're with her."

Jane's mom has been able to move beyond the fact that I have a disability, and now she sees me as a capable person. My initial harsh judgments of her were incorrect and shallow.

I now realize that my negative assumptions about Jane's mom came from my own biases. Yes, she had a hard time accepting my disability initially, but I was not very accepting of her either. I quickly assumed she was ignorant and incapable of change. I judged her in a negative way. My relationship with Jane's mom has improved because we have been able to move beyond our incorrect assumptions about one another.
It is important for new interability couples to understand that initially parents or other family members may not approve of the relationship. However, that does not mean those individuals are unable to change. Couples should be patient. Change is possible, but it may take time. It might be unrealistic for the person with a disability to assume that their partner’s family will immediately embrace his or her disability. Yet, with time it can happen. I realize patience is not easy, but it is worth the effort. I am not sure what the future holds for Jane and me, but I know that I love her and her family.

In this chapter I have explored the way in which my identity development has been influenced by important relationships in my life. There is little doubt that my relationships with my family and Jane will continue to have a significant impact on my identity. Now that I have elucidated the importance of relationships in the process of identity development, I move this analysis beyond the scope of personal relationships. In Chapter Six I examine the way in which my identity as a person with a disability has been storied in public discourse. Furthermore, I will investigate how the public discourse surrounding my disability impacts my identity. It is to that interrogation that I now turn my attention.
Chapter 6: Public Discourse, Disability and Identity Development

Disability, What Disability?

As I examine this picture and headline shown in Figure 1, I am conflicted. I appreciate this picture for several reasons. To begin with, it shows me doing something that I enjoy. I like competing in races, and it shows me racing. I think this picture is a good snapshot of my running style. It shows me in mid-stride; my crutches are off the ground, and I have a look of intensity and focus as I am running hard to the finish line. I also take pride in the fact that I am beating somebody. I am a slow runner so it is not all
that often that there is a picture in which I am beating someone. The runner in me likes this picture because it is a good picture of me doing something that I like to do.

On another level, I am annoyed by the headline “Disability, What Disability?” This headline implies that because I am running I am not disabled. I am irritated by this implication because the fact is that I am disabled. I am disabled, and the fact that I run on crutches does not change that. Running does not cure my cerebral palsy. Moreover, the fact that I run does not change the reality that as a person with a disability, I often encounter discrimination.

At this point in my life I do not run in order to overcome my disability. I am proud of the fact that I have a disability, and proud that I run. Those two ideas are not in conflict with one another. I am proud that I run with crutches because the crutches are part of me, and are part of my running style. My disability impacts how I run. Therefore, it is a mistake to imply that because I run I have overcome my disability. That implication ignores the fact that my disability has an important influence on how and why I run.

As I examine this headline and picture from an academic perspective, it is apparent that there are two prominent discourses on display. First, the picture and headline “Disability, What Disability?” promotes the discourse of normalcy. This headline leaves the impression that because I run I am not disabled. This discourse of normalcy disseminated by the media implies the belief that because I run I am normal. The implication is that through hard work I have achieved normalcy. Second, along with
the discourse of normalcy, the discourse of inspiration is present. In part, this headline promotes the idea that I am inspirational because I run on crutches.

When I look at this picture I am conflicted because part of me feels that it is cool that my picture is on the front page of the newspaper. On top of that, the picture is a great picture of me running. However, I am not comfortable with the idea that I am inspiring to others. I do not view my role as providing inspiration to people. I do not think the fact that I run on crutches is inspiring, instead it is simply the way that I run. While I realize *The Athens News* was trying to put forth a positive portrayal of a person with a disability, they unfortunately fell into the trap of promoting the idea that I am inspirational because I “overcome” my disability in order to lead a “normal” life. Headlines like this one reinforce the idea that people with disabilities are inspirational when they strive to meet the standards of normalcy promoted by able-bodied culture.

**The Public Discourse of Inspiration**

Public discourse often frames me as inspirational because I lead a so-called normal life. While this inspirational discourse is often conveyed by the media, I also encounter it when I interact with people on a daily basis. Often it can be frustrating. For instance, in May 2010, I was named the Student of the Year in the Cultural Studies in Education graduate program at Ohio University. I was recognized at the College of Education’s annual awards luncheon, along with many other undergraduate and graduate students. I was only one of the many students who received recognition at this banquet.

After the banquet ended, a man came up to me and said, “You are an inspiration to us all.” I thanked the man for his words, but deep down I was frustrated. On this day, I
wanted to be recognized as a scholar, not as the inspirational person with a disability.

After the man left, I thought, “Why can’t people see past the crutches? I won this award because I am a passionate scholar, not because I happen to have a disability.” I realize that this man was paying me a compliment, but his assertion that I was an inspiration took something away from the moment. In moments like this one I just want to be left alone. I do not want to hear that I am inspirational. I want to be taken seriously as a scholar, and in these moments I wonder whether that will ever happen.

I have to admit that while there are times when being labeled an inspiration is frustrating; there are other times when it has its benefits. For instance, in August of 2007, I ran the Parkersburg half-marathon that is held in Parkersburg, West Virginia. After I finished the race I went to the awards ceremony where the top runners are given trophies and cash prizes. I enjoy watching the athletes receive recognition for their efforts. The awards ceremony is always a nice end to a good race day.

At the end of the awards ceremony, a woman came up to me with an envelope in her hand. I recognized her face because she was the top finisher in her age group, and had received a one hundred dollar cash prize. She walked up and stood next to my seat. She looked down at me and said, “You are a real inspiration to me. You deserve this more than I do.” She then preceded to hand me the envelope and said, “This is one hundred dollars in cash. It is the prize I received for winning my age group. You deserve it, you are amazing.” I was shocked and responded, “I can’t take this; I did not earn it.” She responded, “Yes, you did; you are an inspiration to everyone here. You ran this race on crutches; I could not do that.” I decided since this woman wanted me to have her money,
I would take it. So I thanked her and took the money. “I remember thinking, being a crippled inspiration is not all bad; I just got one hundred dollars. I am going to eat good tonight! Thus, there are times when being labeled an inspiration has its advantages!

There is no question that my interaction with the public discourse that labels me as inspirational has an impact on my identity. There are instances when being labeled inspirational negatively impacts my identity because it simplifies my existence. In those moments, I want to be seen as a regular person not an inspiration. Conversely, there are other contexts in which being labeled inspirational has a positive effect on my identity. For example, when I get free stuff because of it I am pretty happy.

In this chapter I explore this public discourse and its impact on my identity development. First, I examine how the cultural discourse that often frames people with disabilities utilizes simplistic categories. Second, I interrogate the various ways that my experience as a poster child for the March of Dimes has impacted my identity development. Third, I will examine my interaction with the public discourse that has emerged because of the fact that I run on crutches. Now that I have explained the purpose and organization of this chapter, I will investigate the larger cultural discourse that depicts people with disabilities.

**Media and Disability**

There is little doubt that the media has an influence on how people come to understand the world (Consalvo, 2004; Davis, 1997; Durham & Kellner, 2001; Goggin & Newell, 2003; Kellner, 1995; Riley, 2005). As Kellner (1995) explains:
A media culture has emerged in which images, sounds, and spectacles help produce the fabric of everyday life, dominating leisure time, shaping political views and social behavior, and providing the materials out of which people forge their very identities. (p. 1)

The media helps people construct their values (Consalvo, 2004; Durham & Kellner, 2001; Kellner, 1995; Riley, 2005). Kellner (1995) concludes, “The media culture helps shape the prevalent view of the world and its deepest values; it also defines what is considered good or bad, positive or negative, moral or evil” (p. 1). Moreover, since most people do not come into contact with people who have disabilities, the media is their only exposure to those who are disabled (Berger, 2009; Davis, 1997; Goggin & Newell, Kirkpatrick, 2009; Manco, 2009; Quinlin & Bates 2007; Riley, 2005). Unfortunately, the media often portrays people with disabilities in a negative or simplistic manner (Linton, 1998; Quinlin & Bates, 2007 Thomson, 1997). As Quinlin and Bates (2007) assert, “mass media often presents stereotypes of people living with disabilities” (p. 49). To put it another way, the media often “preprocesses” people with disabilities into simplistic categories.

**Preprocessing**

Beniger (1986) explains that preprocessing is the process by which complex phenomena are placed into simple easily understood categories. Preprocessing enables large complex systems to handle large amounts of information in an efficient manner. For instance, preprocessing allows colleges and universities to move a large number of students through a system effectively. There is little doubt that an institution such as Ohio
University could not function unless it preprocessed students into simple and easily understood categories. Preprocessing allows Ohio University to know the difference between a graduate and undergraduate student, it also allows the university to know who has met the requirements for graduation and who has not. Thus, preprocessing is necessary for Ohio University because it allows the university to move students through the university efficiently.

While preprocessing allows certain complex systems to function efficiently, it is often overused. When the media preprocesses people with disabilities into simplistic categories, it only furthers the stereotypes that provide the public with a distorted view of people with disabilities. For example, the media often preprocesses people with disabilities into simple categories such as “the super crip” or “the charity cripple.” For instance, Riley (2005) discusses the media coverage of Paralympian Aimee Mullins. Mullins who is a below the knee bilateral amputee, is also a sprinter who can run 100 meters in under 16 seconds thanks in part to a pair of prostheses that are designed for world class athletes. Mullins’s exploits on the track have given her national notoriety. She has demonstrated that she can train and perform at the highest level of athletic competition. However, as Riley points out, the media only depicts her in an inspirational manner. He states:

From the local paper where she grew up (Allentown, Pennsylvania) to national exposure in *Esquire* and *People* and guest spots on *Oprah*, Mullins's "inspiring saga" is recycled almost verbatim by well-meaning journalists who never seem to
get enough of its feel-good message even if they never actually find out who Mullins is. (p. ix)

The media's coverage of Mullins pre-processes her as heroic because she overcomes her disability. What is problematic here is that the media only frames Mullins as an inspiration. Riley contends that depicting Mullins in this way shows her not as a three-dimensional person, but a two-dimensional caricature. Moreover, Riley asserts that the media frequently pre-processes others with disabilities in the same way, "Mullins is not the only celebrity with a disability to be steamrolled out of three-dimensional humanity into allegorical flatness" (p. ix). Consequently, people with disabilities are often crammed into simplistic categories by the media. These categories provide a distorted glance at life with a disability. As Riley explains, “By jamming Mullins and others into prefabricated stories-the supercrip, the medical miracle, the object of pity-writers and producers have outfitted them with the narrative equivalent of an ill fitting set of prostheses" (p. x). These stereotypical images do not show the complexities of disability in American society. In addition, this kind of preprocessing masks the fact that Mullins is simply a world-class athlete in the company of other world-class athletes, having earned that distinction based on her efforts and not her disability. Many people who are able-bodied have limited contact with those who have disabilities, and therefore might think that the stereotypical images of people with disabilities shown by the media are the true reality of what it is like to have a disability. Therefore, many individuals who are able-bodied develop a simplistic understanding of the lives of those who are disabled.
More harmful is that this preprocessing adds a layer of invisibility around the person’s whole self and identity.

