Family, Disability and Identity
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Abstract

Many people with disabilities struggle with issues that relate to identity development. Many people with disabilities find it difficult to develop a positive sense of self. There is also no question that familial relationships play a significant part in the process of identity construction for people with disabilities. Thus, it is important to examine how family relationships influence the process of identity development for people with disabilities. Conversely, it relevant to explore how a person’s identity development can impact his or her relationship with family members.

Thus, this article employs an autoethnographic approach to research in order to examine issues that relate to disability, identity and family. This paper elucidates the complex nature of family scripts and identity. In addition this paper contends that the process that an individual goes through in order to “come to terms” with a disabled identity, can transform the relationships that an individual has with various family members.
Introduction

People with disabilities often struggle with issues of identity development (Consalvo, 2004; Davis, 1997; Fries, 1997; Joseph, 2010; Linton, 1998; Williams, 2010). Those with disabilities frequently face isolation and discrimination in their everyday lives that often cause them to have a negative sense of their own 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).

Moreover, 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).

Therefore, 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).

In order to scrutinize the relationship between identity, disability and family, this article will use an autoethnographic approach in order to elucidate the impact that familial relationships have on my identity development as a person with a disability. Conversely, this study also illuminates how my identity development as an individual with a disability has affected my relationships with various members of my family. Hopefully, this article can shed more light on the ways in which familial relationships can impact the identity development of those who have disabilities. Before I further interrogate issues of family,
disability and identity, it is necessary for me to explicate the research methodology of autoethnography. It is to that discussion that I now turn.

**What is Autoethnography?**

In its simplest definition, 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 the ways in which my family’s able-bodied values impacted my identity development as a person with a disability. Conversely, the autoethnographic approach also allows me to explore how my identity has influenced my relationships with various family members. In addition, writing an autoethnography allows me to contrast my own experience with the broader academic discourse that discusses issues of disability, identity and family.
Identity Development and People with Disabilities

Now that I have explained the autoethnographic approach that I will use in this article, it is important for me to define the concept of identity development. The notion of identity development emerged in the late 1960s 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 who 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, 1997; Hernandez, 2005; Ostrander, 2008; Whitney, 2006).

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.

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 multicultural 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).

While Gill’s model ends with the process of *coming out*, I contend that going through the process of identity development is a much more ongoing fluid experience that does not end simply because someone openly chooses to embrace his or her disability. In fact, there can be little doubt my identity development as person with a disability has been influenced by the relationships that I have with those
closest to me. Identity at its core is a relational endeavour, thus 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). Thus, I examine my familial relationships, because family is the place where the process of identity construction begins.
Identity and Family Scripts

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." 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 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. There is little doubt that my family had a tremendous impact on how I perceived my disability. They constructed a family script that pushed normalcy as my ultimate goal. My family's script explicitly and implicitly told me that I should work hard to overcome my disability and achieve an able-bodied standard of normalcy. This family script shaped how I and my family members interacted with my disability.

Before I can further discuss my family's script towards my disability, it is important to discuss the concept of scripts in general. Atwood describes a script as a "device 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" behaviour. 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, but she 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)
To Walk or Not to Walk

I now provide an example from my experience in order to demonstrate how families can pressurize 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.

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 easier 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 were 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 an 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 there 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 as 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 behaviour, 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. It is not an easy choice 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; it was because 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.
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 from the way 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 of 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 whom 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.
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