

Dynamics of Concealed Disabilities among Students
at a Major Research University in a Rural Area

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ABSTRACT

This research explores the experiences and attitudes of nine full-time students with disabilities at Virginia Tech who choose to conceal their identity as individuals with disabilities in various contexts. The definition of disability is expanded to include those individuals who perceive themselves to be disabled, with or without meeting diagnostic or legal criteria, since many of those who conceal their differences may choose not to pursue such forms of official classification and identification. In a series of interviews, participants provide insight into their experiences, labels and discourse that have shaped those experiences, and outcomes of identification as individuals with disabilities. A variety of themes emerging from the interviews, under the categories of experiences, labels and discourse, and outcomes of disability, are analyzed and discussed. This research aims to explore and develop a greater understanding of these individuals and what their stories have to offer through an emic perspective.

DEDICATION

For Evelyn Ballard, my mother, who facilitated my dreams and walked with me as I went through this whole process, demonstrated love and faith in me, and taught me to see the world from new perspectives. We have struggled together to get me where I am, and I am thankful that we have finally gotten to the completion of this part of this journey. Her intellect, strength, and compassion constantly inspire me. And, for my brother Todd King, the real brains in the family, who always had the courage to move forward and has helped me to do the same.

PREFACE

As I sit here on my porch, surrounded by books and articles, I try again to convince myself this is fun. Actually, it is fun at many levels –summertime is just a difficult time to stay lost in articles and library shelves. Somehow, the birds flocking around the feeders, the gentle sway of the hybrid poplars I planted when I started this doctoral program, and of course my cat who has curled up beside me, are a bit more captivating. Sometimes it helps to just sit and think about it all, when I don't notice too many birds and other distractions.

First, I have to ask myself, “What am I trying to achieve here?” Certainly, I must consider who benefits from this work. Many individuals with concealed disabilities want anything except recognition; their disabilities remain hidden because they choose to conceal them. Boler (1999), notes, “These ‘others’ whose lives we imagine don’t want empathy, they want justice” and that she is “not convinced that empathy leads to anything close to justice, to any shift in existing power relations” (Boler, 1999, p.157). Therefore, I am cautious about suggesting a desire for an empathic response from readers. If power differences are not resituated equitably, empathy can too closely resemble pity –pity denoting not only difference, but also inequality. Moreover, I cannot presume to “create” justice with a text.

The population I want to research, individuals with concealed disabilities, ultimately contains all of us. At the best, we are all temporarily abled (Gerschick, 2000; Pfeiffer, 1999), if that. We all have those hidden “flaws” and differences we conceal from one another. There are all those moments when we are marked as deviants from the norm. Some of us remember being in a class where everyone else seemed to catch on more quickly. Some of us recall a game at recess where everyone else was picked for teams first. Some of us cringe when we remember peeling skin, acne, or a pimple that appeared right before school pictures or the prom. Some of us think about how everyone else seemed to have the ability to hold a conversation, while we failed to find a voice. Some of us remember fading into the corner, wishing we could be like the popular, the beautiful, or the talented. Some remember disfigurement, deformity, seizures, sickness, hunger, abuse, depression, pain, or impairment. I do not intend to equate the severity of some conditions with the relative triviality of others. However, it is important to understand that to some degree we all have aspects of ourselves we wish to conceal. In some contexts, we find ourselves privileged, gifted. In other contexts, we have very real deficits.

Disabling conditions have touched my family, friends, and me in many ways: breast cancer, back pain, depression, fibromyalgia, cancer, heart disease, arthritis, high blood pressure – the list goes on. Memory often takes me to places I would rather not be.

I remember cold mornings as a child, while my mother was in the hospital recovering from surgery. Only eighteen years older than me, she was young, and it seemed unfair for her to be going through all of this. I recall the fearful, empty feeling as I nibbled on toast in an empty house, dreading the chilly walk to catch my school bus. I could hardly swallow; held back tears made my throat tender and sat behind my eyes like clenched fists. I needed my mother to hug me.

Sometimes after school, my father would take my little brother and me to see my mother in the hospital. She would smile with her bright blue eyes fixed on my little brother and me. We

would not get to stay long. Other times my father wouldn't get home in time to take us to see her. Often he would not get home before we had to sleep. We would put ourselves to bed, sometimes hungry (we couldn't cook), frightened in the empty, little house. I needed to know my mother would be home soon. I found no reassurance. Another morning would bring another day as bad as the last.

At night, my mind sometimes wanders into a hospital room back in 1981. My grandmother lies against the slightly elevated mattress, her eyes pale as smoke. Her lips are thin and blue. Wisps of her cropped silver and white hair spread across the pillow. She is wearing a flowered hospital gown, faded and stained with iodine. The hiss of oxygen, spewing against her tracheotomy tube, is the only sound besides the beeps and buzzes of the machines keeping her alive. Cancer had taken a breast and her voice, and it had begun to win the fight to take her life.

She is silent. Her hand, strapped to a board and punctured with IV's, taps against the mattress. And, I just stand there, no idea what she is telling me. As I write this, I try to pierce those barriers to communication and understanding. It is too late to know what my grandmother was trying to communicate, but, as I do this research, I hope to develop awareness of the needs and "voices" of individuals around me in this process.

Even now, I think about conditions, many hidden, that plague the ones I love. I know what it means to have a concealed disability myself. I know what it is like to be the misunderstood, the one on the other side, not quite able to communicate my needs. Perhaps, in some way, I want catharsis, a record, an acknowledgement that they survive, that I survive. I do not want this to gain sympathy or empathy; I want to document a truth and share knowledge that will result in empowerment, not pity. Accommodation and acceptance should never be an act of contrition, rather, in a humane society it must become the automatic response to difference.

A nurse escorted a boy into a cold, dark room in a hospital. Three men in white coats and the boy's father followed. The doctors set up a camera and made boy undress and stand in front of a backdrop.

The oldest of the three doctors kept talking throughout the process. He yelled to the boy, "Turn to the left. A little more toward me. Okay, stop."

The boy stopped as the camera flashed three times.

"Get them to turn a quarter of the way to accent the extent of the deformity," the older doctor explained to the others.

Deformity. The word echoed through the boy's mind. Deformity. He was deformed. It had never occurred to him before, but now he stood ashamed, crushed, longing to put a shirt back on and hide his deformity. It had never bothered him before. Being without a shirt didn't bother him, until that moment. He would learn to dread swimming, gym class, the beach, or any other situation where he would be exposed.

After a series of photographs, the nurse escorted the boy and his father into an office where the older doctor asked if he wanted his chest repaired. Everything in the boy screamed "Yes," but the only words verbalized came from the boy's father. "No."

The boy had gone to the doctor with little concern. He left devastated, with a crushed self-esteem, condemned to years of self-conscious shame and self-doubt. He would shrink into corners, trying to live in shadows. He forgot how to laugh, make friends, and even be himself. He consoled himself with religion. He buried himself in books. He died inside, because he didn't want anyone to see his outside. Later, doctors would burden him with other diagnoses – depression, insomnia, ADHD, sleep apnea, anxiety. Doctors were not the only care providers.

The boy's dentist, a member of the church he attended, told him that it was a shame he had never worn braces because his teeth were a mess –crooked, discolored from iron supplements he had to take as a child. The dentist laughed and said, "I guess it's embarrassing. I bet you don't smile too much. Of course, it would be expensive to fix any of it now."

Sure, he was probably trying to drum up business. The attack on the boy's self-esteem didn't sell braces or bleaching though. It did further harm the boy, who learned to keep his mouth shut, who didn't "smile too much" anymore, who began to experience even greater anxiety when he had to be in front of other people.

Teachers complained because the boy seemed distracted and daydreamed. He could listen better in class while he was scribbling in his notebook. Multitasking worked for him, and in the real world would be an advantage. In the classroom, it resulted in punishment. Many things that would have been advantageous in the real world were punished in the classroom. His sixth grade teacher would spend a great deal of time teaching "Bible." The classroom served as a place to proselytize children. The boy made the mistake of asking "the wrong" questions too often during these sessions. As an adult, the boy would recognize the punishment as abuse, but then he was afraid to tell his parents or anyone else what was happening. The floor of the classroom had brown tiles, except for one red tile near the front. The teacher would make the boy stand on the tile until he cried. Sometimes he would spend stretches of two or three entire school days before he could humiliate himself in front of the class by forcing tears. The same teacher, with another teacher, invited every student in the class, four at a time, to eat at his home. While they were there, the teachers tried to get these children to "confess their sins." The boy, who already had become as religious as those adults, still remembers being told he had a "black heart." He never forgot.

The dentist and the teacher were not the only examples of religion's influence. The boy attended a nearby church, because it was in walking distance. Unfortunately, it catered primarily to wealthier individuals. The youth group didn't even bother inviting the boy to their ski trips, camping trips, and beach trips. Perhaps, they knew he could not afford it. They would complain about affordable activities though; so, they never did anything for the few less privileged children. They would however make a point to ask them where they were and why they didn't go on the outings, which they hadn't been told about to begin with. They would talk about how they were all invited to someone's house for a birthday party or had decided to go ice skating. Somehow, they never called or invited the boy. He assumed he just wasn't good enough. The boy stayed after and cleaned up after youth group, played piano, taught Sunday school, helped with vacation Bible school, and volunteered for anything others did not want to do. When thanks was offered in the bulletin or from the pulpit, they always forgot the boy, often crediting someone else.

Service providers became esteem crushers, labeling him as deformed, unattractive, unworthy, and unhealthy. All of the diagnoses were insignificant, compared to the impact of the stigmatization.

I look back at that boy, and I feel sorry for him. I used to feel just shame for him, but years and growth have brought me to a place where I feel compassion for that boy. I wish I could go back in time and tell him that it really doesn't matter, that those insensitive words from a doctor did not have to define his life. I would tell him not to waste his childhood mourning the death of what could have been and to focus on what can be. Of course, I cannot change one moment of the boy's experience, since his experience made me who I am today. I cannot erase the pain of being that boy, and I cannot forget what I know about stigma and shame. It doesn't go away quickly. He never wanted pity, but he needed and still needs empowerment. I find myself in the same old contexts, and I revert to that boy. Away from my hometown, my family, the individuals I grew up around, I am a counselor, an instructor, a leader, an expert, a scholar, and a man. However, if I go back to the places where I grew up, the expectations that have been built throughout my life drown me with self-doubt. The boy appears and quietly hides behind my face, and the man that I am the rest of my life dies, shrinking behind the frail figure of an otherwise abandoned child. The irony remains that our shackles are often our wings as well.

Photographs of my family hang in my home. One captures the image of my grandfather boxing. He is young in the picture, no more than twenty. Only one decade of the twentieth century had passed when the photographer took the picture. He stands poised and tall, facing a man a third bigger than him. I see the stubbornness and determination in his eyes. The little image, fading and blurry, reminds me to fight back. It reminds me we have choices, and we can choose to stand our ground. Another picture shows my grandmother carrying one of the ten infants she mothered, doctored, and somehow fed in spite of shortage. She traveled across the country by train with sick children, my grandfather, and a number of family members to Washington State during the depression years, hoping to find a better life, only to travel back to these mountains. Where hope ended, determination began. My favorite picture shows my mother. She is a little girl holding a leash on a small white dog named Cookie. The late-life child of parents with failing health, her childhood was cut short. I look in the face of that little girl, and I see loneliness. All of her siblings were older and had moved on. Her nieces and nephews, some older than her, lived in their own worlds, children of much smaller families with younger parents. She did not receive the encouragement she deserved. Prompted to marry quickly by aging parents, she missed opportunities for a career. My mother gave me the attention and encouragement she never received. She fought for me to have everything she didn't get to have. These images remind me of where I am from. I want this text to be a collection of similar images, a snapshot of real individuals in real context, or geography, sharing what it means to experience what they do.

Gloria Anzaldúa (1999) wrote about what it meant to her to live between cultures on the Texas/Mexico border, and that is what I intend to capture on the borders of "normal"/disabled, dignified/stigmatized, and marked/markable. As I explore the geography of concealed disability, this area of marginality, I hope to understand the topography of the emotional landscapes, the topology of disability itself, and the spaces and regions in which these individuals live. I want to discover that place between cultures where individuals with concealed disabilities live. I wonder if that place will be as fluid as a river, rising and falling, expanding and shrinking with the

seasons, the weather, and the opening and closing of floodgates. I wonder if, in that confluence, I will find everyone shares the same experiences.