It is true that the media frequently uses stereotypical images in its portrayals of people with disabilities, but it would be a mistake to assume that everyone is a passive consumer of these messages. Even though the media often preprocesses people with disabilities into stereotypical categories that help perpetuate able-bodied hegemony, individuals do have the ability either to accept or reject the hegemonic ideologies that are presented in these preprocessed categories. Individuals may respond to hegemonic media images in contrasting ways. As Kellner and Durham (2001) explain, “Various individuals and audiences respond to these texts disparately negotiating their meanings in complex often paradoxical ways” (p. 1). Thus, it is important to briefly explore the relationship between the way the media encodes hegemonic ideologies into various images on the one hand, and the way individuals may decode those hegemonic ideologies on the other.

**Encoding/Decoding**

Hall (2001) explored this relationship in his work entitled *Encoding/Decoding*. Hall argues that the media helps transmit and perpetuate hegemonic ideologies that promote the status quo. He also argues that various media artifacts are encoded with hegemonic messages that promote the ideology of the ruling class. (Although most U.S. citizens would argue that we do not have a “ruling class” since they equate that with a monarchy, for example, Hall is naming the group/category of a dominant identity culture that holds the majority of power in a given society and/or institution.) However, Hall argues that individuals who consume these messages may decode them in different ways.
In fact, Hall argues that individuals can take three “hypothetical positions” when they are decoding hegemonic images (p. 174). Those positions are: the dominant hegemonic position, the negotiated code or position, and the oppositional code or position.

When someone decodes a hegemonic image from the dominant position he or she accepts without question the messages that are encoded in a media image (p. 174). For example, if someone decoded the headline “Disability, What Disability?” and the corresponding photo that I examined at the beginning of this chapter from a dominant hegemonic position, that individual would simply accept the idea that I have overcome my disability because I run. Furthermore, someone who decodes that headline from a dominant position would not question the idea that running with a disability makes me inspirational. Additionally, an individual who decodes this image from a dominant code or position would buy into the hegemonic notion of normalcy that is being portrayed by that image. The message that attributes “inspirational” to my running perpetuates the notion of normalcy defined by the dominant culture. It does this because running with crutches makes me appear to be more normal...a term and set of values that the dominant culture uses to measure and attribute normalcy to someone. It may not be my notion of normalcy, but I am still measured against the dominant culture’s idea of normalcy.

Conversely, when someone decodes a hegemonic image using a negotiated code that individual takes a contradictory approach to a text. On one hand, while he or she may accept hegemonic ideologies on a macro societal level, he or she will reject the hegemonic message encoded in a specific text on the other (p. 175). For instance, my dad responded to the headline and picture “Disability, What Disability?” by saying, “No, you
are not inspirational because you run, but it is nice to see stories that show people
overcoming their disabilities.” My dad is decoding this headline using a negotiated
position. While, he does not think that I am inspirational because I run, he believes that
the media should portray people with disabilities overcoming their disabilities. He does
not buy into the hegemonic encoded message when it portrays me, but he would buy into
it if it was portraying someone else with a disability. My dad’s approach can be
problematic because he does not apply a hegemonic point of view when a story about
disability relates to someone he knows on a personal level, but he does buy into a
hegemonic message when it applies to someone he does not know. This may indicate that
on some level my dad views people with disabilities that he does not know as the “other”.

Finally, people can decode hegemonic media images from an **oppositional**
*perspective* (p. 175). Those who respond to hegemonic images using an oppositional code
completely reject the ideologies that are embedded within a text (p. 175). For instance, if
someone was decoding the headline and its accompanying picture of me “Disability,
What Disability?” using an oppositional code, he or she would assert that the picture and
headline promotes the idea that people with disabilities should strive for an able-bodied
understanding of normalcy. That individual would argue that this headline and picture is
just one instance in which the media promotes the idea that people with disabilities
should work hard in order to overcome their disabilities. Thus, that individual would
completely reject the hegemonic notions that are encoded in this media image.

While there certainly are individuals who might decode media images that portray
disability using an oppositional stance, for me it is not that simple. When I decode how I
am portrayed in the public discourse, I often take the negotiated code or position. I recognize that the way in which I am depicted in public discourse often perpetuates hegemonic ideologies that limit those with disabilities. Surprisingly, I do not completely reject these hegemonic portrayals. Instead, I am often conflicted about the way that I am portrayed in public discourse. For example, recall my struggle to come to terms with the photograph and headline “Disability, What Disability?” Part of me knows that this picture and headline perpetuate hegemonic notions of normalcy, and that this image ignores the complexities of my experience as a person with a disability. However, another part of me is proud of this image.

This contradiction occurs because I am completely aware that this image of me may be harmful to other people with disabilities. Yet, I am proud because this picture shows me running in a cool manner. Even though I am cognizant that this is a hegemonic image, I accept it anyway. This demonstrates the contradiction that can occur when people with disabilities are portrayed in the media. In the next section, I will describe another example of a hegemonic portrayal of people with disabilities.

**Public Discourse and the March of Dimes**

As I just described, I often decode images that depict my disability in contradictory ways. Consequently, in order to understand how the public discourse frames my disability and the subsequent impact on my identity development, it is important to explore how I interpret and negotiate this discourse. In order to do this, I need to explicate how I define public discourse and some of its processes.
When I refer to public discourse, I am referring to the way the media portrays my disability, and the way that individuals with whom I do not have a personal relationship respond to my disability. It is understood as public discourse because the message impacts not only an individual, but impacts the larger public in our society. It is not simply an insular and individual message. This broad definition of the public discourse allows me to move my interrogation beyond media artifacts. After all, I am not just impacted by how the media depicts me; I am also influenced by the way that people with whom I do not have a relationship interact with me. This understanding of public discourse provides a more comprehensive investigation of how my interaction with this rhetoric impacts my identity development and vice versa. Now that I have explained what and how the public discourse operates I will explicate it further through a story as one example of my interaction with it.

For three years, from the age of 8 through the age of 10, I served as a poster child for local chapters of the March of Dimes in Franklin and Licking County, Ohio. This experience was one of the most significant interactions that I experienced within public discourse. The three years I spent as a poster child in these two counties helped to shape my understanding of my disability as a child, making it important for me to investigate my experience as a poster child.

A Brief History of Poster Children

In order to place my experience as a poster child in the proper context, it is useful to know the way that poster children have been used by charities such as the March of Dimes. I also investigate how disability rights advocates and scholars have
taken a hard stance against the use of poster children as a fundraising tool for charitable causes.

The use of poster children dates back to the 1880’s. As Krueger (2007) demonstrates, during this period children became a mainstay in American advertising. Additionally, poster children were often used as a way to raise money for various charities. Krueger concludes, “Newspapers solicited funds for children and families suffering from debilitating or deadly diseases by pairing dramatic accounts with vivid visual media” (p. 73). This use of poster children in health campaigns combined journalism, advertising, and entertainment. This triad proved to be an extremely profitable way for charities to raise money (p. 74). This is because children with various kinds of ailments are sympathetic which makes them a powerful tool in fundraising campaigns.

By the time The March of Dimes began to raise money in order to find a cure for polio in 1939, the use of poster children was an established practice (Rogers, 1992). Consequently, from its inception the March of Dimes used poster children as a major part of its fundraising strategy (Rogers, 1992). However, the March of Dimes went further than other charitable organizations in its unabashed use of children in order to raise money. For instance, in referring to the March of Dimes, Rogers (1992) states:

Its fundraising techniques were unashamedly sentimental, going beyond the efforts of the American Heart Association, the American Cancer Society, and the National Tuberculosis Association. The Foundation exploited the emotional poll
of crippled children, and March of Dimes posters and donation cans routinely featured a child on crutches. (p. 172)

While the March of Dimes was not the first organization to use poster children, the Foundation used the emotional pull of poster children with greater success than any other organization (Rogers, 1992). Not only did the March of Dimes rely on the sentimental value of children with disabilities, as Krueger (2007) explains, the March of Dimes carefully selected and posed children in a manner that highlighted the possibility of rehabilitation and recovery (p. 72). The March of Dimes used poster children to push the notion that it could create a society without disabled children (Rogers, 1992; Shapiro, 1994). Pairing the sentimental pictures of children with disabilities with the idea that the March of Dimes could help create a society where all children were normal, turned out to be an amazingly successful combination for significant fundraising.

For example, Figure 2 is a picture of me representing the March of Dimes in the 1987 Walk America in Columbus, Ohio. This photograph appeared on the front page of the Columbus Dispatch as an archetypal image of a poster child. I am walking on crutches striving for normalcy. I am also sympathetic because I am a child struggling to walk on crutches. This picture contains just the right combination of inspiration and sympathy to make it an ideal image of a traditional poster child.
In short, the March of Dimes uses images of poster children similar to the one shown in Figure 2 in order to convince people to donate money. The March of Dimes would then decide which research efforts it would support. Almost overnight, this organization became enormously important in the fight to cure polio. Rogers (1992) describes the March of Dimes as “a fairy godmother of quite mammoth proportions who thrived on publicity” (p. 172).

In 1955, the research efforts to cure polio paid dividends, and the Salk vaccine was deemed safe and effective (Rogers, 1992). The cure for polio had been discovered! The Salk vaccine meant that polio was no longer a major threat to the health of children.
in the United States. Consequently, the March of Dimes needed to find a new health issue behind which it could put its massive fundraising organization. Therefore, in 1958 the Foundation declared that it would concentrate its fundraising efforts on the prevention of birth defects (March of Dimes, 2010). To this day, raising money to prevent birth defects remains the March of Dimes’ primary goal.

The March of Dimes (2010) declares that it will “not stop until we reach the day that every baby is born healthy” (A History of Success, section, para. 2). The March of Dimes wants to eradicate the world of birth defects. Just like its promise to eradicate polio, the March of Dimes has declared to the public that it can create another medical miracle. The Foundation still uses poster children as an important part of its fundraising strategy. While this approach remains an effective fundraising strategy, it is not without its problems and tensions that need to be addressed.

**Poster Child as Charity Crippled**

Despite the fact that poster children remain an effective fundraising tool for various charities including the March of Dimes, there are those who oppose the use of poster children. In particular, scholars within the field of disability studies, as well as disability rights activists have strongly argued that charities such as the March of Dimes, who use children in order to raise money, play a role in perpetuating stereotypes that hinder the progress of people with disabilities (Johnson, 2004; Russell, 1998; Shapiro, 1994; Shaw, 1994). For example, Russell (1998) maintains that poster children promote an image of people with disabilities as “charity cripples,” and this charity cripple image depicts people with disabilities as helpless individuals. Russell further contends that the
charity cripple is simply a modern incarnation of Tiny Tim; the helpless "cripple"
portrayed in *A Christmas Carol*, who tugs at our hearts. Russell explains it this way:

The stereotypical images of "cripples" as patient saintly Tiny Tims waiting for
God to take them home, or as totally distraught inferiors waiting for someone-or
some charitable organization-to cure us, have contributed greatly to the
oppression of disabled people. In either case, disabled people are good for one
thing-to assuage consciences by being the object of charitable pity. (p. 85)

Not only do many people with disabilities oppose the way charitable
organizations portray people with disabilities as helpless, many also reject the notion that
charities should seek to cure disabilities (Davis, 1997; Johnson, 2006; Krueger, 2007;
Russell, 1998; Shapiro, 1994; Shaw, 1994). After all, one of the premises of the disability
movement is the idea that the experience of living with a disability is a unique cultural
experience that should be embraced (Berger, 2009; Gill, 1994; Linton, 1998; Longmore,
2003). From this perspective, many people with disabilities are not comfortable with the
idea that charities such as the March of Dimes want all children to be healthy and normal.
That perspective might be hard for able-bodied people to understand. Consider how
Johnson (2006) explains her uneasiness with the March of Dimes, “March of Dimes
declared that it would “Stamp out birth defects”---a slogan that made us defectives
nervous” (p. 50). Johnson’s point is that as a person with a disability, she does not want
to live in a society where people like her no longer exist. Thus, it is fair to say that a
number of people with disabilities are opposed to the use of poster children by various
charities, including the March of Dimes. Many individuals who consider themselves to be
a part of disability culture resent the hegemonic idea and encoded message that charities like the March of Dimes want to cure the world of people with disabilities.

Hence, there is a tension that exists between the charities that use poster children on the one hand, and those disability advocates who vehemently oppose the use of children with disabilities in charity fundraising campaigns on the other. These matters are not just semantic or academic; these issues have a tremendous impact on the individual who has a disability. In order to understand how my experience as a poster child continues to impact my comprehension of my own identity, it is important to understand the tension that I have just delineated. It is in this context that my experience as a poster child and its impact on my identity can best be understood.

It is important for me to note that the purpose of this autoethnography is not to denounce or applaud the practice of using poster children. Instead, my endeavor is to show that my experience as a poster child for the March of Dimes illustrates the complexity and challenges of my identity development as a person with a disability who was also utilized as a poster child within this same dynamic process. In order to understand how this experience sheds light on my identity development, it was necessary for me to investigate that experience.

**An Invitation to Become a Poster Child**

The opportunity to become a poster child occurred when I was eight years old. Representatives from the Franklin and Licking County chapters of the March of Dimes came to my second grade classroom one day and asked me if I would be interested in representing both counties as their local poster child. They explained to me that I would
get to do a lot of fun things, and that I would get to meet really cool people. Additionally, the representatives from the March of Dimes informed me that I would probably get my picture in the paper, and I would have the opportunity to be on television.

I can remember feeling ecstatic that I would be singled out from all my classmates and given this opportunity. I can remember thinking, this is so cool! I mean, what 8 year-old kid would not love to have their picture in the paper, and an opportunity to be on television? At the end of school on that day, I can remember coming home and sharing the exciting news with my parents.

My parents were initially resistant to the idea of me being a poster child. My mom explains their reaction in the following way, "Your dad and I were a little irritated that they did not talk to us first. They went to your school and asked you, but they did not ask us. So you were bursting with excitement, and we were both like, okay, let's hold on for a minute. We needed to find out a little more about this opportunity before we would let you do it."

As I reflect now on my mom's words, I must say I find it surprising and highly problematic that the March of Dimes would talk to an eight-year-old child and present him or her with an amazing opportunity without talking to that child's parents first. It makes me wonder if this approach is a regular modus operandi for organizations like the March of Dimes. That is to say, I wonder if they approach the children first so that the children come home all excited, putting the parents in the position where they cannot really say “no”. Moreover, I have wondered if my parents’ decision would have been different if the March of Dimes had gone to them first. Obviously, there is no way to
know for sure, but it seems that the March of Dimes decision not to approach my parents first was a good one, for them because ultimately my parents allowed me to become a poster child.

**Being a Poster Child Was Fun**

I would spend the next three years representing the March of Dimes at various functions all across Central Ohio. Personally, the experience was a whirlwind of excitement. For example, being from Central Ohio meant that I was a huge Ohio State football fan, and as a poster child for Franklin County, I got to do a television commercial with the then Ohio State football coach, Earle Bruce. If you know anything about Ohio State football, then you know that its coach is always larger than life, and it was no different for Earle Bruce. In fact, he may have been the largest of the large! For an 8 year old who was a fan of Ohio State football, the opportunity to meet Earle Bruce was a fun experience. I was aware even then that this experience came my way precisely because I was the March of Dimes poster child. Who wouldn’t want to be if it meant you were able to have experiences such as this. In another instance, my family and I were given a personal tour of the Columbus zoo by well-known animal naturalist Jack Hanna. I am not going to lie; even as an adult, I feel that the day I got a personal tour of the zoo from Jack Hanna was one of the coolest days of my life.

There were many experiences like the two that I just described during my three-year tenure as a poster child. I had the opportunity to meet people and to do things that were a lot of fun. I truly enjoyed my experience as a poster child. I never viewed it in a negative way. In fact, it was the opposite; I was proud of my involvement with the March
of Dimes. As a young child, I thought it was a good thing that this organization was trying to prevent birth defects like my cerebral palsy. Furthermore, during my time as a poster child I would often tell people that I was going to work really hard so that I would be able to walk without crutches some day. Even though my parents had some concerns when I was approached to be a poster child, they came to enjoy the experience as much as I did.

Figure 3: Article about my involvement with the March of Dimes that appeared in the *Columbus Dispatch* on April 27, 1987.

The article shown in Figure 3 demonstrates the commitment that I had to the March of Dimes. In the article I assert that, "I like to help raise money to prevent birth defects." I was a third grader at this time. Moreover, I tell other children with disabilities
that, "they should think positive." Furthermore, the article claims that I told my mother, "If I work as hard as Pete Rose does, I'll walk someday." These quotes illustrate that as a child I bought into the message of normalcy that is perpetuated by the March of Dimes hook, line, and sinker. It is clear to me as I read this article that by the age of nine I had already internalized the idea that I want to be normal; I accepted it to such an extent that I did not want to be disabled. I did not want to be who I was. As you can imagine, this would play havoc with my identity development.

As I reflect on my experience as a March of Dimes poster child, I realize that part of the reason I enjoyed my experience so much was that the Foundation's mission to create a world where there are no people with disabilities helped to create my own view about people with disabilities. Moreover, I accepted this view so easily in part because it matched the view that my family had about my disability. To put it another way, the March of Dimes script about people with disabilities in general, was similar to my family's script about my disability. Both scripts promoted the idea of working hard to become normal. Therefore, it makes sense that I would swallow the March of Dimes message without giving it a second thought.

**A Different Sense of Identity, a Different Opinion**

Drawing upon my earlier discussion of the stages of identity development, when I was stuck in the coming to feel we belong stage of identity development, I decoded the hegemonic discourse perpetuated by the March of Dimes from a position that Hall (2001) would describe as a dominant hegemonic code or position. That is to say, I did not question the implications of the idea that the March of Dimes wanted to create a world
without people who have disabilities. I simply accepted that this discourse was positive. I also hoped deep down that one day there would be a world where no one was disabled. I did not even consider the idea that there are people who would be opposed to that idea. Moreover, I never questioned the fact that the March of Dimes used poster children such as me to raise money for its cause. At the time, I viewed the use of poster children in an entirely positive way.

However, my perspective on this would radically change when I began to *come out* and embrace my disability at the age of 27. As I started my *coming out* process I began to reflect on my experience as a poster child. At this point, I decoded my experience with March of Dimes using what Hall describes as an oppositional position. That is to say, I completely rejected the discourse of normalcy that the March of Dimes promulgates.

I first came to this stance during a graduate seminar. The class began to discuss the use of poster children. At some point during the discussion, I shared my experience as a poster child. Then a thought hit me like a ton of bricks. I thought, man, I spent three years of my life raising money to prevent birth defects. I am a birth defect. This means that I spent three years of my life helping raise money so that there were no more people who were like me.

I could not believe that I had been involved in something so screwed up. I shared this thought with the class, and then added "I have just realized that my experience as a poster child was evil." The students in the class were stunned by my visceral reaction. In fact, I was too.
The realization that I helped the March of Dimes promote negative perceptions about those with disabilities made me feel like I had been run over by a two ton dump truck. Needless to say, I no longer felt proud of my involvement with the March of Dimes. In fact, I was horrified. I became angry with the March of Dimes. I felt as though I had been duped and used by an organization whose sole purpose was to promote an able-bodied agenda. I was incensed that an organization could blatantly use children with disabilities like me who are unaware that they are being used.

When I experienced these feelings it was overwhelming. Consequently, I shared my strong reactions with the class. I came across so strongly that most of the people in there were not sure how to react. I was so angry at my involvement with the March of Dimes that I did not care what my colleagues thought. I wanted everyone to know how I felt, and I was not concerned about their opinion towards me.