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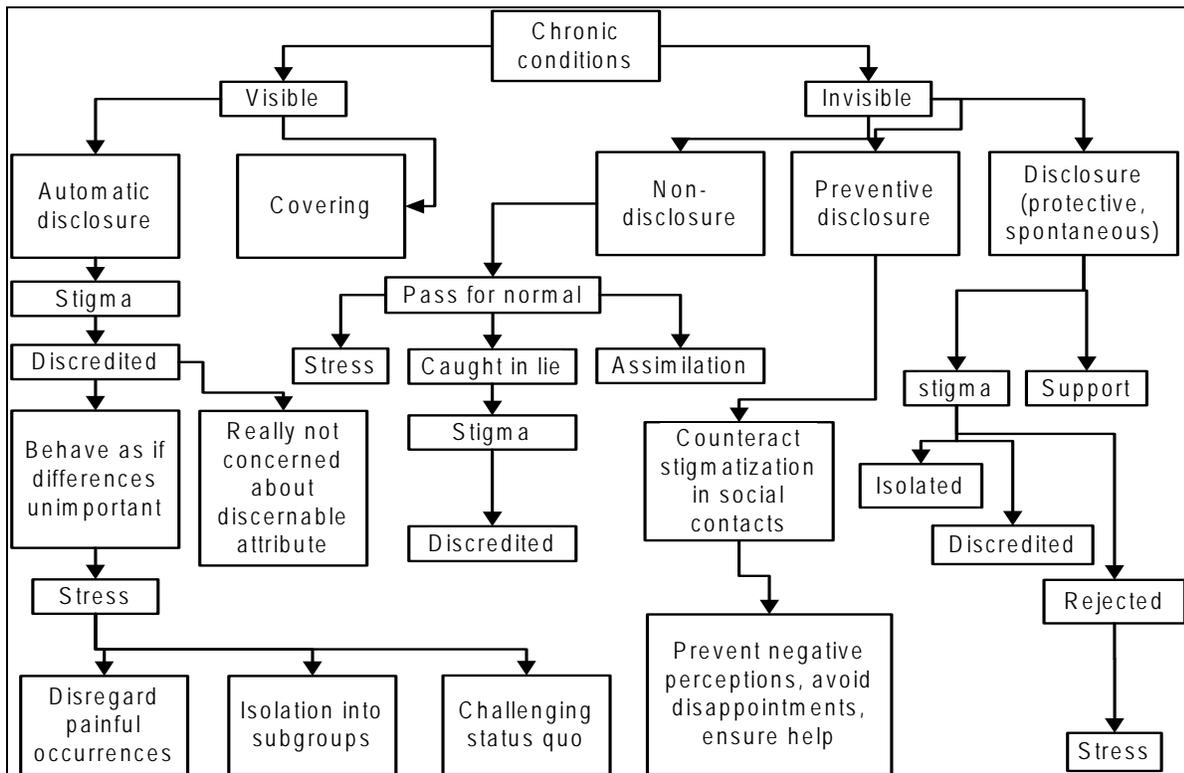
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CHAPTER 1: INTRODUCTION

Concealed disabilities have an influence on us every day, whether we are aware of them or not. Society inundates us with images of “abled” individuals, what it means to be fit, attractive, and worthwhile in our culture. None of us quite measures up to the expectations our society pretends is the norm. This results in stigma. It also leads to more concealed disabilities. With the term, concealed disabilities, I am referring to personally recognized chronic conditions that have been purposefully concealed from others, whether they require great effort to conceal or not (See Figure 1). While most of the time the term “concealed disabilities” is used interchangeably with the term “invisible disabilities,” invisible disabilities more specifically refer to disabilities that require no special effort to conceal. They will not become apparent –even after prolonged contact with another individual. They may include heart disease, cancer, or a learning disability. Invisible disabilities intersect with concealed disabilities. Invisible disabilities may or may not be disclosed, while concealed disabilities and their associated signs are concealed in some contexts. The distinction between the two tends to blur in much of the literature, and, for that reason, I will generally opt for the term, concealed disabilities, unless I do mean to include disclosed imperceptible disabilities. It is worth noting that *invisibility* refers to the perceptions of the observer, while *hiding* and *concealing* refer to the actions of the individual with the disability. Concealment is a choice, which may serve to liberate or oppress.

Figure 1: Diagram of Chronic Conditions (Based on Joachim & Acorn, 2000).



I will use person-first language when referring to individuals with disabilities. This is somewhat problematic, since it equates disability with diagnoses (Zola, 1993). Qualities, differences, ethnicities, and affiliations are typically expressed in adjective-noun constructions

(e.g. friendly person, Black woman, Jewish teacher). Defined as an identity, disability describes what a person is, not what a person has. When we use the construction “people with,” we are suggesting that individuals incidentally have something; however, culture is a matter of being not having (Lane, 1997). If disability places us within a group and assigns an identity, the adjective-noun construction would remain more appropriate. In some cases, a group’s members have defined groups of people with disabilities as a cultural identity, such as deaf culture. I do not dismiss the power of a group-identity on the experiences of an individual with disabilities, even though my particular population may be less likely to interact with others with disabilities. Social forces shape our identities. Still, I am choosing to use person-first constructions to designate individuals within any model, as seems to be the trend in most of the literature. Looking at disability as a stigmatized condition, many opt for person-first language and avoidance of equating disability with primary aspects identity.

A widespread error has been an assumption that we can generalize disability across society, especially when we consider the differences between disclosed and concealed disabilities. An assumption of homogeneity, because we cannot see an impairment or difference in others, does not excuse insensitivity. Consequently, a study of concealed disability experiences becomes a study of the nature of difference and, unfortunately, often stigma. It also becomes a study of the nature of marginalization. It addresses important questions: What does it mean to only superficially fit into multiple communities? What does it mean to have a concealed difference? When does this difference become disability? What constitutes a disability, and who gets to draw the artificial line that separates abled and disabled?

Ellen

Throughout public school, I knew a young woman whom I will refer to as Ellen (pseudonym). She never attended gym class, never participated in recess, and always seemed to be wearing long pants and a man’s long-sleeved shirt. Even on the hottest of days, she wore long clothes. I noticed, but I paid little attention to it. I remember her thick glasses with dark frames and how they made her sad eyes seem enormous. She wore her long auburn hair with bangs that generally hung over eyes, and she buttoned her shirt up tight around her neck. Sometimes she wore a silk scarf around her neck or an oversized turtleneck.

I thought she was strange. She just faded into the background though. Few individuals talked to her, and I am not sure I remember her talking even once throughout school. We all ignored her for the most part. Compassion or recognition of her isolation never occurred to me. It was years after finishing school that I saw her walking at a local park in shorts and a short-sleeved shirt. Her hair was short and curly, and her glasses were gone, but I recognized her immediately. Scar tissue, pale and wax-like, probably from a fire, covered her neck, arms, and legs. Suddenly, I understood why she was “strange.” It all made sense. In her attempt to hide her scars from us, she still could not overcome the stigma of difference. I smiled and nodded at her as we passed on the path. She quickly looked away and kept walking. There was no reason why she should remember me. I was left wondering if she perceived my recognition as a privileged gaze or a stigmatizing stare.

Anna

A few years ago, a student I will call Anna (pseudonym) settled into a seat in the front in my literature class on the first day of the semester. She got there a little bit early, pulled her straight black hair back into a ponytail, and took out a small cassette recorder.

“May I record the class?” Anna asked politely.

“Sure, but we will have more discussion and activities than lectures, I’m not sure it will help you that much,” I responded.

Anna smiled and carefully inserted a tape into the recorder.

I was familiar with the type of student Anna seemed to be –attentive, prepared, ready to participate, taking notes about everything. I was mistaken. Anna just sat silently in her seat, doing nothing beyond turning the cassette tape over half way through the class.

Teaching a literature class, I had a habit of referring to the textbook during class. I began class as usual, giving an overview of what we would be studying, sending students from one text to another to supplement our discussion. I would sit quietly, giving them an opportunity to absorb and think about the texts. As others quickly located the pages in their textbooks and read the selections over, Anna just sat there. She didn’t even open the textbook.

I wondered as I led the discussion why this young woman would choose to sit in the front but not participate. At the end of class, while I gathered my class materials, I glanced up to greet students as they filed from the room. Anna was standing at the desk, hands folded in front of her, holding a sheet of paper.

“Yes, Anna?” I asked, perhaps sounding slightly annoyed with her.

She handed me a form explaining that she had a visual impairment and that she would need special accommodations. I realized as I read and signed the form that I had unintentionally excluded Anna. I had misjudged her. Her blindness had been invisible to me, because I had projected my beliefs about classroom behavior onto her. I had interpreted her deviance from the classroom norm as a character flaw, not considering other possible explanations.

Jesse

Jesse (pseudonym) attended a section of my Introduction to Expository Writing class at the university where I was teaching. He usually sat in the front row, dressed in khakis and crisply ironed shirt, and attentively listened and participated in class. He seemed to understand every concept, and he showed excellent analytical skills when we dissected compositions in class. When I received his first paper, I reread it in amazement. It was indecipherable. I stopped him after the next class before he left.

“Jesse, I wanted to talk to you about your paper. Could we sit down and go through it together?” I asked. I privately kept wondering if he been drunk, sick, sleepy, or otherwise impaired when he wrote the essay.

He glanced at his watch, shrugged, and sat down as I opened his paper and put it on the table between us.

“Could you read the first paragraph, and then we’ll talk about it?” I requested, turning the paper toward Jesse.

He stared at it a moment and looked up. “I’m trying to say that I think the reason Alice Walker shows the two sisters’ dispute over the quilt is to show two parts of herself. She has two sets of values she is wrestling with.”

“That’s a fine thesis for your essay,” I told him. “I need for you to read what you actually wrote, though.”

Jesse stared at the jumble of words on the page for a few minutes in silence and then looked up at me. “I’m trying to say . . .”

I interrupted. “Just read what you wrote. I understand what you were trying to say; I need to hear how you said it.”

He fidgeted for a while, looking down at the paper. Then, he nervously glanced up at me. “I’m sorry,” he mumbled. His eyes were turning red and moist.

We talked for a while, and he eventually produced an accommodation form. He had not wanted to let anyone know he had a learning disability.

Apparently, Jesse had many issues to work through during his transition into college. He had a lingering fear of failure and a mythology that all learning disabilities magically disappear in adulthood. Here he was in college, and he was quickly discovering that problems like this do not just disappear suddenly. However, even with the accommodations in place, Jesse had not been successful. He still could not write and, as a writing teacher, I could not report that he could. Waiver of the writing element of the general studies program was denied, primarily because of Jesse’s silence about his disability when making these requests. The cycle of probations, suspensions, and warnings finally culminated in dismissal. Still, I believe that seemed more tolerable for him than disclosure.

Jesse is just one of many students who suffer from a learning disability. Houck, Asselin, Troutman, and Arrington (1992) note an increase of students with learning disabilities on college campuses. They also noted that these students might be reluctant to inform their professors about learning disabilities, as I saw with Jesse, preventing them from receiving the services they need. As Stage and Milne (1996) discovered among college students with disabilities they interviewed in interviews with college students with disabilities, students are often unwilling to participate in classroom activities that could possibly draw attention to their disability or to being treated differently.

Ellen, Anna, and Jesse present just three examples of concealed disabilities and the interplay of stigma associated with them. They happen to be associated with educational settings, but these situations occur in every facet of life. There is no way to know exactly how many individuals have conditions they are able to conceal from others successfully. Still, it is important

to understand that the ability to function is a temporary condition (Gerschick, 2000; Pfeiffer, 1999). Everyone goes through periods of incapacitation—sickness, pain depression, exhaustion. Everyone grows older and eventually becomes unable to function as they once did. Of course, since these existential factors are common to us all, we have company in the process and an opportunity to remain part of a community with shared experiences. However, many individuals try to conceal these changes. The dynamics of how we cope with these changes, stigma associated with them, and our own disability, as well as our responses to others with disabling conditions, is integral to our development. Concealed disabilities present a particularly interesting set of concerns, since the decision to conceal or disclose these disabilities will have a powerful impact on relationships, opportunities, and personal identities.

Rationale

With legislation, such as section 504 of the Rehabilitation Act, and awareness as impetus, universities have made great strides toward the accommodation and inclusion of students with disabilities. In spite of the provision of these resources, some individuals prefer their anonymity to access to the services they need to be successful. Also, we must keep in mind that creating a welcoming environment involves more than removal of physical and psychological barriers. A social climate must be developed that provides acceptance for differences. Learning about the feelings and experiences of individuals who have felt the need to conceal those differences will help create an understanding of what contexts and situations remain intimidating or restricting. Through this knowledge, we can perhaps begin to explore the directions higher education should move in order to promote equity and inclusion at all levels of the academic experience.

Statement of the Problem

College students with concealed disabilities seem to exist on the borderlands between the experiences of “abled” and “disabled.” Joachim and Acorn (2000) add, “The relationship between visibility and invisibility and disclosure and non-disclosure is poorly understood” (p.247). Researchers may be able to depend on quantitative methods to explore some answers that lend themselves to dissection and simplification, but qualitative methods can allow a means for exploration of areas we do not understand in depth (Sofaer, 1999). We can explore what questions we need to ask. Still, there can be reluctance to new methodologies, especially a hybrid, as I suggest here. Reid (2001) notes:

As a field, special educators have been reluctant to move beyond quantitative conceptions of science that privilege generalization and quantification. As a result we have innocently disempowered the voices of people with disabilities who speak to us mostly through autobiography [. . .]. (p.104)

These students have an option to disclose, as well as a fear of discovery. The outcomes of inhabiting both sides of this border may be profound, as is any other type of division and marginalization between two divorced entities. The manner in which individuals experience and survive (or are destroyed) should teach much about both sides of the imaginary border and the borderlands, the blurred area somewhere in between.

On one side of the imaginary border society constructs, we find individuals who do not perceive themselves to be disabled in any manner. Even though they may have superficial or long-term impairments, they do not consider these to be disabling. They do not consider themselves part of any group or category of people with disabilities, with no thought of that being a temporary condition. They have imagined ability as a blank slate on which disabilities may be written to mar the surface and, perhaps, may be erased. They assume “ability” is the *natural* condition. Being abled, however, from a biological point of view remains the minority condition. If society has a norm, it would more likely be that of impairment, difference, or disability to some degree.