I rejected the hegemonic rhetoric of the March of Dimes once I came out and began to embrace my disability. As a child, I simply accepted the notion that the March of Dimes should create a world where there are no children with birth defects. I did not even consider whether or not the March of Dimes should even try to create a world where there are no children with disabilities. Moreover, I never thought to question the Foundation's use of poster children. Thus, as I reflect back on the way I decoded the hegemonic discourse of the March of Dimes when I was a poster child, I realize I was internalizing the Foundation's message from a dominant hegemonic position.

Furthermore, once I began to come out and embrace my disability I began to rethink my experience as a poster child. It is fair to say, that during this period of my
identity development I was appalled at my involvement in the March of Dimes. Additionally, I felt the use of poster children by this organization was immoral because the March of Dimes manipulates children with disabilities and their families in order to raise money. Consequently, when I began my own coming out process I chose to decode the hegemonic discourse that the March of Dimes uses from an oppositional perspective. In short, I saw my experience with the March of Dimes as shameful, and I had no respect for the organization.

As my journey of identity development has continued, my attitude toward the March of Dimes has softened. Presently, as I look back on my experience as a poster child, I have mixed feelings. My experience as a poster child was a positive one. As a child, I never felt used or abused by the March of Dimes in any way. In fact, I relished the opportunity to be the center of attention. I had the opportunity to do a lot of cool things. If I am being truly honest with myself, I cannot say that the March of Dimes is immoral. The organization treated me well, and gave me a number of really unique opportunities and experiences.

Still, there is a part of me that is uneasy with the tactics used by the March of Dimes. Even though my experience as a poster child was a positive one, I am uncomfortable with organizations that use poster children as a major part of their fundraising tactics. I am not sure whether or not children are capable of understanding the hegemonic discourses that an organization like the March of Dimes perpetuates. Additionally, there is just something "icky" about an organization having children with
disabilities ask for money so that organization can create a world where there are no children with disabilities.

If adults with disabilities want to take part in March of Dimes fundraisers that is another issue; if an adult with a disability wishes they were not disabled and wants to promote an organization that can help rid the world of that disability that is his or her choice. Adults have the capability to make informed decisions about how an organization such as the March of Dimes represents them; conversely, children are not capable of making these informed decisions about how they are depicted. Consequently, the March of Dimes should use adults with disabilities in its fundraising efforts.

Currently as I reflect on my experience as a poster child, I decode it using what Hall (2001) terms a negotiated code or position. On the one hand, I view my personal experience as a poster child in a positive way and I am grateful that I had the opportunity. On the other hand, I generally oppose the use of poster children by any charity organization. Therefore, even though I have fond memories of my experience as a poster child, when I see depictions of other poster children I cringe.

It is clear that as a poster child, I became part of a public discourse that often preprocesses people with disabilities into simple categories that promote able-bodied notions of normalcy. Yet, my interaction with the discourse in this instance is anything but simple. My attitude toward it is fluid, and evolves as I continue my ongoing journey of identity development. Hence, my experience as a poster child illustrates the complexity of the relationship between disability in the public discourse and identity development.
In the next section I examine another example of how I have been storied in public discourse. I investigate my interaction with the rhetoric that has emerged because I run with a disability. It is to this task that I now move.

**Wrestling with a Disability**

As a child, I never thought I would become a runner. I wanted the opportunity to be an athlete, but running was not something I ever considered as a young child. This part of my story explains how I came to the sport of running.

I was enthralled with sports from the time I was five years old. I loved to watch sports, but more than anything I wanted to play them. However, very early on in my childhood I started to think I would not have the opportunity to play sports. As I entered junior high school, I was jealous. Many of my classmates were playing sports, and I did not think I would be able to because of my disability. I used to lay awake at night thinking, “I want to play sports, but I am never going to get that chance.”

Luckily, I was dead wrong in my assumption that I would never be able to play sports or be an athlete. At the beginning of my seventh grade year, the high school wrestling coach approached me. Coach Taylor came up to me one day outside of school and said, "Cort, you have a real strong upper body. Have you ever thought about wrestling?" I responded, "No. I have never considered it. But I would be interested." Coach Taylor then said, "You should come out for wrestling. We would love to have you."

As Coach Taylor walked away I was filled with excitement. Here was a coach who was asking me to turn out for the wrestling team. “This is awesome!” I thought to
myself. After I told my parents that Coach Taylor had asked me to go out for wrestling, they were both excited about this opportunity for me. They gladly signed the permission slips that allowed me to join my school wrestling team. When I first joined the team I had dreams of becoming a disabled Dan Gable, a storied Olympian in the sport of wrestling. I pictured myself dominating my opponents and winning championships. I soon found out that my dreams of becoming a championship wrestler were far from the reality. I was a terrible wrestler. I spent most of the matches on my back getting pinned. In fact, I often describe my wrestling career to people by saying, "I spent so much time on my back that I memorized the lighting grid of every gym in Central Ohio."

Despite the fact that I was one of the worst wrestlers on our team, I was proud that I was on the team at all. However, by the time I was a sophomore in high school I had given up my dreams of becoming a championship wrestler. In fact, I soon realized that I would not even be good enough to win a varsity letter. I had resigned myself to the fact that I would spend the rest of my career as a junior varsity wrestler. While I was happy to be on the team in any capacity, my disappointment with the realization of the fact that I would never be good enough to earn a varsity letter was deflating. I wondered again, would I, could I, ever be an athlete? Could I ever fulfill this one childhood dream? My brothers had already earned their letterman jackets, and I wanted one desperately. Perhaps it was to “prove” I was normal like my brothers, and like my peers; regardless of why I wanted that varsity letter, knowing that I was physically unable to compete and earn one contributed to my quest not to be disabled. Little did I know that in the summer
before my sophomore year, my opportunity to earn a varsity letter arose when I joined the cross-country team…our school’s cross-country team!

**The Kid Who Can't Walk Decides to Run**

Our high school had a student named Steve who was one of the top distance runners in the state of Ohio. At that time, we did not have a cross country team at our high school. However, since Steve had the chance to be really successful, our school decided to start a cross country team. Coach Taylor agreed that he would coach the team since he also ran cross country in college. Coach Taylor decided that in order to make sure the team had a full roster of runners, he would "encourage" any wrestlers who were not playing another sport to run cross country in order to get in shape for wrestling season. His "encouragement" meant that if he asked you to run, you had no choice in the matter.

Once again, Coach Taylor approached me. During a summer workout session he came up and said, "Cort you are going to run cross country this fall to get in shape for wrestling." I had never heard of cross country before this point so I responded, "What's cross country?" Coach Taylor explained, "It's a sport where you run 3.1 mile races." I was stunned. I can remember thinking, why would Coach Taylor ask me to compete in a sport where you have to run? Doesn't he know that I can't walk?

Thus, I responded to Coach Taylor by saying, "You do know that I can't walk, right?" He quickly responded, "Don't you pull that crap with me. I know you can do this." In my usual sarcastic way I asked, "Yeah I can do it, but why would I want to? I will be
terrible. I will finish dead last. I can't beat anybody in a race. I wouldn't be of any value to the team. Why would you want me to run?"

Coach Taylor listened to me with a thoughtful expression on his face and then stated, "I expect you to run because you're just like anyone else on my wrestling team. If you want to wrestle in the winter, then I expect you to run cross country in the fall. Besides, I want you to run because I think it will be great for you." I took in Coach Taylor's words and seriously reflected on them. After all, this was the man who had given me the opportunity to play sports in the first place; still, I wasn't convinced that I should run cross country; this was a sport that until now I did not even know existed. So I asked him, "What is the sport going to teach me other than the fact that I am slower than everyone else? I already know that. I just don't see the point."

Coach Taylor carefully listened to my words and said, "Cort, cross-country, like any other sport, teaches the importance of hard work. Also, I promise you that if you show up for every practice, and run as hard as you can, and if you run every race as hard as you can, then you will earn a varsity letter." I could earn a varsity letter? I could be an athlete? After the disappointment with wrestling, Coach Taylor’s invitation and promise energized me to continue to reach for that elusive goal: my identity as an athlete and normalcy. While the opportunity to win a varsity letter was extremely appealing, I had never run a distance over one mile; still I decided to run cross country. For me it was all about the varsity letter. I thought, “If I get a varsity letter, then I’ll be just like my brothers.” In short, earning a varsity letter was one way that I could prove how normal I was. Little did I know that by running cross country I would encounter the public
discourse that preprocesses people with disabilities, and once again it profoundly impacted my identity.

**I Become a Super Crip**

In the summer before my sophomore year of high school, I began to train for cross country. I did not know much about running, but I was prepared to work as hard as I could. What I was not prepared for at all was how other people would react to me. While there might be some people who might call me "inspirational," I assumed that most people would not see running cross country on crutches as a big deal. This assumption came from the fact that I was a wrestler. Wrestling is a very inclusive sport, meaning that it was not uncommon to see individuals with a variety of disabilities who wrestle. Yes, during wrestling matches there were a few fans that would call me inspirational, but for the most part people at high school wrestling meets did not seem to care that I was disabled. I expected a similar reaction from fans at cross country races. I was completely mistaken.

In August of 1993 I lined up for my first race. As I stood with my crutches at the starting line it was clear I was not at a wrestling meet. People were stunned to see a guy on crutches who was ready to run a race. In fact, one spectator yelled, "Is the kid on crutches really going to run?" I tried my best to tune out the crowd's stunned reaction at my participation so that I could focus on running the race. “Racers ready?” Then the starting gun rang out. Wherever I went on the course I heard shouts of, "You're an inspiration to us all!" They sounded like they were coming from everywhere. It seemed that everywhere I turned on the course there was someone telling me how amazing it was
that I was able to run. In fact, the top 10 finishers in my race all came back to cross the finish line with me, and every one of them shook my hand.

I was conflicted by this experience. I was extremely touched that the best runners wanted to shake my hand, but I also felt embarrassed. I was running to earn a letter so I could become normal, and here these runners were treating me differently than everyone else. This story illustrates the tensions that exist between normality-abnormality. I was trying to assert my normalcy, but the actions of these runners demonstrated to me that I was anything but normal. It seemed that no matter what I did I would always be abnormal.

Everywhere I raced that season I encountered a similar reaction. Perhaps, my grandfather’s words explained it best when he told me "I watched high school track for over 30 years, and I never saw the excitement on a cross country course that you generated. It was amazing to watch people's reaction to you. I have never seen anything like it." My grandfather's words made me feel proud. I appreciated his approval, and the fact that he was moved by my actions as an athlete touched me.

Pretty soon the attention that I generated at cross country races caused the Columbus media to take notice. The Columbus Dispatch and the local CBS affiliate 10 TV ran feature stories on me. Both of these stories depicted me as an inspirational athlete who overcomes extreme odds in order to compete (Blackledge, 1993; Tiberi, 1993). Moreover, both the television story and the newspaper article highlighted the fact that I was overcoming my disability in order to be normal (Blackledge, 1993; Tiberi, 1993).
Even though I did not know the term and its subsequent implications for my identity, people were portraying me as a super crip.

The super crip is one of the most common portrayals of those with disabilities (Berger, 2009; Goggin & Newell, 2003; Quinlan & Bates, 2008; Riley, 2006). This hegemonic image shows people with disabilities as heroic because they strive to lead a normal life in spite of their disabilities (Berger, 2009; Goggin & Newell, 2003; Quinlan & Bates, 2008; Riley, 2005). In my case, the people I encountered at cross country races and the local media were framing me as a "super crip". People kept telling me that I was inspirational and amazing simply because I ran on crutches. I was labeled as an inspiration to others throughout my entire cross country career.

I was conflicted by this label. I like the attention, but I did not like being labeled as inspirational. I felt when others labeled me as inspirational it detracted from my efforts as an athlete. I wanted to be judged by what I accomplished as an athlete. I did not want to only be known as the disabled athlete who is inspirational.

People continued to praise me at cross country races, and the Columbus media continued to write about me all throughout my high school career. For instance, during my junior year, the Columbus Dispatch wrote another story on my experience as a disabled athlete. Figure 4 is the headline for this article. It is the archetypal example of a super crip portrayal.
The article stressed that I was just like any other kid despite my disability (Smeltzer, 1994). The article also stressed that I worked hard in order to overcome my disability (Smeltzer, 1994). As I reflect on the headline in Figure 4, I find it amusing. This headline illustrates two important things. First, it demonstrated how determined I was at that point in my life to prove that I was normal. Second, it illuminated the fact that others did not view me as normal, despite their insistence that I was normal! Yes, this headline goes out of its way to demonstrate that I am "Just Another Kid." But if others really saw me as Just Another Kid, it seems unlikely that the Columbus Dispatch would have written multiple stories about me. It seems apparent that though I was trying to act normal, others still did not see me that way due to my disability. To many people who are able-bodied, I
could "strive" to be normal, but in their eyes I never really would become normal. This paradox arises because if they saw me as truly normal, there is no reason that I would also be inspirational. Moreover, even though I did not realize it at the time, I was becoming the perfect example of a super crip.

**Conflicted About Being a Super Crip**

During these years I was conflicted about the attention that was given to me. Part of me enjoyed it; what high school kid does not want to be in the newspaper and on television? Furthermore, the exposure that I got from the local media gave me an opportunity to get into the field of broadcasting as a sophomore in high school and found this might be my career choice. This opportunity occurred because the Columbus media began to do stories on me during my sophomore year. After seeing and reading the stories about me, a radio station in my hometown contacted me and asked if I wanted to be part of the crew that announced local high school football games for various teams in Central Ohio. Thus, before I turned 16 years old I was announcing high school football games on a radio station in Columbus. This was like a dream come true for me. Like the opportunities that came to me as a March of Dimes poster child, in many ways I viewed the attention I received for running cross-country on crutches in a positive manner.

As you might imagine by now, there was another part of me that resented the attention that I received. First, I did not feel that I deserved it. I was the worst runner in Central Ohio. I finished last in every race and yet I received all this media attention. There were other more deserving runners than me who did not get the attention that I received, and at times I felt like a fraud. Second, I wanted to be seen as normal because I
competed in cross country, but instead, people saw me as inspirational because I ran. There was a part of me that just wanted to be left alone. After all, I joined the cross country team to get a varsity letter and to get in shape – not to garner praise from others. I had no desire to inspire others. It became frustrating when people would tell me how much I inspired them. I would think to myself, it is not my job to be your personal savior. Just leave me alone and let me run.

In fact, by the time I finished my senior season of cross country I became so annoyed at being labeled as an inspiration that I stopped running. I just reached the point where I resented being labeled an inspiration. Thus, I gave up running after high school so I would not have to endure that label. When I was mired in my *coming to feel we belong* stage of identity development, I wanted to be viewed as normal by others. When I ran on crutches the exact opposite happened. So I gave it up, from 1996 until 2004, I did not run a single step.

**Ambiguity and the Super Crip**

In 2004, around the same time that I started to come out, I started running in order to stay in shape. Once I started running I fell in love with it all over again. From that point on until now, running has become an important aspect of my identity. I view running differently now than I did when I was in high school. In high school I ran to prove how normal I was. Once I came out I no longer cared if people saw me as normal or not.

I was surprised, but I found that not caring about being normal gave me the freedom to enjoy running on a whole new level I had never experienced. Today, I run for
my own reasons; I do not care what others think. Yes, sometimes it is still frustrating when people refer to me as inspirational because I run, but I realize that is just a fact of life. If I choose to run, there will be people who think that I am inspirational. I used to tell people that they should not view me as inspirational because I run. Now I realize that I cannot control how other people view me. In short, I decode the way I storied by others differently as my identity development has evolved.

I am not going to lie. Sometimes I become really frustrated when others label me as inspirational. I want to say to them, "Get over it. I am not inspirational, and I do not want to be inspirational." Yet there remain other times when I am honored that people think I am inspirational. In truth, my reaction often times depends on what mood I am in on a given day. Some days I see it as a blessing; other days I see it as a curse.

My experience demonstrates the complexity for understanding and deconstructing this issue. Part of the complexity lies within the dynamics related to my own identity development simply as a growing human being, as well as a person with a disability. Another aspect of complexity arises when we situate this experience within the concept of public discourse. As noted earlier, within the public discourse I am often viewed by others as a super crip. There are many people with disabilities who would view this interpretation and attribution in a negative way. For instance, scholars in the field of disability studies are quick to argue that the "super crip" image is an entirely negative hegemonic image which hinders the progress of all people with disabilities (Berger, 2009; Riley, 2006). Conversely, many disabled athletes tend to view the super crip image as a positive portrayal of those with disabilities. For instance, Gilbert and Schantz (2009)
discovered that many elite athletes with disabilities interpret this image as positive in that it highlights the determination of individuals and as such, can be inspiring to others, disabled and nondisabled alike (p. 29). Based on varied individual perspectives and contexts, individuals may decode the super crip image differently.

I often decode this image drawing upon what Hall (2001) terms a *negotiated* code. On the one hand, I understand how the hegemonic preprocessed image of the "super crip" promotes an ideology that can hinder the progress of people with disabilities as a cultural group. At the same time, (and I have struggled with the complexity of this lived experience) I do not feel that this image is completely negative. There are people with disabilities such as Lewis (2007), who want to be viewed as inspirational because they do have a disability and they have worked hard to “overcome” it. It would be a mistake for me or others to judge someone like Lewis because she wants to be an inspiration to others.

One of this autoethnography's major critiques of Gill's (1997) model of identity development is that it oversimplifies people with disabilities as a cultural group. Gill’s model of identity development assumes that people with disabilities are either *out*, or they are unhappy. This autoethnographic inquiry contests that view, living with a disabled identity is a complex reality. There needs to be room in disability culture for people to make sense of the world in contrasting ways. I may not want to be an inspiration to others, but other people do. Hence, as a member of the culture of people with disabilities I am willing to accept that other people may feel differently than I do.
It is an oversimplification to view being framed as an inspiration in the public discourse as negative. Like most other aspects of my identity, I must constantly negotiate how I interpret my feelings toward the public discourse that is directed toward me. Sometimes my interaction with the public discourse makes me feel proud to have a disability because people respond to me in a positive way. Conversely, there are times when my interaction with the public discourse makes me resent my disability because people oversimplify my experience as a person with a disability when they only view me through the preprocessed image of the super crip. Part of my ongoing identity development will be impacted I decide how I will interact with the public discourse that is directed towards me.

As I have demonstrated in this chapter other people with whom I do not have a personal relationship have often framed my disability from an able-bodied perspective of normalcy. Whether it was my experience as a poster child for the March of Dimes or people's reactions to the fact that I run on crutches, I am often depicted as an individual who overcomes his disability in order to lead a normal life. Moreover, I have illustrated that I am personally conflicted about this discourse. Sometimes I embrace it, and sometimes I resent it. I am also uncertain whether the public discourse that has surrounded my disability is positive or negative. What I do know is that this public discourse about my disability is a part of my ongoing journey of identity development.
Chapter 7: Conclusion

Struggling to Fit in

As a person who was born with cerebral palsy I have spent most of my life trying to understand what living with an obvious physical disability means to me. This autoethnography has helped me reflect on the various ways that my disability has impacted my life up to this point. For much of my life, I tried to act as though my disability was not an important aspect of my identity. In fact, I often worked hard to prove that I was normal. It was as if I was in a never-ending race to achieve a standard of normalcy that I could never achieve. This quest came at a significant cost. It often filled me with anger and resentment that isolated me from the people around me.

My attempts to create an identity that did not include my disability failed. Despite my attempts to show others how normal I was, I never felt I was normal. Moreover, I came to resent my disability. In fact, I came to dislike myself because I had a disability. I wanted to be viewed as normal, and I felt like my disability was the reason that I was not seen that way.

By the time I was 17 years old, I had internalized my hatred toward my disability to such an extent that I projected these feelings on to other people who have disabilities. Recall that when I visited Wright State University I was disgusted by the people with disabilities that I encountered. In particular, my interaction with a disability counselor who had cerebral palsy reinforced my dislike of people who had disabilities. I saw people like this counselor as needy, whiny, and ridiculous. Therefore, I had so internalized the
hatred of my own disability that I came to dislike anyone who reminded me that I was disabled, or in reality, anyone who reminded me of myself.