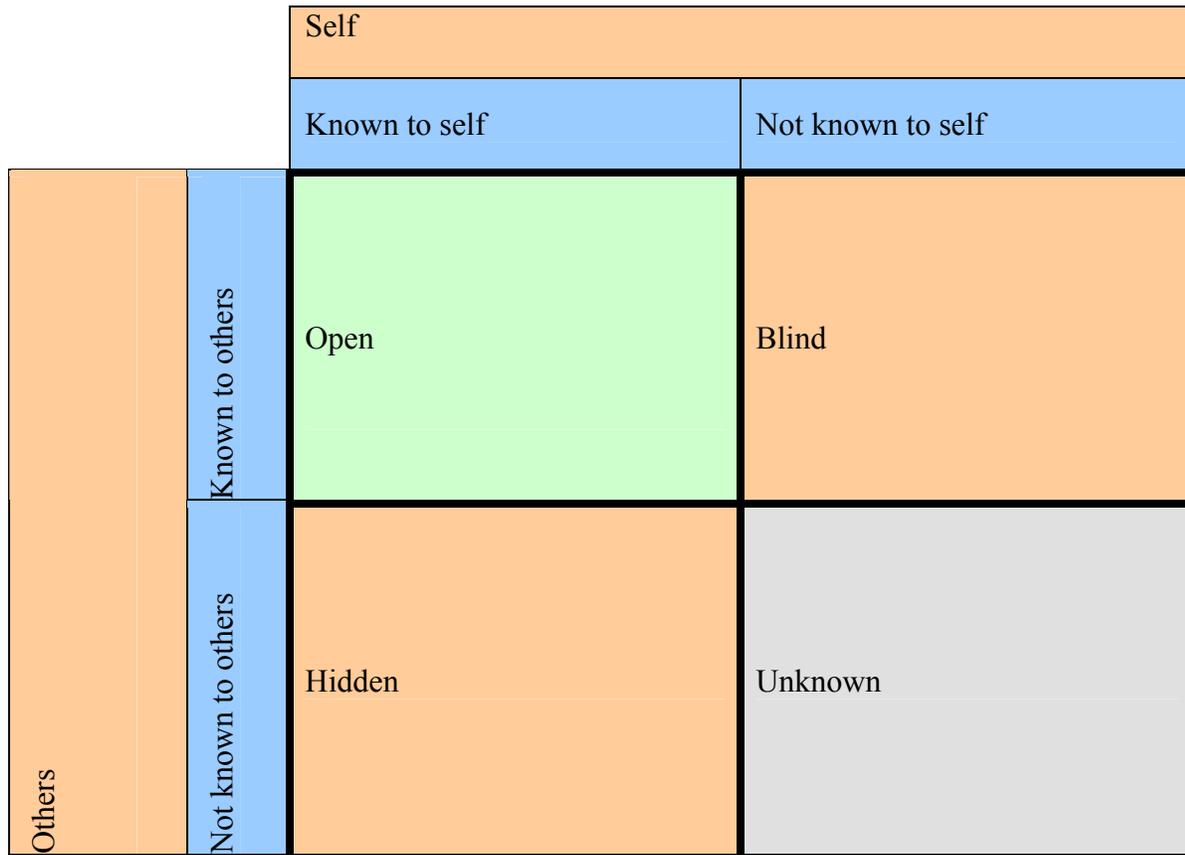
On the other side of the border from the “abled” would be individuals who perceive themselves as having a disability and identify, perhaps reluctantly, with a disability community. The physical or psychological existence of an actual impairment does not justify or negate one’s perception and belief regarding having a disability or being disabled. The use of “disability,” as a generic term without qualification, refers to a self-concept, not necessarily a diagnosis or physical condition. Of course, a person’s self-concept may be associated with an actual difference, diagnosed impairment, or handicapping factor. Often, disabilities are visible, but they may also be invisible. Invisible disabilities are those disabilities that do not need to be concealed to go unnoticed; they simply do not have easily identifiable signs readily detected by casual acquaintances. Of course, significant others are more likely to recognize the signs and changes due to an invisible condition or a socially constructed condition. Identifying oneself as having a disability may include behaviors such as disclosure, use of support or services when needed, activism, awareness, interaction with others because of shared disability status, membership in a community (such as a Deaf community), and recognition of others with similar conditions. Denial of disability may result in isolation and deprivation.

The reality is that most individuals do not fit on either side of this imaginary border between “ability” and disability. Their participation and identification are contextual. They may perceive themselves as having a disability, but they choose to conceal the disability and attempt to pass as part of the “abled” community in at least one social context. They may travel back and forth between communities, only partially participating and belonging. As imposters in both contexts, they may have difficulty utilizing the privileges of either. Concealed disability is a much more complex issue than impairment or perceptions of impairment. The real issue here is a stigma felt (or feared) by an individual that perceives herself or himself to have deficit or disability of some sort. Rather than embracing difference, these individuals may feel shame, inferiority, and fear of alienation. An actual diagnosis is not important; becoming marginalized may be a result of self-esteem, mental health, physical health, or aesthetic appraisals of oneself. These individuals may forego support, services, and even treatment in an attempt to conceal their “disabling condition.” For these individuals, disability is perceived as a condition, rarely a culture or an identity.

To illustrate this, the Johari Window may be helpful (Luft, 1969). (See Figure 2). The open quadrant refers to those aspects of oneself known by oneself and others. The hidden quadrant refers to those aspects of oneself known by oneself but not by others. The blind quadrant refers to aspects of oneself not known to oneself but known by others. Finally, the unknown quadrant refers to aspects of oneself that nobody knows about, aspects yet to be discovered. I am most interested in the open and hidden quadrants pertaining to disability. These

are quadrants to the left that involve the knowledge of the subject and personal volition. They grow or shrink according to the amount of feedback received. Notice that with feedback the “Blind” quadrant shrinks and the “open” quadrant grows. In the same manner, with disclosure, the “Open” quadrant grows and the “Hidden” quadrant shrinks.

Figure 2. Johari Window (Luft, 1969)



Purpose of the Study

This study will seek to illustrate and examine concealment of disability and the dynamics surrounding concealment among individuals with disabilities in higher education. Through an analysis of life stories, I will examine the nature of social, academic, and work-related interactions and the effect that concealed disability has on the lives of students. Because of their hidden differences, individuals operate between the worlds of the non-disabled and the disabled. The nature of their marginalization may help us to understand their experiences and needs. This may bring us closer to a unified theory of disability and gender, which may offer a greater respect and acknowledgement of all experiences. Eisner (1997) suggests:

To the extent that experience itself can be conceived of as the primary medium of education, stories are among the most useful means for sharing what one has experienced. Narrative –which means a telling– makes it possible for others to have

access not only to our own lives when our stories are about them but also to the lives of others. (p.262)

Perhaps, this project can provide some access into the lives of students with concealed disabilities and illuminate what marginalization means to them. I intend to pattern this analysis after cultural studies, speaking to an audience of cultural critics. Since I am essentially exploring a dynamic condition, it cannot be isolated and scrutinized outside of a complex context. Therefore, I see part of this process involving the development of vocabulary that will mediate understanding, creating a metatextual dialog that explores the texts participants present as an interpretation of their experiences.

As a cultural critic, the researcher will examine disability as culture, borrowing an anthropologist's definition of culture: "Man is an animal suspended in webs of significance which he himself has created. I take culture to be those webs" (Geertz, 1973, p.14). These webs, or cultural identities, certainly include such group memberships as shared-disability, shared-perceived norms, and what is considered mainstream, since all have rules, rituals, traditions, artifacts, and expectations for behavior.

A common thinking-skill activity involves magic boxes. These are opaque containers of some sort. There are usually about six holes in each box. Each hole has the end of a rope hanging out. Inside the box, the ropes have been connected in some manner. It is the goal of the participants to hypothesize how they are connected by pulling on the ropes and seeing what happens. In a sense, I view culture as a magic box, containing a set of characteristics that defines a group, earns privilege or acceptance, and dictates behavior. I hope that by "pulling" on the stories my participants provide, I will be able to hypothesize and test connections between them. Perhaps, this will give me a means to explore the significance of concealment and the contexts in which it occurs, especially in relation to the academic experiences at this university. The study will help illuminate the factors involved in concealment and, perhaps, provide insights into alternative modes of interaction, accommodation, and retention of individuals with disabilities. There is no way of knowing precisely how many students forego support and accommodations that would have given them the resources to be successful or how much of the attrition among students is due to choices not to pursue accommodations.

Methodology

The researcher interviewed participants and analyzed results of the interviews to collect data for this qualitative study. A total of nine participants with a self-identified, concealed disability were interviewed and audio recorded. The process was as open-ended and nondirective as possible, relying on prompts only when necessary. These interviews were transcribed and incorporated into profiles, descriptive narratives of their stories, the interview, observations during the interviews, and artifacts participants may share. The researcher analyzed these texts for themes, unique experiences, substantiation or conflict with theories and studies synthesized in the literature review, elements justifying cultural critique, and insight and understanding of the participants' perspectives.

Research Questions

I want to understand in a small way what it is like to be in each of my participant's worlds. The main research questions, simply stated, are:

- What dynamics lead some individuals to identify themselves as having a disability while others try to conceal their conditions?
- What is unique to those individuals who conceal their disabilities? How do they express themselves? How do they “behave” as individuals with disabilities?

Other questions can be explored, such as the following, through the narratives of participants in this study:

- In what contexts do individuals with disabilities conceal their perceived differences?
- With what types of life experiences does concealment/disclosure seem to be related? From the participant's points of view, which behavior does society seem to encourage and why?
- How do individuals with concealed disabilities express their identities? How is disability performed? How is concealed disability performed? The same way “ability” is performed?
- Do individuals with concealed disabilities embody disability in a particular way that is different from other individuals with disabilities? What discourse frames their communication?
- Is the outcome of disclosure/concealment big enough to outweigh the benefits of the alternative from their perspectives?
- What does the label of having a disability mean to participants? Where do negative/positive perceptions about disability status originate?
- Is the convergence of social expectations and disability significant? What do participants perceive the interrelationship between them to be?
- What features of society alienate and encourage concealment among individuals with disabilities? Legal? Educational? Attitudinal? Architectural?
- What can we learn from the life experiences of individuals with concealed disabilities in higher education? Are there dynamics that teachers, students, administrators, researchers, and service providers should consider?

Limitations

A few limitations must be acknowledged:

- A representative group of individuals with concealed disabilities would not elect to be in a study. This study cannot be generalized beyond the participants involved.
- The population of potential participants is limited to individuals who opt to volunteer. How representative this may be of the total population of individuals with concealed disabilities can only be speculated.
- Participants will develop differing degrees of trust and comfort, resulting in differing degrees of disclosure.
- There is no way to check the accuracy of self-reported experiences. Participants are likely to present information in a manner that preserves the image they hope to project.
- Immediacy and current affect will influence the manner in which information is presented and what information is salient at that time.
- Self-serving bias and differences between the researcher and participants will color the self-presentation the participants try to project and how the data they provide is interpreted.

Still, the diversity of individuals with concealed disabilities makes this type of research even more imperative. The individuals who participate will contribute insight into some of the possibilities.

CHAPTER 2: REVIEW OF LITERATURE

By disabilities, I am referring to a socially constructed identity that may grow from any combination of impairment, social values and stigmas, media portrayal of normality and ability, internalized assumptions about proper functioning and appearance, and personal psychology (Corcoran, 2000; Corker, 2001; Joachim & Acorn, 2000; Kravets, 1996; Overboe, 1999; Pfeiffer, 1996, 1999). In fact, nearly every member of society should be able to identify personal deficits, inadequacies, or differences that in some way serve to hinder or stigmatize.

While our culture stigmatizes all disabilities, this research will focus on concealed disabilities. By concealed, I am referring to individuals with differences they attempt to hide, which may include ADHD, cancer, rheumatoid problems, learning disabilities, and fibromyalgia (Kravets, 1996; Ozer, 1990). The overarching concern of my research is how individuals with concealed differences experience life, which I believe will include being marginalized and feeling stigmatized. Drawing from Anzaldúa (1999), I employ the metaphor of borderlands to explore marginalized identities. In a meta-analysis of classroom research, Reid (2001) notes that within the first four years of grade school “at risk students’ perceptions of their own levels of academic competence, their teachers’ expectations of them, and their own self-concept increasingly come to be perceived more negatively than those of their peers” (p.101). This type of research clearly suggests the construction of disability, as well as the causal link between environments –not just internal matters– and the attitudes and performance of individuals. Trying to protect disabled individuals by insisting on medical justifications for behavior, researchers may inadvertently do a great disservice to these individuals by ignoring the powerful influences of external factors. For example, Hahn (1997) notes:

The examination of disability and the industrial system indicates that the unemployment rate of disabled adults may be traced to broad economic forces rather than individual impairments and that the existence of persons with disabilities as well as other marginal groups reduces the pressures which might otherwise disrupt the operation of capitalism. (p.173)

On the other hand, a person may feel stigmatized for behaviors related to disability, even when that disability is undetectable.

Moser (2000) notes that society’s labels and descriptions of disability limit individuals with disabilities. Hegemony draws the borders between disability and “normality.” Then, individuals with disabilities face discourses, which erect the various social barriers on those borders with which they must contend. Language constructs identities. According to Pfeiffer (1999), the term “disability” subjugates another to an inferior position. A hegemonic relationship is established, or sometimes a more overt form of oppression. The label itself becomes a stigmatizing mark. As Charlton (1998) explains, on a socioeconomic level, individuals with disabilities are excluded. These individuals do not receive the approval, support, and esteem most Americans take for granted. In fact, the stigma and alienation that individuals with disabilities endure may exceed the oppression faced by almost any other group. Still, with as many as seven percent of the population in some states, individuals with diagnosed disabilities represent the largest minority group other than women. This does not even take into account the number of individuals with undiagnosed and concealed disabilities (Wheratt, 1988).

Disability, Ability, and Impairment

There are multiple theories of disability. Of course, disability experiences are diverse, as well as the perspectives of researchers. Researchers in the United Kingdom tend to focus on class perspective, as working class, while in the United States theories of disability focus more on individual rights and guaranteed services (Pfeiffer, 1996). Even the definition of disability varies. As Gilson and Depoy (2002) point out, “Social Security defines disability as the inability to engage in remunerative employment as a result of a disabling condition,” and the American with Disability Act (ADA) defines an individual with a disability as “a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment” (Justice, 2002, par. 3). Of course, these definitions grow from particular assumptions and models of disability that serve to justify particular stances regarding disability services, support, and acknowledgement. For example, Charlton (1998) explains that poverty and powerlessness must be considered when framing a theory of disability oppression, since these factors are often central to the experiences of individuals with disabilities. Rather than focusing on the outcomes of disability, this research seeks a definition that focuses on personal identity. It will explore why individuals simultaneously self-identify as disabled and conceal that identity. P. A. Murphy (2004) best expresses why I choose self-identification as the definition when she writes:

[J]ust as Women's Studies is not the study of women's reproductive organs, Disability Studies is not the study of medical/psychological/legal definitions of disability. Both subscribe to standpoint theory. That is, you cannot understand my experience unless you look at it from my point of view. (par. 7)

Of course, not all models of disability accommodate an identity-based definition of disability. Still, in order to discuss the issue of disclosure and concealment, it is necessary to abandon definitions of disability that require disclosure for inclusion.