Even while I was angry and hated my disability, I also was not happy when I was trying to be normal. I was not happy trying to be normal and I was not happy being disabled. In this regard I developed what Gill (1997) describes as a “fractured identity.” In order to move beyond my unhappiness, I had to change my perception about my disability. I needed to stop seeing different aspects of my identity as good and bad. In short, I had to embrace my disability so that I could develop a unified sense of self. Little did I know, I would find this much needed change in a graduate seminar.

A New Understanding of Disability

My perception towards my disability would radically change in the summer of 2004 when I was transformed from a person who rejected his disability into an individual who embraced his disability. For the first time in my life, I came to view my disability not as a personal failing, but as an area of social discrimination. The fact that I had a disability means that I encounter discrimination on a systemic level. The oppression that I face because of my disability is similar to the oppression that members of other minority cultures encounter. The recognition that living with a disability made me an oppressed minority caused me to change my perspective. To begin with, I stopped trying to obtain a standard of normalcy. This was exiting. I now felt as if my world was full of possibility. As I came to believe that able-bodied society would never view me as normal, I stopped trying to be normal. I also began to embrace my disability as a positive aspect of my identity.
Not only did this transformation alter how I viewed my disability on a personal level, but it also changed my professional goals. I was no longer satisfied with the idea of becoming a high school history teacher. Rather, I wanted to focus my efforts toward helping people with disabilities. I decided to become a scholar and made the decision to obtain my doctorate in Cultural Studies in Education so that I could become a scholar, educator, and advocate for those with disabilities.

Despite the newfound pride that I gained toward my disabled identity, my decision to embrace my disability was only one part of my journey. In the years since my transformation, I have continued to try and understand how my disability impacts who I am. In fact, this dissertation is my attempt to understand how my identity has been shaped by my disability and vice versa. While my identity as an individual with a disability and all this implies was a strong motivator for this study, I also had a hunch, a feeling, that in undertaking this research, I would find new understandings and synthesize ideas that would assist others who either are disabled or those who are able-bodied in order to understand the experience of living in the world with a disability.

In this autoethnography I have explored various aspects of my identity as a person who has an obvious physical disability. First, I examined how I was transformed from a person who rejected his disability into a person who embraced it. Second, I investigated dynamics in interability relationships and the impact that has on my identity development. In particular, I explored how my relationship with my family and my able-bodied girlfriend impacted my identity development. Third, I interrogated the way I am storied in public discourse and the impact that has on my identity as a person who has a
disability. Since I have explored these aspects of my identity development individually, it is necessary for me to posit some conclusions based on the research that is contained in this dissertation.

Discussion of My Research Questions

Research Question:1

RQ1: How does my identity development as a person with a disability compare with the dominant ability identity development model that has been postulated by Gill (1997)?

Gill’s model posits that individuals with disabilities often progress through four stages of identity development. These stages are: (a) coming to feel we belong: integrating into society, (b) coming home: integrating into the disability community, (c) coming together: internally integrating our sameness and differentness, and (d) coming out: integrating how we feel with how we present ourselves. I discovered the linear nature of this model in itself is problematic because it oversimplifies the lived experience of people with disabilities.

According to Gill, individuals often begin the process of identity development with a desire to fit into the able-bodied world. Through this process, individuals with disabilities often come to realize they have a place within the larger culture of people with disabilities. The felt need to fit in to the able-bodied world is moderated through this process. Resultantly, the recognition that an individual is part of disability culture allows him or her to begin to develop an integrated identity that includes that individual's disability. Ultimately, Gill argues that in the final stage of identity development, an
individual will reach the point where she or he will embrace their disability without hesitation. In this way, Gill's model frames the process of identity development as a set of discrete tasks. That is to say, once individuals have completed one stage, they can progress onto the next phase until they reach the point where they come out and publicly embrace their disability. At that point they have completed the identity development process as it is explained in Gill's model.

Juxtaposing my own experience with Gill’s model provides what I feel is a more nuanced and fuller understanding of the process of identity development for people with disabilities. For most of my life, I was mired in the coming to feel we belong phase of identity development. That is to say, I tried to fit in with people who were able-bodied by attempting to ignore the fact that I had a disability. As I have previously mentioned, when I was in the coming to feel we belong phase of identity development, I was not very happy, and as a result I became an angry bitter person. Luckily, my outlook changed in the summer of 2004 when I underwent a transformation that changed my life. After, this transformation I began to come out and publically embrace my disability. Thus, coming out was the first step in my journey to understand what my disability means in my life.

Therefore, my identity development differed from Gill’s model because for me coming out was the first step in my identity development, while her model argues that coming home is a prerequisite to the coming out process. According to Gill, coming home to a community of people with disabilities allows people with disabilities to recognize that having a disability makes them a member of disability culture. Moreover, contact with other members of disability culture allows an individual to realize that he or she has
a common bond with other people with disabilities. Furthermore, this common bond helps an individual who has previously rejected his or her disability to see value in it.

However, my own experience demonstrates a possible weakness in Gill’s model. I had so internalized my own oppression regarding my disability, that I often rejected other people who had disabilities simply because they were disabled. Recall that I once told my dad, “I hate crippled people.” Moreover, my experience at Wright State University demonstrated my discomfort with people who were part of disability culture. In other words, I could not *come home* in the way that Gill describes the process because in order to accept others with disabilities I first had to change the way I understood my own disability. Once I reached the point where I could *come out* and embrace my own disability, I then could begin to *come home* and embrace other people with disabilities. Thus, my experience differs from Gill’s model because I began to *come out* before I began the process of *coming home*.

While this might seem to some a small or inconsequential distinction to draw, I would argue that it is not insignificant, and if we pass over this difference with little attention, we pass over a significant dynamic in the identity development process. We would slide by the hegemonic messages from our dominant able-bodied culture that lead to such a strong internalized sense of self-hatred. If we ignore these processes or diminish their importance by overlooking the alternative view my research here provides, i.e., that *coming out* precedes *coming home*, then we allow the dominant cultural system to remain in place and un-interrogated. Without interrogation, we will not be aware that these dynamics exist, which is a prerequisite to doing anything about them.
Perhaps, the biggest contrast between my own experience and Gill’s model lies in the different way we approach the end result of identity development. Gill argues that once an individual *comes home* he or she will *come together* and begin to realize that he or she is part of two worlds: the culture of disability, and the world of people who are able-bodied. Moreover, Gill argues that when people with disabilities *come together* they can happily move between these two worlds. After a person *comes together* he or she can *come out* and publically embrace his or her disability.

According to Gill, the *coming out* process is the “final step” in the identity development process (p. 45). In fact, for Gill *coming out* is the most important aspect in this process (Darling, 2003; Hernandez, 2005; Ostrander, 2009). Consequently, in Gill’s (1997) model, each stage of identity development enables an individual to take another step toward the final goal of *coming out* and publically embracing their disability “without hesitation” (p. 45).

Needless to say, my journey of identity development is different from the experience that Gill describes in her model. For me, the process of identity development is an ongoing journey in which I constantly negotiate when and how I will embrace my identity. There are times that I embrace my disability without hesitation. For example, when I use my handicap parking pass I am proudly asserting the fact that I am a member of disability culture. Conversely, there are times when I do not want to assert my disability. For instance, recall the incident when I fell ten minutes before my job interview at the University of Toledo. In that moment, I wanted my disability to “go to hell.” In short, I had no desire to assert my identity as a person with a disability. This
points to a weakness in Gill’s model; its stages are too rigid and linear and do not account for the complexity of living a life with a disability. There are times when I embrace my disability proudly and without hesitation. However, there are other times when I do not.

Therefore, for me the process of identity development is an ongoing process. I frequently negotiate my existence between the culture of disability on the one hand, and the world of people who are able-bodied on the other. If we simply accept Gill’s model with its discrete stages, we do a disservice to the struggles of people with disabilities and we do not provide those who are able-bodied with the ability to understand and/or to assist those with disabilities. These are not small consequences in the life of a person living with a disability.

The process of coming together and living in these two worlds is a never-ending process. In fact, I suspect that as long as I am alive I will continue to negotiate my existence in both worlds. Thus, unlike Gill my research concludes that the process of identity development is not simply a linear progression that ends once an individual comes out and embraces his or her disability in a public way. Instead, I view identity development as a never-ending part of my existence as a person with a disability and a human being. Hopefully, this autoethnography has illuminated the complicated nature of identity development, and in so doing, demonstrates that it is difficult to capture this complicated process in a linear model.

Research Question: 2

RQ2: What are the dialectical tensions that I perceive to be present in my relationship with my partner who is able-bodied? How do I experience those dialectical
tensions? How does the process of managing those dialectical tensions within our relationship alter my identity development as a person with a disability?

One aspect of my life that illustrates the complex nature of identity is my relationship with my able-bodied girlfriend Jane. Jane and I have been involved in a romantic relationship for over three years. Not only is our relationship an interability relationship, but is a cross-cultural relationship as well. I maintain that it is a cross-cultural relationship as well as interability because we are constantly negotiating our existence in two worlds: the culture of disability, and the culture of people who are able-bodied.

One reality that Jane and I experience as a result of being involved in an interability relationship is the fact that we must manage dialectical tensions that are present in our relationship. Moreover, the process of managing these tensions not only impacts our relationship, but it also affects my identity (as I am sure it impacts her identity as well). These tensions are: openness-closedness, stability-change, autonomy-connection, and visibility-invisibility.

There is little doubt that the dialectical tensions present in my relationship with Jane have an impact on my identity development. While the tensions I have articulated in this dissertation are not an exhaustive list, they are the most significant ones evident at this time. As our relationship progresses new tensions will undoubtedly arise. Consequently, as an interability couple, Jane and I will continue to encounter tensions that impact our relationship. It is clear that part of my identity development is impacted
by having to manage these tensions. Therefore, in order to understand my identity development, it was important to examine my relationship with Jane.

**Research Question: 3**

RQ3: How am I storied in public discourse? How do the various ways that I am storied in public discourse shed light on my identity development as a person with a disability?

As a person with a disability, many people with whom I do not have a close personal relationship often frame me as inspirational. An exploration of my experience as a poster child for the March of Dimes, as well as the discourse that exists because I am a runner who has a disability, makes it clear that I am often framed as inspirational. In most cases, others view me as a super crip. They do so because in their eyes I overcame my disability in order to lead a normal life. By framing me in this way, they are simplifying my complex experience as a person with a disability into a preprocessed stereotype of people with disabilities.