Thomas (1999) discusses the medical model and the social model of disability. The medical model is built on the assumption that impairments cause disabilities, and disability is internal to individuals with disabilities. An internal focus, such as this, presents disability as an abnormality, a defect. The assumed impairment prescribes individuals with disabilities with solutions for physical, behavioral, psychological, or sensory defect “remedies,” rather than describing experiences (Gilson & DePoy, 2002). The role of services using this model would center on cures. As Winzer (1997) explains:

Throughout history, the medical aspects of disability have been paramount; other concerns relating to disability have been secondary, where they have been considered at all. [. . .] The “medicalization” of special education can be traced back to the Greeks and beyond. Medical investigation typically preceded attempts at education; certainly, no formal training facilities for disabled people were available until the mid-eighteenth century, though attempts to treat medically were widespread long before that. Typically, the causes of a condition have garnered far more attention than its impact. (p.84)

Causality may have implications regarding prevention, but causality has little to offer in the study of personal experience.

The social model assumes social barriers create disabilities; disability is seen as “a multilevel social justice concern embedded within particular cultural, sociopolitical, economic, and relational environments” (Gilson & DePoy, 2002, p.154). Context is central to an identity of one who is disabled. Recognition of impairment and identification as disabled are not synonymous, and they do not necessarily have a causal relationship. As Corker (2001) explains, “The bifurcation of impairment and disability is analogous to the traditional feminist bifurcation of sex and gender, which was conceived as a way of focusing attention on the social nature of women’s oppression” (p.34). Those following this model, of course, would focus on societal changes to accommodate each individual. Coleman (1997) writes:

To conceptualize stigma as a social relationship raises some vital questions about stigma. These questions include (a) when and under what circumstances does an attribute become a stigmatized one? (b) can a person experience stigmatization without knowing that a trait is devalued in a specific social context? (c) does a person feel stigmatized even though in a particular social context the attribute is not stigmatized or the stigma is not physically or behaviorally apparent? (d) can a person refuse to be stigmatized or destigmatize an attribute by ignoring the prevailing norms that define it as a stigma? (p.223)

Even though a social model is more empowering and greater impetus to bring about change, Thomas (1999) recognizes the failure to incorporate impairment negates many of the experiences of individuals with disabilities. She proposes a biosocial definition: impairments and social barriers create disabilities. This extends the definition to include not only barriers to “doing,” but also barriers to “being.” Perhaps, this also removes some gender, age, and economic biases that existed in the social model alone by relocating areas of concern from a focus on the workplace and public institutions to the body itself. Still, impairment may be better understood as a personal identification or perception rather than a diagnosis. Limiting a definition to only diagnosable conditions would limit disability experiences to those not medically negated. This begins to exclude individuals who may identify as disabled or impaired who do not present diagnosable symptoms. It also may exclude others by requiring disclosure to diagnosticians for recognition. The more prescriptive our understanding of disability, the less we can learn. A descriptive approach opens the door to a greater diversity of experiences. As Gilson and DePoy (2002) note the traditional view of disability as a deficit is being replaced with an understanding of disability as another example of human diversity. Neither perspective can accurately account for the inter/intra-personal needs and qualities of individuals with disabilities. Writing about disability from a sociopolitical perspective, Hahn (1997) explains:

The basic thrust of the “minority-group” model of disability asserts that disabled men and women have been subjected to the same forms of prejudice, discrimination, and segregation imposed upon other oppressed groups which are differentiated from the remainder of the population on the basis of characteristics such as race or ethnicity, gender, and aging. Disabled persons not only have exhibited one of the highest rates of unemployment, welfare dependency, and poverty in the United States; but they have also experienced a more pervasive form of segregation in education, housing, transportation,

and public accommodations than most rigid policies of apartheid enacted by racist governments. (p.174)

Admission of the tentative and precarious nature of being “abled” is a frightening prospect. It is easier and more reassuring to imagine the (dis)abled body as somehow different. Therefore, the general population has a tendency to have irrational beliefs regarding stigmatized others: they aren’t really human like “normal” individuals, they are dangerous (especially the individuals with behavioral and psychological disorders), they have a fault that caused their condition, they are evil or possessed, they are particularly saintly or virtuous, they are asexual (Joachim & Acorn, 2000). Thus, individuals may not assume they are at risk of becoming impaired in any way. Davis (1997) notes that society tends to loosely associate disability and many forms of nonconformity. Criminal activity, mental incompetence, sexual deviance, laziness, and inability has been so commonly associated with disability that individuals with disabilities have difficulty overcoming the resulting stereotypes, which have become strong elements of social discourse. Erroneous beliefs and associations grow out of oppression and social rejection of individuals with disabilities. As Charlton (1998) explains, “Backward attitudes about disability are not the basis for disability oppression, disability oppression is the basis for backward attitudes” (p.7). Individuals have a tendency toward a self-serving bias and naturalistic fallacy that supports presuppositions. The status quo is maintained with a discourse, which perpetuates stereotypes and rationale for oppression.

Theory must somehow address the dynamic and multifaceted elements of disability as experience, impairment, and identity. Thomson (1997b) writes, “Feminism’s often conflicting and always complex dual aims of politicizing the materiality of bodies while rewriting the category of women are exactly the kinds of interrogations that should be brought to bear upon disability” (p. 281). Like Thomas (1999), other critics have argued for a theory on disability and body, also noting the dual oppression experienced by women with disabilities, which further develops the case for an inclusive theory of ability (Corker, 2001; Gershick & Miller, 1994; Wendell, 1996; Zola, 1991). However, current approaches have failed to account for all aspects of disability. Thomson (1997b) notes how disability and femininity are entangled. Debilitation has often been associated with femininity –“Chinese foot binding, African scarification, clitoridectomy, and Euroamerican corseting” (p.286). For women, normalization and beautification often entails modification. Again, preexisting oppression becomes justified by discourse centered on hegemonic traditions. The media presents and enforces images of the normal/(dis)abled/perfect body, which sets social expectations somewhere well outside the true norm. The images presented often illustrate unhealthy or unnatural proportions that one would think would be evolutionarily rejected and aesthetically distasteful, if they were not growing out of a system of misogyny and patriarchy.

Too many theories and definitions compete in variety of settings. Moser (2000) argues, among other catalysts, “Differences are (also) created by means of, and exclusion (also) feeds on language –the way we speak, write and describe” (p.210). Thomson (1997b) reframes semantics that have devalued and labeled disability as an inadequacy. She advocates a “universalizing disability discourse which draws on feminism’s confrontation with the gender system [...] asserting the body as a cultural text with is interpreted, inscribed with meaning, indeed *made*, within social relations of power” (p.282). Researchers, acknowledging the sociopolitical construct of body, would be able to address and revise discourse that de-privileges and

negatively labels difference and variation among bodies. This may expose arbitrary evaluations and diagnoses of impairment based on social expectations and imposed uniformity. Oftentimes, rather than isolating issues of functioning, diagnoses are enforcing social hierarchies, gender-role expectations, and hegemony. Fowler, O'Rourke, Wadsworth, & Harper (1992) describe the dominant discourse that includes a binary of abled/unabled, into which all individuals fall, if level of ability is treated as a primary trait. This is, as a rule, a binary relationship where "abled" individuals receive privilege and "unabled" individuals become further oppressed and stigmatized. This assumes that all individuals with disabilities are victims.

Still, not all individuals with disabilities consider themselves victims. Some individuals with disabilities have replaced their victim status and self-degradation with a raised consciousness that, instead, responds with anger, indignation, and self esteem, which changes the way in which they interact socially and politically with society (Charlton, 1998). When disability is not concealed, the power of such reactions may elicit meaningful change. As Coleman (1997) writes:

Many stigmatized people begin to understand that the stigmatizer, having established a position of false superiority and consequently the need to maintain it, is enslaved to the concept that stigmatized people are fundamentally inferior. In fact, some stigmatized individuals question the norms about stigma and attempt to change the social environments for their peers. (p.223).

Unfortunately, according to Charlton (1998), few individuals with disabilities who have a raised consciousness have become politically active. The power and knowledge is accessible. As Audre Lorde (1994) proclaimed, "There is a terrible clarity that comes with cancer that can be empowering" (p.36). Certainly, the vantage point of having a disability, such as a terminal disease, could bring personal values and priorities into sharper focus. Perseverance in the face of pain demonstrates strength often not attributed to the disabled, causing discomfort or denial on the part of the observer. Refusing to conform to the expectations and stereotypes attributed to a group in which individuals belong, empowers them to exercise greater freedoms by removing societal barriers. Power does not simply grow out of the gaze or even the stare that disability can attract. Is it not simply fear, apprehension, nor aversion. Disability can become knowledge of the unknown, a passport between borders and a voice of wisdom from experience. Labels may impose economic, political, and social limitations, which some individuals may learn to transgress. This type of empowerment would not be available to individuals in situations where they conceal their disabilities. It depends on visibility and self-efficacy. It depends on being labeled and boldly negating the stereotypes associated with that label. It depends on a willingness to become proactive. Some individuals gain great affirmation from the accentuation of differences, rather than similarities, to the dominant majority's values (Hahn, 1997). This type of self-identification should not be confused with a masochistic, self-demeaning attitude or with self-handicapping, which create greater stigma. Valued differences become empowering and stigma reducing, creating opportunity, instead of enhancing oppression or introducing hegemony.

As they set up their theoretical perspective, E. E. Jones, et al. (1984) discuss the attaching of a label, "mark," to a person; a mark is something that defines an individual as:

Deviant, flawed, limited, spoiled, or generally undesirable. The mark may or may not be physical: It may be embedded in behavior, biography, ancestry, group membership. It may be possible to conceal it. [...] Mark is thus our generic term for perceived or inferred conditions of deviation from a prototype or norm that might initiate the stigmatizing process. [...] Words are not only important in organizing experience, but that they shape affect, or emotions, and behavior. (E. E. Jones et al., 1984, p.6-8).

Language becomes the medium through which a person can be marked, or labeled. It has been the primary tool used by dominant groups to maintain the status quo (Zola, 1993). Discourse serves as a primary lens through which we perceive others with differences. The discursive politics of difference does not clearly delineate anything more than power-centered stereotypes. Dunne (1986) writes:

If we hope to survive in this terrifying age, we must choose our words as we choose our actions. We should think how what we say might sound to other ears as well as to our own. Above all, we should strive for clarity . . . If clarity (is) the essence of style, it is also the heart and soul of truth, and it is for want of truth that human freedom could perish. (Quoted in Zola, 1993).

Ambiguous and fluid definitions of disability do not suffice. It is in this ambiguity that stereotypes may be perpetuated. It is in this ambiguity that individuals are labeled (or not) and burdened with the baggage and barriers attached to those labels. As long as definitions remain indefinite, society will depend to stereotypes as a means of identifying disabilities. This makes disability, in practice, the condition of being *caught* with a difference. A person can be marked, markable, a marker, or marking. Words become the instrument for this action. A marked person may or may not become stigmatized. This is often due to the marked person's or the marker's ability to justify a stigmatizing reaction. Unjustified reactions may result in ambivalence. "At the other end of the continuum, negative affect is seen as totally justified, supported by a belief system often designated as a stereotype because of its rigidity and unresponsiveness to ameliorating information" (E. E. Jones et al., 1984, p.9). Therefore, it seems, individuals become stigmatized because of justifications and rationalizations, not simply perceptions.

The act of labeling not only identifies deviations, but it also perpetuates stigmatization. Even innocent diagnoses may result in a destructive mark. A diagnosis often exposes an individual to societal oppression and pressures. Winzer (1997) writes, "Once labeled as 'multiply handicapped' in this way, deaf children are treated differently –for example, placed in a less demanding academic program where they learn less, so the label is self validating" (p.159). The same happens to many students with disabilities, which often leaves graduates with disabilities with profound deficits and disadvantages vocationally. Relief programs that empower individuals to develop self-efficacy and autonomy should be created, rather than programs that continually reinforce dependence and maintain the status quo. Our society fosters a great deal of this Pygmalion-like construction of prototypical stereotypes –the disabled, the poor, and the illiterate. These self-fulfilling prophecies compete to create the issues they pinpoint. Similarly, suggestions that poor rural schools should lose funding when their students do not test as high as urban schools in wealthy areas creates conditions for perpetuating the problems in the school. Schools without equitable resources and opportunities, which would help their students to score

higher, lose what few resources they did have. Not even questioning the validity of these tests, the system maintains a status quo through unjust means.

Stigma

Erving Goffman (1963) delved into issues of stigma, conformity, and social acceptance or rejection. He discusses in the seminal work *Stigma* how deviance from cultural expectations may cause individuals to be stereotyped, rejected, and accused of immorality. Stigma, which comes from a Greek word describing outward signs of difference or “badness,” attaches social meanings to individuals and their behaviors (Goffman, 1963). As Porter (1998) noted that our exclusion of individuals with impairments allows us to rationalize our wholeness and immutable abilities. This creates a mythology of superiority and inferiority grows from stereotyped characteristics based on categories of labels. A competitive power difference associated with one’s privilege at the expense of another’s seems to evolve naturally from human interaction.

Stigmatization is a culturally learned behavior. Children often do not show signs of stigmatizing behavior until they have been exposed to an adult’s signs of judgment. As Coleman (1997) writes:

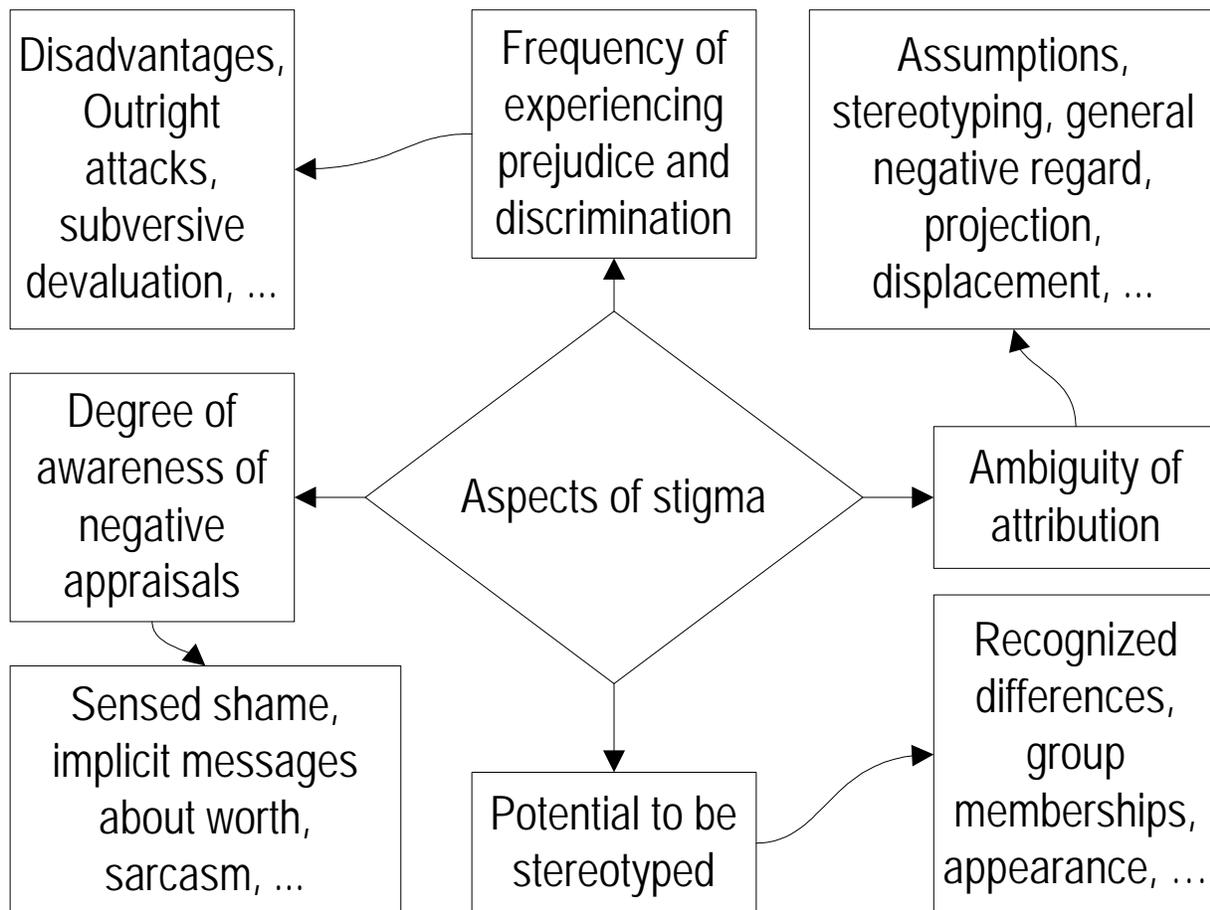
Self-referencing, or the use of another’s interpretation of a situation to form one’s own understanding of it, commonly occurs in young children. Infants often look toward caregivers when encountering something different, such as a novel object, person, or event. The response to novel stimuli in an ambiguous situation may depend on the emotional displays of the caregiver [...] We may continue to learn about how to stigmatize from other important figures (e.g., mentors, role models) as we progress through the life cycle. (p.220)

Of course, individuals probably do not consciously model other individuals’ attitudes. Generally, I do not believe compliance is the primary catalyst for attitudes that foster the alienation of others. Certainly, a few individuals in positions of power may instigate excuses for racism, ableism, heterosexism, and misogyny. The vast majority simply internalizes beliefs and attitudes modeled and reinforced over a period. Prejudice is handed down from one generation to the next. Tradition becomes a powerful force in maintaining the status quo concerning privilege and oppression. As a primitive force, stigmatization of others serves as competitive advantage, as well as a means of self-preservation.

Simone de Beauvoir introduced the idea of “otherness,” which Goffman (1963) tries to account for in the social context of stigmatization (Thomson, 1997a). His study creates a useful vocabulary for discussing disability. In the process of stigmatization, differences are redefined as deviances. These differences are not merely arbitrary, they are classifications typically belonging to minorities, impaired individuals, and other individuals who did not match the social norm. Goffman (1963) defines three types of differences; they include “physical disability,” “deformity,” or “anomaly”; individual behaviors such as addiction, dishonesty, and unpredictability, sexual habits, or ignorance; and demographics such as race, ethnicity, gender, or beliefs. Of course disability may suggest the first category to most individuals; however, less visible disabilities result in individuals being categorized according to the last two, whether or not those categorizations are accurate or not. As Thomson (1997a) writes, “Stigma theory

reminds us that the problems we confront are not disability, ethnicity, race, class, homosexuality, or gender; they are instead the inequalities, negative attitudes, misrepresentations, and institutional practices that result from the process of stigmatization" (p.32). Society's scapegoats are perhaps only the unfortunate groups used to rationalize, externalize, and give a face to internal fears and insecurities. Society may be moving past the evolutionary practicality of xenophobic behaviors, but that has not decreased the prevalence of stigma. In the twenty-first century, it is difficult to come to terms with arbitrary attacks, equitable to name-calling among children. Like an abused child, who finds self-degradation more palatable than admitting parents are culpable, individuals with differences have difficulty accusing the whole of society when they are victimized. Stigmatization needs to be understood from the perspectives and experiences of those being stigmatized, with an understanding of the psychology that filters their understandings of those experiences. Crocker, Major, and Steele (1998) posited four aspects of stigma that stigmatized individuals used to understand their experiences: *the frequency of experiencing prejudice and discrimination, the degree of awareness that others view them negatively, the potential to be stereotyped, and ambiguity of attribution* (Figure 3).

Figure 3. Aspects of stigma used to understand experiences (Crocker et al., 1998).



The first aspect, the *frequency of experiencing prejudice and discrimination*, refers to the amount of prejudice and discrimination the stigmatized person notices. They may experience limitations, unfair disadvantages, outright attacks, or subversive devaluation. As Coleman (1997) explains,

“There are many ways in which individuals communicate social rejection such as speech, eye contact, and interpersonal distance” (p.224). The types of behavior associated with prejudice and discrimination have not been fully enumerated, but the possibilities are perhaps limitless. How one recognizes these behaviors remains subjective and unresolved, which locates part of this aspect within the stigmatized individual. The degree of stigma experienced rests within the ability of individuals to recognize behaviors and hegemony that rejects their value, autonomy, and contributions. An individual experiencing the stigma may not always accompany the act of stigmatizing or rejecting. One may, whether due to impairment or not, fail to recognize behaviors intended to alienate her or him.

The second aspect refers to *awareness of negative appraisals from others*. By the time they reach adolescence, most individuals can tell what attitudes and ideas others have about them (Crocker et al., 1998). This will have a major effect on self-esteem and identity. Not only do negative peer appraisals damage adolescents, but also familial degradations have a powerful impact on the personality and attitudes being developed. Sensed shame from parents, siblings, and peers carries more weight than vocalized assaults. Yet, significant others may become quite adept at sending implicit messages about another’s worth. Most of us have no difficulty deciphering the sarcasm directed toward us – “You aren’t going to wear that are you? Don’t you have something you need to be doing? You should try harder?” Scambler (1998) explains, “[F]elt stigma typically proves more disruptive of individuals’s lives than enacted stigma. [...] felt and enacted stigma can pose threats to the self-esteem, security, identities, and life chances of those with certain diseases or symptoms” (p. 1054). The awareness, feeling stigma, proves to be the most damaging.

The third aspect, *stereotype threat*, refers to the awareness of the likelihood of being judged or treated stereotypically. With differences comes greater threat of stereotyping. Comorbid characteristics only accentuate the differences and create greater chances of alienation and the attachment of stigma. Charlton (1998) explains, “People with disabilities, at least as a group, may have been the first to join the ranks of the underclass. Since feudalism and even earlier, they have lived outside the economy and political process” (p.24). Individuals with disabilities have been excluded from compensated labor, position, and often medical treatment. Of course, even medical treatment has not been guaranteed to all citizens of the United States, not to mention employment or political voice. Ironically, even nations, with which the US government takes issue for “humanitarian reasons,” have more effectively eradicated medical and educational disparity due to poverty. Individuals may assume their treatment of another is conscientious, not demeaning. For example, a charitable gift to someone financially strained may be offered with good intentions, but the public presentation of the gift may reinforce stereotypes and damage the recipient’s self-concept. Rather than creating a society that guarantees a chance for autonomy, it may be an easier task to offer short-term resources. This increases their dependence by taking away degrees of employability, respect, and acceptance. Visibility may be a more costly decision, however. To benefit from these types of resources, individuals must allow themselves to become visible and marked. Concealment may cost access to economic relief, medical resources, and political power. Revelation of disabilities by the public may relegate an individual to stigmatized stereotypes and oppression.

Visibility, “outward signs,” seems to be central to stigma. Recognition of disability creates the possibility of stigmatization, and our society has a clear history of stigmatizing and

stereotyping the disabled. Comic portrayal of individuals with disabilities has been a common theme. Tom Shakespeare (1999) notes:

People with visible impairments are among the key comic stereotypes of western culture, and the use of physical difference as a humorous device suffuses both professional and everyday performance. [...] Of course, while dwarves and stutterers and epileptics and blind people and people with cerebral palsy and people with learning difficulties are core to these forms of joking, anyone who is physically out of the ordinary – nondisabled people who are fat or short or spotty or spectacled or slow – are also subject to this normalizing verbal barrage. (p.48)

Of course, we all can remember images from the media that perpetuate these jokes – Elmer Fudd, Mr. Magoo, Dopey, Porky Pig, and so on. Similar humor has grown up around every stigmatized group. Even Bugs Bunny cartoon, as innocuous as they may have seemed, were filled with racial stereotypes. It doesn't take long to find examples of negative stereotypes on television.

Observers may project many stereotypes, and they do receive many stereotypes. Robinson's Model on Social Discourse identifies several privileged characteristics, which attempt to justify binaries, such as male/female, white/nonwhite, or abled/disabled.

The fourth aspect deals with *attributional ambiguity*, the awareness that others may evaluate one's performance and ability with bias. Awareness of the stigmatized condition may influence the observers' perspective, preventing a true evaluation. Stereotypes may replace direct observation and experience, especially when personal experience is lacking.

Summarizing research prior to 1982 on stigmatization, Jones, et al. (1984) note the subjects were generally homogenous and often represented those who stigmatize others, not the stigmatized individuals. Still, six dimensions of stigmatization reoccurred. They discuss the six dimensions of stigma within interpersonal relationships throughout *Social stigma: The psychology of marked relationships*. These include *concealability*, *course of the condition*, *strain*, *aesthetic qualities*, *cause*, and *peril*.

Concealability refers to the degree of visibility or invisibility of a condition. For example, learning disabilities or diabetes would receive much less stigma than a disability presenting deformity, dependence on equipment, or tics and spasms. By exposing impairments, appearances, identities, or even behaviors outside social norms, people open up possibilities of victimization. Once exposed, the options for privacy and concealment become diminished. Often attempts to conceal differences fail, but the concealer may not always be cognizant of the unintentional disclosure. Several factors may have an impact on how readily a condition may be hidden. Economic and social status may influence opportunities for treatment or cosmetic concealment of differences. The underprivileged and previously marked individuals with stigmatized attributes have less opportunity to conceal conditions because of the conditions.

Course of the condition has to do with how the condition changes over time. Rapid deterioration and physical changes create a variety of reactions from observers. Ultimately, visible changes do mark an individual. Since the mid-eighties, rapid weight loss and blemishes among men, especially gay men, has triggered AIDS-phobic reactions in communities. In the same way that, a century earlier, disfigurement, even from burns or trauma, may have looked

like or suggested signs of congenital syphilis to paranoid masses. The impending death or hospitalization of an individual with a progressive condition, whether Alzheimer's, AIDS, or Lou Gehrig's disease, will signal individuals to begin to pull away. This rejection process is a natural exercise of self-preservation. The same dynamic takes place before a longtime friend moves far away. After all, it is easier to say goodbye to an enemy. Common sense would suggest that conditions with negative prognoses would incite greater stigma. The course of other conditions may create skepticism or ambivalence. What do observers feel about the person, who cannot get out of bed for weeks at a time, who they see out doing a strenuous activity? Conditions such as chronic fatigue, fibromyalgia, arthritis, migraines, and carpal tunnel syndrome may seem to remit and increase at random intervals. This causes as much stress as a more consistent progression of a condition.

Strain, which may be related to the course of the condition, affects the degree of stigma directed at an individual. When relationships become difficult because of the condition, separation and ensuing stigma may follow. As in the case mentioned earlier, when a chronic condition becomes terminal, emotional strain may become debilitating for the caregiver. A roommate or spouse with disabling conditions may require additional understanding and responsibility. Accommodations, equipment, and behaviors can be disruptive. The odor of colostomy bags, the sound of a wheelchair, the schedule of medications or care, anger or depression, the distress of seizures, and other emergencies can tax any relationship and increase stigmatization. Retirement from a career, instead of respite, may signal the beginning of constant care of a partner. Without relief, the strain can become damaging to the caregiver. Guilt related to a repressed desire to pull away often results in anger and resentment. Questions of responsibility may emerge among significant others providing care for an individual. Stigma by association may become an additional fear creating strain, especially when negative connotations have been assigned to a condition. It may be easier to deal with hereditary illness than a disease spread through contagions, especially a sexually transmitted illness, which may not pose a contagion risk without sexual contact, but does create a risk of association.