Unfortunately, instead of viewing my life experience as a person with a disability in a complex way, the public discourse stories my experience in a simplistic way. Moreover, there are times when being labeled in this way is frustrating even though there are times when being framed in this way benefits me. For example, during my experience as a poster child for the March of Dimes the opportunity to have a personal tour of the Columbus zoo from Jack Hanna was an awesome experience. As I described earlier, this example shows the complex nature of this issue.
On the one hand, as a poster child my experience as a person with a disability was preprocessed into the stereotypical depiction of a "charity cripple." In my role as a poster child I was framed by others as simultaneously tragic and inspirational. There is little doubt that the way I was portrayed as a poster child for the March of Dimes was not a positive portrayal of people with disabilities. To be honest, that still bothers me to this day. I am annoyed by the fact that as a poster child I helped perpetuate negative stereotypes about people with disabilities. On the other hand, my experience as a poster child allowed me to meet Jack Hanna and have a really cool experience. In fact, the majority of my experiences as a poster child were beneficial to me; even though I may regret my experience as a poster child on one level, I view it as a benefit on another.

Furthermore, my interaction with the public discourse that surrounds the fact that I run with a disability is similar to my experience as a poster child. Yes, there are times when I wish I could run and have no one notice me. I do not see myself as inspirational and sometimes I wish others did not view me as inspirational either. However, there are moments when being labeled as a super crip has its advantages. Clearly, when the woman gave me one hundred dollars in cash because I inspired her, I did not mind being preprocessed as a super crip.

Another dynamic that adds complexity to this issue is that I often decode this public discourse differently depending on how I feel about my identity on any given day or period in my life. For instance, when I was in the coming to feel we belong stage of identity development, I decoded my experience as a poster child from a dominant hegemonic position. Conversely, when I began my coming out process, I decoded this
experience using an oppositional code or position. Additionally, as I reflect on my experience as a poster child at the present time, I view it from a negotiated code or position. The way I view my experience as a poster child evolves as my identity development changes. Given this is true, my perceptions will always be fluid.

My interaction with the discourse that exists because I am a runner is similar. In high school I resented being called an inspiration because I wanted to be seen as normal. During that period of my life I ran in order to fit in with the able-bodied world. I resented being labeled as an inspiration because the super crip label separated me from the able-bodied world. However, as an adult I no longer run in order to fit in with the able-bodied world. I run now because I enjoy it. Since I no longer run in order to achieve normalcy, I do not care whether or not I am storied as inspirational by the public discourse. Hence my attitude toward this discourse has evolved over time, and it will probably continue to do so as I move through life.

My evolving attitude toward the way I am storied in public discourse was one of the most important revelations that occurred during the process of writing this autoethnography. When I began writing my story over three years ago, I thought that my experience with the March of Dimes was negative and that the organization was evil because it uses poster children. I have come to view the March of Dimes use of poster children in a more nuanced way. While I wish the March of Dimes would not use children in order to raise money, I no longer see the practice as purely evil. Furthermore, I have come to believe that charity organizations such as the March of Dimes are a positive force in the lives of many people with disabilities. Thus, they are necessary, and
probably should not be viewed as immoral. Additionally, it will remain important and useful to raise this question, all the while understanding that it is not helpful to stereotype every charity organization that uses them.

On a broader note, the identity development of individuals with disabilities is impacted by how disability is framed in public discourse. Professionals that work with other people with disabilities need to recognize the impact this discourse can have. Professionals should avoid preprocessing individuals into stereotypical categories. Instead, anyone who works with people who are disabled must strive to look beyond simple labels of disability. Professionals need to understand that those with disabilities are more than a label. They are people first.

Other Emergent Research Themes

The Stigma of Disability

While my interaction with the public discourse that depicts my disability was one of the major themes of this dissertation, there were other significant themes that emerged as well. Some of these themes cannot be encapsulated in my discussions of my three research questions. Therefore, I will now explore those significant themes that emerged in this dissertation. They are: (a) the Stigma of Disability, (b) Cultural Identity and Contradiction, (c) the Role of Family Scripts in Identity, and (d) Identity Development as a Relational Endeavor.

One significant theme that emerged in this dissertation is that people with disabilities are often stigmatized (Devlieger, Albrecht & Hertz, 1997; Gilson, Tulser, & Gill, 1997; Hahn, 1997; Juette & Berger, 2008; Onken & Slaten, 2000; Siebers, 2008).
That should not be news to many. What we often neglect is that because many people with disabilities face stigma in their everyday lives, they internalize oppression about their own disability (Berger, 2009; Butler & Parr, 1999; Corker & French, 1999; Davis, 1997; Siebers, 2008; Snyder, Brueggemann & Thomson, 1997). As a result of this internalized oppression, people with disabilities often develop a negative self-image.

In fact, much of my own struggle with identity was a result of internalized oppression. That is to say, I had so internalized negative cultural images about disability that I came to dislike myself because I had a disability. In order to develop a positive self-image I had to move beyond my own internalized oppression. It stands to reason, that there are other people like me who have disabilities who must overcome internalized oppression in order to develop a positive sense of self. Hence, internalized oppression remains a significant barrier to identity development for those with disabilities.

**Disability as a Cultural Identity and a Contradiction**

While acknowledging that disability is a stigmatized identity was an important theme in this dissertation, the notion that my disability was a cultural identity as well was a significant theme. In other words, the fact that I live with an obvious physical disability makes me part of a unique culture that is separate from the world of people who are able-bodied (Davis, 2001; Gill, 1994; Juette & Berger, 2008; Shakespeare, 2006; Shaw, 1994). Moreover, part of my identity development process involved my realization that I wanted to be a member of disability culture. As a person with a disability I lead a co-cultural existence. I try to assert my existence within my disability culture on the one hand, as well as my right to be part of the world and culture of people who are able-bodied on the
other. Negotiating my multicultural existence continues to be an ongoing reality and tension in my identity development as a person with a disability.

A theme related to my cultural identity that emerged in this dissertation is the concept that my identity as a person with a disability is often a contradiction. My life as a person who has an obvious physical disability is fraught with dialectical tensions that I must negotiate on a daily basis. This realization was another surprise to me. When I began the process of writing this dissertation I only thought tensions were present in my personal relationships. However, as I began to reflect on my identity development, I began to realize that the idea of disability itself is a dialectical tension.

In this dissertation, I explored some of the most significant dialectical tensions present in my life. I will not include the dialectical tensions that I have already described in this chapter. In addition, this is not meant to be an exhaustive list; these are simply some of the most important tensions that impacted my identity development.

One major tension that exists in my life as a person with a disability is the push and pull between the physical reality of my impaired body on the one hand, and the socially constructed reality of disability on the other. My disability is partly a physical reality. I walk on crutches, struggle with my coordination, and have trouble doing anything that takes dexterity. That is a physical reality of my disability that needs to be acknowledged. (It is not as if I could ignore it anyway!)

Along with this acknowledgment though, I understand that my disability is also socially constructed by others in a way that limits my access to mainstream society. For example, the Office of Disability Services at Ohio University has placed many of its
critical advisor and director’s offices in inaccessible locations. In so doing, the Office of Disability Services has constructed my physical inability to walk upstairs into a socially created barrier.

Furthermore, my identity as someone who has a disability is affected by the interaction between the physical reality of my impairment on the one hand, and the social construction of impairment on the other. This realization illustrates another way in which the process of writing this dissertation has changed my understanding. When I started writing this dissertation I viewed disability entirely and only as a social construction. I felt that the way society discriminated against me because of my cerebral palsy was the most important factor in my identity development, and that my medical condition was not relevant. However, as I reflect on my life, I now understand my identity has been shaped both by the physical reality of my impairment, as well as the social construction of my disability.

Another important dialectical tension exists between the social forces that may limit or enhance persons with disabilities access to mainstream society, versus an individual's ability to take an active role in his or her own life. While many people with disabilities are limited by social forces that impact their ability to take part in society, most individuals have the ability to act and effect change in their own life. As someone who has cerebral palsy, I encounter discrimination on a frequent basis. Whether I am denied physical access to a building because of my disability or I am treated differently because I walk on crutches, this discrimination does impact my life. Yet, I still retain and claim the ability to define for myself what my disability means. I have the personal
agency that allows me to choose either to see my disability in a positive or negative way. Therefore, my identity development has been affected by the tension between social forces on the one hand, and my personal agency on the other.

Another important dialectical tension that has impacted my identity development is the tension I feel between abnormality-normality. This tension highlights the difficulty I often have when I try to move between the culture of disability and the culture of people who are able-bodied. Part of me happily embraces my abnormality and also enjoys my place in disability culture. Another part of me wants to be able to assert my normalcy in the world of people who are able-bodied. There is a constant internal struggle between my willingness to be abnormal and my desire to be normal. In fact, I am never quite sure whether I want to be normal or abnormal on any given day. It is fair to say though, that much of my journey to understand my identity has been impacted by the dialectic between abnormality-normality.

Realizing how the dialectic such as abnormality-normality impacts my own identity development helps bring a deeper understanding to that the process. All the dialectics that I described have had a significant effect on the way that I view my disability. These dialectics also demonstrate that the process of identity formation is a complicated endeavor. There are frequently contradicting forces that can impact the process of identity development. Therefore, scholars who are interested in issues of identity would benefit by trying to discover the significant dialectical tensions that may impact a person's identity.
The Role of Family Scripts in Identity Development

While dialectical tensions play an important role in the process of identity formation, the central role that families play in this process should not be overlooked. One major theme of this autoethnography is the impact that my family's script about my disability had on my identity. Certainly, my family played an important role in helping me shape my identity. Moreover, my family like all other families, created various scripts that allowed our family to function (Atwood, 1996; Byng-Hall, 1995; Terry & Campbell, 2009). These family scripts help to shape individual identities within our entire family unit. Clearly, having cerebral palsy not only affected my identity development, but as part of a family and its attendant family script, my disability affected the identity development of each person in my family to varying degrees and in different ways, just as their identities impacted me.