Sometimes oppression takes the form of cloaked repression, appearing on the surface as concern. Warnings about physical activity, commands to get out and do more, reprimands about not following "correct" regimens of care, and encouragement to keep the status quo become a means of handicapping the person with a disability. This may not be a malicious action on the part of the oppressor, but the effect is stifling. A coping mechanism resulting from this can be disengagement (C. T. Miller & Kaiser, 2001). This counter-productive social withdrawal does protect the person from facing discrimination and prejudicial stereotypes, but it further isolates the person and introduces additional stressors. The researchers explain:

If stigmatized people cannot avoid or find alternatives to situations in which stigma may create stress, they may withdraw socially. One form of social avoidance is avoiding comparisons with nonstigmatized people. By avoiding social comparisons with outgroup members, stigmatized people are able to avoid the stress that might result from acknowledging that others are doing better than they are. [...] Disengagement coping responses [...] are related to increased psychological distress, including maladjustment and physical symptoms. (C. T. Miller & Kaiser, 2001, p.80)

Ironically, attempts to avoid stress result in distress. Oftentimes, a person's attempts to help others with disabilities results in out-group comparisons and disengagement. Perhaps, this grows from an inability to sympathize with the needs and concerns of individuals with disabilities. On the other hand, perhaps, it grows from something less altruistic. Concern, that other individuals get more benefits, privileges, or attention, leads to jealousy for many individuals. Admonishments from others might be attempts to assert control and reestablish their privileges over the person with a disability. Ambivalence, comparisons to the speaker or others, or contradictory advice points to this possibility –you need to get out more, if you want to feel better, and, if you were not going out so much, maybe you would not feel bad. This may lead to the person with a disability feeling ambivalence regarding the person giving the advice. The advice giver may be dually perceived as an ally and as an attacker. The resulting isolation at this point can be easily justified and, at many levels, warranted. “Feelings of shame over an illness, disability, or perceived inadequacy may lead to perceptions of peer rejection or an unwillingness to form social bonds” (Newman & Newman, 2001, p.527). Manipulation and control tactics foster these types of feelings, ultimately resulting in some reaction, like withdrawal.

Individuals with concealed disabilities are not exempt from judgments and external attempts at control. Often, the hidden nature of these disabilities may increase external interference, especially from family and friends. Layered onto the comparisons with others are assumptions and skepticism regarding the nature of the disability itself. A friend of mine who suffers from chronic migraines once complained that one of her family members would call her when she had headaches and would not get off the phone. When this person was told my friend was sick and didn't feel like talking, she would dismiss the headache with a comment like, “I get headaches too” and offer quick advice. Because she is in school, she is often told that she is just reading too much. Generally, the family member begins a long story about her own headaches and her remedies for them. Because my friend's condition is not readily visible, others may assume that it can be dismissed. Referring to her family, my friend complains, “They treat me like I'm the boy that cried wolf. If they felt the way I do for just a day, they'd change their tune.”

As Zola (1993) writes:

Call a person sick or crazy and all their behavior becomes dismissable [sic]. Because some has been labelled [sic] ill, all their activities and beliefs –past, present, and future– become related to and explainable in terms of their illness. Once this occurs, society can deny the validity of anything which they might say, do, or stand for. Being seen as the object of medical treatment evokes the image of many ascribed traits, such as weakness, helplessness, dependency, regressiveness, abnormality of appearance and depreciation of every mode of physical and mental functioning. (p.168)

In this way, labeling itself becomes the handicapping factor in a person's life. Family, friends, and other acquaintances may be reluctant to accept any changes the person tries to make. At the micro level, the individual becomes victim to control, manipulation, stereotypes, and prejudice. Ironically, it is often the most intimate relationships that may foster the most damning and demeaning attributions and oppression.

Competition is common among individuals with and without disabilities. One person or group may guard members of their social circle from other friends or relationships. This form of

shielding purposefully excludes rivals for attention. Unfortunately, some individuals have learned that impairment can be used as a means of attention. Ironically, these individuals often attempt to project antithetical images of themselves. On one hand, they may want to be the pitiable, impaired, economically deprived, lonely victim, while on the other hand they may present themselves to the same individuals as well off, healthy, and popular. This creates an awkward situation for individuals with serious concerns who become suspect because of attention seekers' empty complaints.

The complexity of the social landscape that individuals with concealed disabilities populate remains impossible to map accurately. It is much more than an intersection of cultures. The divide itself contains a culture unique from the ability and disability. Theory has attempted to bridge the space between disability and ability. Without an acute awareness of what is in between, theory may pass over the needs and experiences of individuals with concealed disabilities.

Aesthetic qualities also play a role in stigma. Appearance itself has the power to motivate acceptance or rejection. Often physical limitation is not the markable characteristic. Instead, physical appearance is marked. It is easy to imagine physical beauty parallels integrity and worth. The beautiful are more likely seen as victims, while the not so beautiful may be seen as more likely responsible for their conditions. This is not to suggest that attractive individuals get an easy ride. Beauty itself, while creating positive appraisals, may incite sexual abuse, violence, and victimization, as during pre-seventies institutionalization, where cognitively and emotionally impaired individuals had few avenues for exercising self-actualization. Attractiveness to others may serve as an incentive for predators to victimize them. I remember a young homeless man. I had spoken to him before, and I could tell that he had severe burn scars on his face. What I did not know until later was that his face had purposely disfigured. He had done it to himself to avoid the sexual abuse that was happening to him, which he believed had been triggered by his appearance. He receives less charity than more attractive young individuals without homes do, but he also receives less attention and less abuse. Of course, beauty more often has a more positive outcome in regards to privilege. Jones, Farina, Hastorf, Markus, Miller, and Scott (1984) explain:

Research has shown that someone's degree of attractiveness influences his and, especially, her interpersonal relationships in very important ways. Many studies have unequivocally demonstrated that how others perceive us is determined by our beauty or lack of it. (p.53)

This aesthetic element of interpersonal relationships oftentimes marks the person with disabilities as tarnished, especially when those disabilities are visible. This does not only influence intimacy and friendship, it has a definite impact upon professional relationships. Hahn (1997) writes:

The ubiquitous power of pervasive images of acceptable physical appearance seems indisputable. Clearly, immunity from these influences has not been extended to employers who make hiring decisions. In fact, many personnel manuals stress the importance of presenting a favorable appearance; and visibly disabled persons often are

encouraged to attempt to minimize the prominence of their disabilities on employment applications and interviews. (p.182)

However, we do see “mascots” in nearly every social group. Mascots are treated like pets. They are individuals given only superficial membership and expectations, who do not receive the respect and support given to others. These individuals may be included, or hired, to reach diversity goals or to appear magnanimous. These mascots do not feel included, and they are offered only superficial displays of friendship. Their stigmatized status has not been removed. Members of the group only associate with them in a group-related context. As a friend with a visible disability once wrote in an E-Mail to me about her work:

They are nice enough at work, but we live in a small town. It hurts when we pass in the grocery store and they pretend they don't notice me. They are always getting together after work to walk in the park or grab coffee. It makes it even worse that they whisper about it and all so they don't have to invite me. I walk into the break room, and they all just stop talking.

Media, advertising, employment, and social connections teach us whom we “should” associate with. Nonconformity may create a low glass ceiling for those seeking autonomy.

Even beyond the “mascot” role, society has further associated individuals with disabilities and nonhuman attributes or dispositions. For example, it has fostered a fascination with the feral child raised by animals –wolves, apes, bears. This fits neatly into the patriarchal mythology of primal masculinity or femininity. The same fascination and loathing that the nineteenth-century freak show instigated still may haunt the person with cosmetic deviance. Folklore and superstition clearly chronicle the associations made between animal characteristics and disabilities. Especially in the case of appearance, animals and fear of animals have been associated with disability.

Sometimes, ironically, the public may equate disabling conditions with beauty. Wealthy, white, antebellum women in the southern United States took a pinch of arsenic daily. It gave them the frail, sickly appearance the patriarchal culture found appealing. Anorexia and bulimia seems to have replaced the arsenic. Of course, these cultural fads tend to serve the political power structures or to grow from direct opposition. Generally, women with disabilities have been deemed unattractive, unfeminine, and clumsy by various groups studied, including college students, clinicians, and peers (Asch & Fine, 1997). The apparent visibility or invisibility of the disability did not change the results. Awareness of a condition seemed to be the only factor, not observation. This suggests that the appraisal of these women resulted from projected stereotypes and attitudes, rather than observation. Generally, majority opinions of beauty have existed within gender role expectations. The female models in advertisements have ranged from iron maidens and seductresses to waifs and androgens. Paradoxically, society would have stigmatized these women for their appearance in other eras.

Cause of the condition seems to be an important factor for many reasons. Asch and Fine (1997) share interesting results from a study that illustrates the fundamental attribution error being applied to sex. The researchers asked Students “without” disabilities to posit a probable cause for others having been confined to wheelchairs. When presented with the

individuals in wheelchairs, they tended to attribute the impairment to differing causes depending on the sex of the person in the wheelchair. Males' impairments were typically attributed to external situations, such as accidents and physical injuries. They attributed females' impairments to internal factors, such as birth defects or disease. Are the individuals victims? On the other hand, are they to blame? "Society teaches the disabled to regard their condition as a punishment that is somehow deserved – 'a self-delusion that lurks in our fears and fantasies'" (Stronach & Allan, 1999, p.38). Of course, we have a plethora of cultural artifacts that connect disability with sin or evil. Villains are generally marked or marred mentally or physically – "scarred, deformed, or mutilated" (Davis, 1997, p.21). Evil stepsisters, witches, and tyrants are described as impaired – psychologically, if not physically. The image of the "grotesque" pervades modern literature (Mitchell, 1997). Pirates have wooden legs or hooks for hands. Captain Ahab in *Moby Dick* has a wooden leg and body-length scar. Davis (1997) also writes:

I am not saying simply that novels embody the prejudices of society toward people with disabilities. That is clearly a truism. Rather, I am asserting that the very structures on which the novel rests tends to be normative, ideologically emphasizing the universal quality of the central character whose normativity encourages us to identify with him or her. (p.21)

Darth Vader in the *Star Wars* movies we find relies on machines and prosthetics to stay alive. In the most recent movie in the series, *Attack of the Clones*, we see him lose his arm and gain a prosthetic arm. Dr. Migilitto Lovelace in the *Wild, Wild West* series is a small person. Frankenstein's creature has physical deformities and disfigurements. An endless list of megalomaniacs has filled our fiction with their attempts to take over or destroy their world. The Green Goblin, Spiderman's archrival in the recent *Spiderman* movie, is also mentally ill. In fact, in the comic book genre, many villains have either a physical or a mental impairment. In *The Fugitive*, the main character chases a one-armed murderer. The crime-mystery genre often refers to criminal characters by their disabilities (Zola, 1993). Urban legends also highlight our vilification of the disabled, with escapees from asylums with prosthetic hooks for hands and other such characters. Even the Judeo-Christian scriptures associate illness and disability with evil or sin: Cain given a visible mark, Nebuchadnezzar going mad and living like an animal, the sister of Moses struck with leprosy, the demon-possessed boy, and numerous instances of individuals or groups cursed with impairment for transgressing cultural norms. Historical Christian leaders added to the stigmatization. Winzer (1997) writes:

John Calvin preached that mentally retarded persons are possessed by Satan; Martin Luther was of the opinion that a mentally retarded child is merely a mass of flesh (*massa carnia*) with no soul. Luther further subscribed to the belief that the Devil is the father of idiots; he denounced the mentally handicapped as "filled with Satan" and even suggested one child be taken to the nearest river and drowned. (p.94)

Of course, Christianity and Judaism do not have a monopoly on the stigmatization of individuals with differences. They are, however, major influences of attitudes among many American students. I could not find many examples of religions that, if not in dogma, in practice, exercise some degree of stigma toward individuals with differences. In spite of scientific progress, in the recesses of consciousness, society still clings to these archetypal associations and a persistent desire always to assign blame. When there is nobody culpable, some person or group

will become the scapegoat and carry the stigma for displaying characteristics illogically associated with evil. Contemporary literature presents a morality tale in which the ultimate attainment and the ultimate evil are expressed through individuality and nonconformity, and society creates value and stigma relative to the type of difference (Bakhtin, 1984). Central to all of this is the Manicheistic ideology inherent in most American discourse. With such beliefs, physical defect illustrates the evil of the flesh, while mental deficit or defect becomes synonymous with moral deficit or defect. As Hevey (1997) writes:

The US “crip” symbol denotes alienation. The impaired body is the site and symbol of all alienation. It is psychic alienation made physical. The ‘contorted’ body is the final process and statement of a painful mind. (p.345)

The body becomes characterized as the mirror of the soul or, perhaps more accurately, the embodiment of the soul.

Along with these negative associations, poverty brings additional assumptions. While poverty may be the outcome of disabling conditions that prevent work, medical personnel often have negative perceptions of the poor and uninsured, which may affect the quality of treatment a person receives (G. Becker, 2001). Even though it is generally untrue, they may believe that these individuals are inattentive, uncooperative, and overburdened with health problems. These perceptions may overlap with religious and social implications of ideas about willingness to work equating success and all good individuals are blessed. Our Puritan past as a nation may reinforce such a work ethic where it is believed that “God helps those who help themselves.” Certainly, beliefs that imply a causal correlation between health and goodness would have major implication regarding the treatment of individuals with disabilities.

Blame has been strongly associated with responses to children with attention deficit disorders. Kendell (1997) noted how the child with ADHD creates distress primarily with what may be construed as defiant behaviors and opposition to order. The children are often blamed for “misbehavior” and parents for poor discipline strategies, when the children show symptoms of the disorder in their behaviors. The absence of all signs except for behaviors leads to denial and debate regarding the impairment and often refusal to accept it as a biological condition. The over-prescription of stimulants may in fact be a greater problem than the condition, but that does not negate the fact that many children and adults experience functional difficulties in tasks requiring singular, sustained focus and attention to detail.

Finally, *peril* has to do with perceived risk. Fear of contagion, harm, or association can lead to rejection and avoidance. Working for Services for Students with Disabilities (SSD) at Virginia Tech, I quickly learned that programs and groups for students with disabilities rarely work. When I made invitations, these students often expressed concerns about being associated with individuals with disabilities. They feared being labeled, even when they already had a visible disability. Most felt they were exceptions; they were not like the others with disabilities. Some illnesses, such as AIDS, have been particularly stigmatized because of societal fear of contracting the condition (Keigher & Jurkowski, 2001). Especially when the condition has been blamed on the victims.

Hahn (1988) noted that, unlike other groups stereotyped because of physical differences, both women and men with physical (or psychological) disabilities have never been able to refute biological arguments of inferiority, when disability has been defined as impairment, deficit, or lack of functioning. Equating disability with impairment, in effect, makes “disability” a diagnosis, a diagnosis centered on what individuals lack or are unable to do. Still, it is important to understand that “the normal and the stigmatized are not persons but rather perspectives” (Goffman, 1963, p. 138). A plethora of research seems to suggest that these perspectives are often shrouded in ambivalence, suspicion, and discomfort (Albrecht, 1999; Albrecht & Devlieger, 2000; Asselin, 1993; Beilke & Yssel, 1999; Bento, 1996; Cavet, 1998, 2000a, 2000b; Clements, 1970; Goffman, 1963; Huvelle, Budoff, & Arnholz, 1984; N. B. Miller & Sammons, 1999; Patterson & Blum, 1996; Perlin, 2000; Resnick, 1984; Nancy J. Schweitzer, 1982; Nancy J. Schweitzer & Deely, 1982; Seibold & Thompson, 1978). As Bento (1996) explains, “Ambivalent feelings are a typical reaction to minorities who are, for some reason, stigmatized. [...] Ambivalence has historically characterized societal reactions to individuals with physical or mental disabilities, who alternatively receive help and special consideration, or mistreatment and disregard” (p.498). Bento (1996) cites several sources regarding ambivalence and stigmatization. Numerous works have addressed the subject (Dovidio, Gaertner, Anastasio, & Sanitioso, 1992; Esses, Haddock, & Zanna, 1993; Katz, Wackenhut, & Glass, 1986; Stone, Stone, & Dipboye, 1992).

Goffman (1963) explains the role of stigma associated with deviances from what society considers normal. As always, difference becomes justification for suspicion and stigmatization. Audrey Lorde argued:

Institutionalized rejection of difference is an absolute necessity in a profit economy which needs outsiders as surplus people. As members of such an economy we have all been programmed to respond to human differences between us with fear and loathing and to handle that difference in one of three ways: ignore it, and if that is not possible, copy it if we think it is dominate, or destroy it if we think it is subordinate. But we have no patterns for relating across our human differences as equals. As a result, those differences have been misnamed and misused in the service of separation and confusion. (Cited in Charlton, 1998, p.25)

With disabilities, these deviances can be apparent, such as blindness or paralysis. This causes the person to be “discredited.” They can also be concealable or hidden, such as learning disabilities or diabetes. This causes the person with the disability to be “discreditable,” meaning that the disability has the potential of becoming known and causing the person to become stigmatized. This condition of discredited or discreditable grows from social constructs of perceptions and interpretations. Fein and Nuehring (1981) discuss the intrapsychic effects of stigma. “Reality shock” occurs when individuals realize that they are part of a stigmatized group or when there is dissonance between their perceptions and interpretations and those of others. Often the reaction is denial and disbelief. Fein and Nuehring (1981) summarize:

Many of the effects of stigma, including subjective feelings and actual patterns of adjusting, occur through an intrapsychic process related to the construction of social reality. During this process, the actor’s private system of valuations is broken and then reconstructed under the constraints of a different system. [...] It was noted that both the

breakdown and reconstruction can sometimes result in a fulfillment of the stereotypes attached to the given stigma. (p.6)

With stereotypes comes prejudice and discrimination, which create stress for individuals who have stigmatized characteristics (C. T. Miller & Kaiser, 2001). Those without stigma rarely share that type of stress. The differences between stigmatized and nonstigmatized individuals, normality and abnormality, leave individuals with disabilities exhibiting identities between familiar sets of negative and positive characteristics. Charlton (1998) explains:

Most people with disabilities actually come to believe they are less normal, less capable than others. Self-pity, self-hate, shame, and other manifestations of this process are devastating for they prevent people with disabilities from knowing their real selves, their real needs, and their real capabilities and from recognizing the options they in fact have. False consciousness and alienation also obscure the source of their oppression. They cannot recognize that their self-perceived pitiful lives are simply a perverse mirroring of a pitiful world order. In this regard, people with disabilities have much in common with others who also have internalized their own oppression. (p.27)

It is important to recognize that geographical and cultural contexts will have a major influence on how the disabled identity may be experienced and understood.

Marginalization and Crossing Borders

Many critics have explored the differences between impairment and disability (Albrecht & Devlieger, 2000; Corker, 1999a, 1999b, 2001; Hillyer, 1993; Morris, 1993; Resnick, 1984; Scambler, 1998). While impairment, such as blindness, mobility limitation, or dyslexia, can be described as a physical limitation or disorder, disability is an identity. For example, from the social perspective, a person with a sensory impairment such as blindness may be given a text in Braille. They are still impaired (blind), but they may no longer be debilitated. This social construct is based on the context of difference, and it creates an identity of someone disabled or not disabled. Of course, blindness, as well as many other forms of disability, may be readily visible to an observer. Society can easily categorize these individuals by appearance or behavior, labeling them as different.

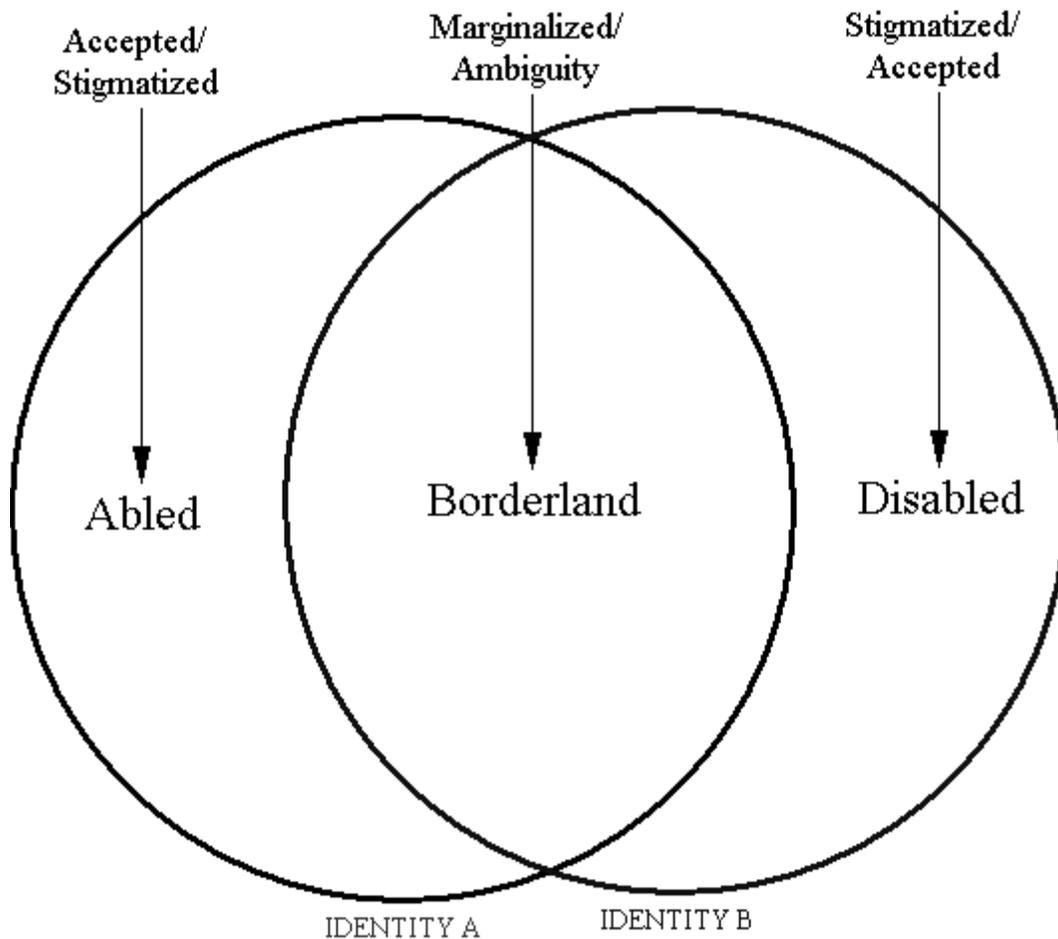
Individuals with concealed disability, however, may feel more confusion regarding their identity. Zola (1993) argues:

While most minority group members grow up in a recognized subculture and thus develop certain norms and expectations, people with chronic diseases and disabilities are not similarly prepared. The nature of their experience has been toward isolation. The vast majority of people who are born with or acquire such conditions do so within in families who have neither these conditions nor associate with others who do. They are socialized into the world of the 'normal' with all its values, prejudices, and vocabulary. (p.167)

People with concealed disabilities are likely to be marginalized among the disabled and the non-disabled. Newman and Newman (2001) explain, "Group identity emerges out of continuous interactions, through which one becomes visible and known to other group members, and they

become visible and known to you” (p.524). Paradoxically, as a person with a disability reveals more about self to a “normal” group, which should lead to assimilation into the group, the differences from the group become more apparent, making membership less possible. If, as Butler and Parr (1999) suggest, identities are performative, the behaviors of a person with a concealed disability may seem incongruous among any group –“normal” or deviant. In the same way a group may stigmatize “foreigners,” individuals with concealed disabilities may become outsiders within the community they live in, at some point becoming part of a marginalized population. (See Figure 4).

Figure 4. Borderland Diagram.



Western society oppresses its marginalized members; it denies access to resources, reserves recognition for the dominant group, and perceives the marginalized individuals as deviant (Migliaccio, 2001). This results in a number of problems faced by these marginalized individuals. Research has demonstrated, “Chronic conflict about one’s integration into a meaningful reference group can lead to lifelong difficulties in areas of personal health, work, controlling anger, and the forming of intimate family bonds” (Newman & Newman, 2001, p.527). This potentially creates a vicious cycle where the symptoms of group rejection become catalysts for further alienation and rejection. Charlton (1998) associates this with hegemony exercised by the “non-disabled” members of society; he explains:

Alienation unfolds over a long time. It involves the everyday experiences of individual people in their own homes and communities, at work, in schools, as women, as workers, as colonized peoples, and as people with disabilities. Alienation is similar to hegemony in its organic link to the institutions and realities of everyday life as well as its psychological outcome –hopelessness, rationalization of oppression, and the inconceivability of power. Hegemony’s relationship to alienation can be simply summarized: hegemony relates to power in the context of ideas like alienation relates to ideas in the context of power. (p.73)

In a sense, alienation of individuals with disabilities occurs not only in the context of power, but also as the source of power. By creating an underclass, the privileged create an antithesis, a complementary container for blame and stigma.

Individuals with concealed disabilities face other difficult situations because of neither fitting totally into a disabled nor non-disabled set of expectations, as well. Migliaccio (2001) explains:

Being marginalized constitutes being defined as “other” by the dominant group, which designates an individual to a lower status in the social hierarchy. It is a determinant of power that maintains the inequality of the system. (p.207)

People with concealed disabilities are marginalized in two communities simultaneously. David Sibley (1995, Cited in Cullen & Pretes, 2000) comments:

There is a history of imaginary geographies which cast minorities, ‘imperfect’ people, and a list of others who are seen to pose a threat to the dominant group in society as polluting bodies or folk devils who are then located ‘elsewhere.’ This ‘elsewhere’ might be nowhere, as when genocide or the moral transformation of a minority like prostitutes are advocated, or it might be some spatial periphery, like the edge of the world or the edge of the city. (p.216)

People with concealed disabilities live in this type of an imaginary geography. These individuals live on two sides of the border between disability and no disability. Metaphorically, they live in what Gloria Anzaldúa (1999) called borderlands; she describes the borders and borderland:

And before a scab forms [where one has been severed from cultures] it hemorrhages again, the lifeblood of two worlds merging to form a third country –a border culture. Borders are set up to define the places that are safe and unsafe, to distinguish us from them. A border is a dividing line, a narrow strip along a steep edge. A borderland is a vague and undetermined place created by the emotional residue of an unnatural boundary. It is a constant state of transition. The prohibited and forbidden are its inhabitants. (p.25)

It is this place, between normal and deviant, these individuals must navigate. Some see themselves as disabled individuals who can pass without detection into normal communities. Others deny they have a disability at all, sometimes forgoing the needs their condition might demand. Keigher & Jurkowski (2001) explain:

Invisible disabilities present our social institutions with an array of unprecedented challenges. Institutions of all kinds –not just government and public buildings but workplaces, schools, businesses, religious congregations, criminal justice systems, not to mention health care itself and professionals from city planners to meter maids– must anticipate the needs of people who do not really consider themselves disabled. (p. 212)

Joachim and Acorn (2000) discuss the attempts of individuals with concealed disabilities trying to “pass” as members of the “normal” group. Passing involves hiding conditions, crossing borders, blaming signs of the condition on less stigmatized conditions, and even doing things harmful to oneself to cover up health restrictions imposed by the disability. Anzaldúa (1999) includes discussion and poetry that sketches a map of what it means to be the new mestizo (person of mixed descent) living between cultures, belonging to each and marginalized in each. She creates a landscape culminating in power and choice rather than exclusion and oppression. Anzaldúa (1999) describes the nature of hiding conditions:

To avoid rejection, some of us conform to the values of the culture, push the unacceptable parts into the shadows. Which leaves only one fear –that we will be found out and that the Shadow-Beast will break out of its cage. Some of us take another route. We try to make ourselves conscious of the Shadow-Beast. [...] Yet, still others of us take it another step: we try to waken the Shadow-Beast inside us. (p.42)

The Shadow-Beast, at least on one level, may refer to that part of ourselves that we push into the shadows, the part of ourselves that makes us different. Our culture has a tendency to attach a negative connotation to the word “beast.” However, I believe Anzaldúa (1999) would view this as a cultural distortion. The term beast suggests something primal, central, and not assimilated. Hentinen described how young diabetics eat and drink things harmful to them in order to be perceived the same as their peers (Cited in Joachim & Acorn, 2000). Great stress is generated, because individuals trying to pass as not disabled must constantly risk being discovered and suffering the same stigmatization as individuals with visible disabilities.