Perhaps the most powerful family script for me was the family script that promoted normalcy. In other words, my family script encouraged me to overcome my disability in order to lead a normal life. This script had a profound effect on me and for most of my life I have tried to live up to it. However, once I began to come out and embrace my disability, I no longer felt the need to live up to my family script, at least on a conscious level. Furthermore, choosing the attitude that I had towards my disability altered the way in which I interact with my family. In particular, my mom struggles to understand my new attitude about my disability. There is little doubt my identity development is impacted by these changing interactions with my mother.
Therefore, disability scholars who are interested in issues of identity could benefit by examining the role that family scripts play in the process of identity development. For instance, not only did my family script impact how I saw my disability as a child, but it still affects the way in which I interact with my family at the present time. In order to comprehend my journey in order to understand what my disability means, it is important to interrogate the role that my family script plays in the journey. It also stands to reason that family scripts play an important role in the process of identity formation for other individuals who have disabilities. Consequently, more research needs to be conducted that explores the relationship between family scripts and identity development.

**Identity Development is a Relational Endeavor**

Another major theme this dissertation produced is that identity development is largely a relational endeavor. That is to say, personal relationships have a tremendous impact on how an individual may view his or her identity (Baxter & Ebert, 1999; Baxter, & Montgomery, 1996; Braithwaite & Harter, 2000; Fiduccia, 2007; Frame, 2000; Guter & Killacky, 2004; Tepper, 1999). There is little doubt that my relationships greatly affect my identity as well. Thus, in one sense this dissertation is a dissertation all about my relationships. I explored many different relationships that I have with people. Some of these relationships, such as the one I have with my girlfriend Jane, are intimate and personal. Other relationships, such as the one I have with my advisor, are professional. Still, other relationships are more distant, such as the interactions between me and individuals in the media who have depicted my disability. Even though I interact with
these individuals differently, these relationships all have had a profound effect on my identity development.

I must admit that when I started writing this dissertation I did not think that I would spend so much time examining relationships. When I began writing this dissertation I had initially intended to examine how I interact with social institutions such as the Social Security Administration, and how those large societal institutions script my identity. However, as I began to delve into the significant factors that have impacted my identity development I realized that social institutions did not have as big an impact on my identity as I initially thought. What I did discover was that relationships with other people, whether those relationships were personal or distant, had the most significant impact on my identity development.

In turn, this made me realize that scholars who explore disability and identity will benefit if they understand the important role that relationships play in the process of identity development. My own experience taught me that while institutions such as the Social Security Administration do play an important role in the lives of people with disabilities, it is important that scholars avoid the trap only of focusing on those institutions. At a minimum, examining the relationships between those who work within these institutions and how they interface with persons with disabilities would bring an important focus that could be as or even more enlightening than the institutional role only.

Relationships are central to the identity development of people with disabilities. Hopefully, this autoethnographic dissertation illustrates the complexities that occur in
interability relationships. As I continue on the journey that is my life, I am certain that I will continue to engage in various relationships that will affect my identity development.

**Recommendations**

Autoethnography is a relatively new research methodology. Some people immediately think it is simply telling one’s story, such as an autobiography. Those who have worked with this methodology understand that when done well, it is a powerful format for inquiry and research. Because its focus draws on the life stories of an individual or individuals, it almost goes without saying that an autoethnography would generate powerful recommendations for practice. Autoethnography values the role of narrative and story as processes for making meaning. It would follow as well that autoethnography would generate recommendations that point us in the direction of things that will assist us in co-creating our human stories. The recommendations that I make here are intended for educators, scholars, and professionals who are impacted by and care about issues that affect individuals who have disabilities.

1. There is a need for more research that explores the complexity of identity development for people who have disabilities. Counselors, teachers, and other professionals need to be aware of the way that identity development can affect people with disabilities. For instance, an individual who is trying to “fit in” with people who are able-bodied may reject an accommodation if he or she feels that accommodation will separate them from people who are able-bodied.

   For example, when I was in high school I would often choose not to use accommodations because I wanted to be normal. Therefore, I would reject
accommodations that I needed so I could fit in with my able-bodied classmates. In those instances, my intense desire to be normal impacted my ability to effectively adapt to the world around me.

While some people with disabilities might reject an accommodation because they want to fit in with the world of people who are able-bodied, others may turn down an accommodation because their desire to fit in with a certain segment of disability culture. For instance, many individuals who identify themselves as members of Deaf Culture reject medical procedures such as cochlear implants that are designed to “fix” a hearing impairment. Many members of Deaf Culture do not see themselves as disabled and they do not have a desire to be fixed via the biomedical model.

Whatever the reasons are that people with disabilities may choose to reject accommodations, professionals and scholars need to be aware of the process of identity development. Awareness of the identity development may help scholars and professionals understand how the process of identity development may impact the way that people with disabilities interact with the world around them.

2. Building upon my findings regarding the importance of relationships, further relational research could explore the issues of sexuality and disability with a particular focus on the way in which sexuality might impact the identity development of those who have disabilities. For instance, I developed a negative attitude toward my own sexuality in part because of my negative attitude about my disability. It stands to reason that other people with disabilities may have similar experiences to my own. Thus, it is important for scholars explore how the issues of identity, disability, and sexuality interact. Studying
these issues will provide scholars and professionals with a deeper understanding of intimate issues that impact the everyday lives of people with disabilities.

3. My family had a profound impact on my identity. Part of my journey to understand my identity has been a struggle to redefine my family’s script about my disability. Furthermore, now that I have come to view my family’s script about identity differently than I did when I was younger, my relationships with family members are impacted. Therefore, additional scholarship could endeavor to explore the role that families play in the process of identity construction for people with disabilities, including the way that family scripts can impact the process of identity development both for the individual with a disability as well as able-bodied family members.

4. There is little doubt that my identity development has been impacted by the contradictory nature of my identity as a person with a disability. It also seems reasonable to assume that other people with disabilities might have to deal with the contradictions that are present in their identities as people with disabilities. Thus, scholars in the field of disability studies should continue to investigate the conflictual nature of disabled identity. Furthermore, more scholarship could explore how the inherent dialectical tensions that are present in the construct of disability might affect an individual’s identity development.

5. Although I did not explore these concepts in this dissertation, it is possible that my story contains elements of survival and resistance. It also seems likely that these elements impacted my identity development as a person with a disability. In fact, the issues of survival and resistance can certainly have a significant impact on the process of identity development for many individuals with disabilities. Therefore, scholars should
examine the way the dynamics of resistance and survival impact the process of identity
development for those with disabilities.

6. The journey of writing this autoethnography has not only given me a deeper
understanding of identity development for people with disabilities, but it also has given
me a better understanding about how the process of identity development may affect
people who are members of other minority groups. In short, the study of issues of
disability and identity has enhanced my knowledge of issues that relate to other diverse
populations. Therefore, faculty who teach courses in areas where diversity is a focus
should address critical disability issues, including the topic of identity development. This
will allow professors and students to explore the differences and similarities between
people with disabilities and individuals who are members of other diverse groups as it
relates to identity development and how that impacts the interaction between society and
marginalized groups.

In addition, those undertaking research that explores the process of identity
development for minority groups (outside of people with disabilities) should juxtapose
how the process of identity development might compare for individuals who have
disabilities. Including people with disabilities in their scholarly endeavors may help them
broaden their perspective.

Ah-hah! Autoethnography as a Tool for Personal Growth

Now that I have discussed some recommendations for educators, scholars, and
other professionals who may be impacted by issues that affect people with disabilities, I
discuss the impact that the process of writing this autoethnography has had on me
personally. The act of telling one's story can have a powerful effect on an individual. As Byng-hall (1995) states, "Undeniably, the story itself is more powerful than the events it has been created to reveal and explain" (p. v). This has certainly been true in my case. The act of telling my story has changed who I am. It has also helped me understand certain aspects about my personality about which I was previously unaware.

To begin with, writing this autoethnography helped me realize that sometimes I have an overinflated ego that tends to make me think that I have the right answer. I also tend to think that I can solve any issue or problem. By reflecting on my own journey of identity development I have come to feel that often there are no right answers to a problem. Moreover, what I thought I "knew" about my identity as a person with a disability at the beginning of this process is not what I ended up "knowing" by the end of it.

My experience as a poster child for the March of Dimes is the perfect example of how utilizing this methodology surprised me. When I started writing this dissertation I knew that my experience as a poster child was horribly negative, and that the March of Dimes’ use of poster children was evil. After reflecting on my experience, my attitude towards my experience as a poster child for the March of Dimes has changed. I now view this issue with more ambiguity. That is a direct result of what I learned during the course of writing my autoethnography.

Another thing I learned about myself is that I can be hard on able-bodied people that I feel do not understand what is like to live with a disability. In the past, I have been quick to judge people, and often my judgments about them are incorrect. For example,
after the fiasco that occurred during my comprehensive exams I was extremely upset with
my advisor. I was quick to assume that she did not understand nor care about my
experience as a person with a disability. However, I was completely wrong in this regard.

As I have worked closely with my advisor during the process of completing this
dissertation I have come to see that she does care about disability issues. I have also come
to realize that she cares about me as a student and a person. My experience with my
advisor has shown me that I need to be more careful not to judge people who are able-
bodied too quickly.

Finally, the process of writing my autoethnography has helped me appreciate the
journey that I am on. When I began writing this dissertation I could not wait to get to the
end of the process. In short, I was only concerned about my destination. I was only
worried about where I would end up. I was not concerned with what the process of
writing an autoethnography might teach me. Little did I know then that the methodology
itself, if one allows it to unfold, would become an integral part of my journey both
personally and academically.

However, now that I am finished writing my “story” of inquiry I realize that the
process itself was more important than the journey. After all, if the process of inquiry
does not change us or the world and space in which we live, what is the point of that
inquiry? While I am proud of the finished product that is my dissertation, I am more
proud about what I learned about myself along the way. I have learned to embrace the joy
of this intellectual journey. Perhaps, I can explain it best by paraphrasing one of my
favorite poems: Two paths converged in the woods, I took the one less traveled by, and that has made all the difference. Rock on!
References


Blackledge, S. (1993), Admire him but forget the pity. *The Columbus Dispatch*, pp. 01E.


Community Development Journal, 42(4), 501-511.


Qualitative Health Research, 12(9), 1184-1201.


Smeltzer, N. (1994), Just another kid. *The Columbus Dispatch*, pp. 06B.


Ware, L. (2001). Writing, identity, and the other: Dare we do disability studies? *Journal of Teacher Education, 52*(2), 107-123.