Stage & Milne (1996) noted an interesting paradox. Peers assumed students with concealed disabilities highly intelligent, because they spent long hours trying to keep up by studying and working in the library. Some students preferred to let peers keep this impression. Some students, however, were unable to convince others that they had a disability. Many reported that disclosure resulted in negative reactions from faculty and peers. An assumption of intelligence among library workers is easily explained by an ignorance of causality, but often superstition and religion can create an additional level of expectations and belief regarding the disabled. For example, Anzaldúa (1999) says of her culture:

[T]here is a magic aspect in abnormality and so-called deformity. Maimed, mad, and sexually different people were believed to possess supernatural powers by primal cultures’ magico-religious thinking. For them, abnormality was a price a person had to pay for her or his inborn extraordinary gift. (p.41)

Still, this expected ability would need to be displayed, another cause of stress, if not distress. These expectations of ability do not prevent stigma and rejection, unless perhaps members of the community need services or advice from the individual. Historically, failure successfully to

demonstrate special powers could result in execution or punishment as easily as successful demonstrations. Ironically, performance has little to do with outcome finally. Difference is always a threat.

One of the most significant details about concealed disabilities centers on their pervasiveness. According to Gershick (2000), there are more individuals with disabilities than any other minority population in the United States except women, and the proportion of disabled individuals will probably continue to grow. Still, many individuals live with disabilities invisible to an observer, and these individuals face unique barriers and hardships. Murphy (1990) notes, "The greatest impediment to a person's taking full part in this society are not his physical flaws, but rather the tissue of myths, fears, and misunderstandings that society attaches to them" (p.113). Anzaldúa (1999) warns, "Deviance is whatever is condemned by the community. Most societies try to get rid of their deviants" (p.40). Thus, individuals with disabilities are strongly motivated to hide any impairment associated with the disability. Ironically, individuals whose disabilities are visible to others have much less stress and self-conscious behavior than individuals who are trying to conceal their disabilities (E. E. Jones et al., 1984). A shift of stress seems to occur with changes in visibility. As a condition becomes more visible, the stress associated with it relocates from the subject to the observer. As Shakespeare (1999) explains:

For the disabled person, who has lived with difference perhaps for their whole lives, the abnormality is invisible anyway. But for the stranger, it is absolutely overwhelming. Therefore, the disabled person must find a way of acknowledging the difference, showing that it is not important, and that interaction can now progress. (p.50)

Of course, humor serves as a common strategy. Still, the response may be forced laughter and increased anxiety. Interactions often walk a thin line between tolerance and rejection. Individuals with differences may incite curiosity, hostility, or pity (Shakespeare, 1999). Still, concealment may not come easily. Patterson and Blum (1996) explain that invisible conditions can be more stressful and psychologically damaging, because of the ambivalence regarding level of disclosure and explaining restrictions associated with the disability. Students with concealed disabilities may have a low self esteem (Stage & Milne, 1996). They may choose to appear to be a "goof off" than to admit difficulties related to a disability. According to Cast and Burke (2002):

Self-esteem refers most generally to an individual's overall positive evaluation of the self. It is composed of two distinct dimensions, competence and worth. The competence dimension (efficacy-based self-esteem) refers to the degree to which people see themselves as capable and efficacious. The worth dimension (worth-based self-esteem) refers to the degree to which individuals feel they are persons of value. (p.1042)

These students may have been accused of not trying and being lazy. They begin to question themselves and their disabilities, feeling as if they are worth less than others are. As one woman with a concealed disability described her experience:

Like a fearful horse, I stand before the hurdle of the past, wading in the quagmire of old injuries. Will I be able to rise above this, too? Will I be able to transcend it and make it meaningful instead of destructive? (Ozer, 1990, p.69)

In the case of this person, the story is about triumph. Still, we cannot diminish the obstacles these individuals face. For each person that finds a meaningful resolution, many more become trapped in place where they feel they must hide themselves and their disabilities.

Most individuals have difficulty disclosing their disabilities, because they fear a negative response from others (Joachim & Acorn, 2000). Fear of revelation of the disability through uncontrolled signs, such as seizures, frequent trips to the bathroom, tremors, food and activity restrictions, or acute flatulence or diarrhea, can create additional stress and signs. Other concerns also motivate the degree of disclosure. Gerschick (2000) explains, “The age of onset combines with the type, severity, and visibility of a person’s disability to influence the degree to which she or he is taught and subjected to gendered expectations” (p.1265). For example, men with disabilities cause a discomfort among other men, since, as Gershick & Miller (1994) explain, they undermine traditional constructs of masculinity. As a result, they are marginalized and stigmatized. In fact, Collins (1989) claimed that a disabled man’s body is a paradoxical contradiction, privilege/stigma. As Gerschick (2000) writes, “Women and men with disabilities share similar experiences of devaluation, isolation, marginalization, and discrimination [; however] two stigmatized roles converge in women [, but disability in men] erodes much, but not all, masculine privilege” (p. 1265).

Cullen and Pretes (2000) note, “What theorists such as hooks and Shields seem to be suggesting is that marginality and marginal regions offer us access to other points of reference that the center has denied us” (p.217). bell hooks describes marginality as a potential site of resistance, while Rob Shields sees it as a “condition of possibility” allowing the marginalized individual to transcend cultural or social norms (Cullen & Pretes, 2000). This raises the possibility of more positive personal discourse surrounding disability, which offers more complexity surrounding the construct of disability. As a place of resistance, this borderland offers the possibility of synthesis. It presents a unique position from which to affect change. Corker (2001) points out Anzaldúa’s view:

If language ratifies and expresses social hierarchies, it must also provide a medium for liberation as new meanings are created at points of language conflict. For example, people who are deaf are frequently assumed to live their lives between Deaf and hearing worlds, occupying marginal positions to both. This is sometimes a direct consequence of the rigidity of minoritizing identity politics that produces spaces of in-betweenness, populated by ontologies that are similar to the nondualistic “mestiza consciousness” described by Third World feminist writing. (p.40)

As a place of change and resistance, these in-between spaces dually oppress and empower. Without clearly defined labels, or marks, individuals with concealed disabilities bypass the expectations and stereotyping. Society has no clear definitions or cues to identify them. This results in an opportunity to choose and move between cultures to meet needs that can be met on either side.

The ability to conceal one’s identity to traverse cultural borders and straddle binary divisions always has been a device employed by storytellers and writers. These characters are called tricksters. According to Albrecht (1999):

Trickster characters in novels or short stories who have disabilities span the mainstream and disability worlds providing insight into both and illustrate the difficulty in moving back and forth between those two frames of reference. [...] In doing so, they offer useful strategies to members of marginalized groups like people with disabilities. (p.70)

This character appears often in folklore and stories. A common example, Jack from the Jack Tales, embodies the characteristics of a trickster –and perhaps significantly some of the stereotypes of individuals with concealed disabilities. Jack’s family and neighbors accuse him of laziness, inability, foolishness, and ignorance. Ultimately, Jack proves himself more than capable, often using nontraditional means. Smith (1997, Quoted in Albrecht, 1999) shares:

In virtually all cultures, tricksters are both folk heroes and wanderers on the edges of the community, at once marginal and central to the culture. Tricksters challenge the status quo and disrupt perceived boundaries. Whether foolishly, arrogantly, or bravely, tricksters face the monstrous; transforming the chaotic to create new worlds and cultures. (p.70)

While I do not insist that individuals with concealed disabilities have recognized this potential, the possibility of such empowerment could be realized. In fact, recognition of what it means to live in the borderlands, having the “mestiza consciousness,” should empower any marginalized group that chooses to act on the convergent nature of cultures that have been bridged. By assuming the “trickster” persona, the mestiza, they can access the best of both cultures and prove a powerful catalyst for change. Bringing about change may come at a price. As Fanon has argued, any kind of “emancipation from oppression” must begin with visibility (Charlton, 1998, p.74).

In addition to membership in marginalized groups, individuals with disabilities also face the existential factors of being human. The role of psychology and sociology in the identity development of individuals with disabilities presents many interesting possibilities, especially when trying to understand the motivations for concealing a perceived disability. Researchers have looked closely at reasons for disclosing personal information.

Disability presents a number of concerns and possibilities. As a stigmatized role in society, disability brings about personal and social changes. Crew and Athelston (1985) enumerate changes that have an impact on key social roles. These include self-care, mobility, employment, communication, and socialization. With these roles, society presents a bias which privileges those who can or do have the perceived ability to carry out “essential” tasks of social inclusion (Carlson, 2001). These include not only carrying out these key social roles, but producing them in a manner consistent with social norms. Of course, individuals with disabilities often present themselves in ways that conceal how they transgress social norms (Troiano, 2003). In order to function in society, they often must learn to become experts at adaptation (McRuer, 2003).

Self-care may change in that individuals with disabilities may lose some of the autonomy they once enjoyed, and the acceptance of help may introduce additional difficulties. Several studies have focused on acceptance of help from others and the role of reciprocation (Pratkanis & Turner, 1996; Schneider, Major, Luhtanen, & Crocker, 1996; Shell & Eisenberg, 1992). When

an individual cannot reciprocate, they are likely to feel threatened. Even a small token—a flower, a keychain, a magazine—will incite individuals to give to a charity more than feelings or facts (Whatley, Webster, & Smith, 1999). The act of giving aid without reciprocation imposes a hierarchical position, where one individual becomes dependent on another. Unfortunately, many programs foster this type of relationship, where resources are supplied without even a token repayment. While individuals may enjoy “free” help, their self-concepts may pay the price. In disclosing the need for these resources, they are permitting themselves to be on the unprivileged end of the binary. With a lower position, they gain the stigma and projections of society regarding the stereotypes about individuals with similar needs.

Mobility for some individuals with disabilities may also become an issue. Of course, this is a restricted group of individuals that face this issue. This may increase feelings of marginalization and force individuals with disabilities into an imposter role, when they try to navigate areas that were designed for the “abled.” Even when ramps, elevators, and electronic doors are installed, they often are placed in out-of-the-way locations. The act of choosing such an entrance, when it is not common to everyone, may feel stigmatizing and isolating to a individuals with disabilities.

Individuals who feel stigmatized or socially anxious, even when it is situational, tend to attribute incidental events as pertaining to them and to overestimate others’ awareness of them (Fenigstein & Vanable, 1992). Other common outcomes of social need may become twofold. Some individuals with social anxieties become more distanced from others by self-medicating with herbs, alcohol, drugs, and other “discovered” cures, which may or may not have any effect (Hull & Young, 1983). Still, others begin to present illness and infirmity as a badge. As with socially constructed epidemics (Small, Propper, Randolph, & Eth, 1991), they may believe the impairment to be real, and they may suffer actual limitations because of it. Identifying these socially constructed conditions may be problematic, since signs and symptoms may be displayed. Such individuals may experience disability, even if there is no physical cause of the limitations they experience. Self-esteem may be a major factor in the limits and abilities individuals recognize. Individuals with high self-esteem show more determination and lead more active lives than individuals with low self-esteem (Modrein-Talbott, Pullen, Ehrenberger, Zandstra, & Muenchen, 1998)

Concealed disabilities cannot be normalized. As long as they remain concealed, the reality of these disability experiences is not confronted, leaving society with noematic assumptions.

Gender and Sexuality

Gender presents another layer to the discussion of disability. As Asch & Fine (1997) point out, advantage and privilege rests inequitably positioned more within the male experience. Disability, while stigmatizing men, leaves women at an even greater disadvantage. Numerous examples of misogyny in our society is disturbing. For example, women are expected to be obedient, dependent, and selfless caregivers; their personal feelings and even health are relegated to secondary issues (McBride, 1990). Breast cancer, even though it kills more individuals than many other illnesses, does not get nearly the funding or attention it needs, since society views it as a female disease. In addition, more hysterectomies are performed in the United States than

most modern nations, twice as many as in Great Britain (Balch & Balch, 1997). Very few are because of life-threatening conditions. Many are unnecessary. Yet, this type of extreme medical treatment would be unlikely, if the clients were male. Social pressure has encouraged women to facilitate gender-role expectations through plastic surgery, liposuction, dieting (sometimes leading to eating disorders), uncomfortable clothing, make-up, and subservient behaviors. Biologically there are surprisingly few differences between men and women, and none of these differences validate any of the inequitable treatment and expectations imposed by society (Fausto-Sterling, 1992).

Society tends to impose gender beliefs even on infants. Male children, even though more vulnerable than female children, get played with rougher. Fausto-Sterling (1992) showed that adults tend to project gender beliefs onto children. If a male child is startled and begins to cry, adult subjects attributed the crying to anger; when a female child was startled and began crying, the same adults attributed the crying to fear.

Lloyd (2001) discusses a borderland that women with disabilities populate and could perhaps create synthesis. These women “have been caught between [disability theory], on the one hand, an analysis and movement in which they have been in which they have been invisible as women, and one [feminist theory] in which their disability has been ignored or subsumed, on the other” (p.716). Women tend to be desexualized within the constructs of disability theory. Asch and Fine (1997) note, “Women with disabilities are less likely than non-disabled women or disabled men to fulfill roles customarily reserved for the respective sexes” (p.241). This, perhaps, affords more freedom to assume nontraditional roles, if this is indeed a preference and not a default. Too often, researchers have located the woman with a disability within the framework of the immediate family and necessary caregivers, leaving unaddressed issues of sexuality and intimacy. Sixty percent of men with disabilities marry someone with a disability, while only forty-nine percent of women with disabilities marry at all (Asch & Fine, 1997, p.241).

Feminist theory has ignored disability for the most part. Some areas of contention have arisen, especially regarding stances regarding reproduction (Lloyd, 2001). After an era of automatic sterilization and other eugenic movements, issues of reproduction become especially volatile. A major argument has been the agreement between both sides of the abortion debate regarding an “abnormal” fetus. Disability does not politicize women toward either side of the debate. The general concern grows from the stance that late-term abortions of “abnormal” fetuses should be nearly automatic upon detection, while “normal” fetuses should require at least more thought. Individuals with disabilities recognize the disparity in the value given to those with disability and those without.

Gender and disability have been the catalysts for societal oppression on many levels. This oppression can take many forms. Gerschick (2000) writes:

Bodies are central to achieving recognition as appropriately gendered beings. Bodies operate socially as canvases on which gender is displayed and kinesthetically as the mechanisms by which it is physically enacted. Thus, the bodies of individuals with disabilities make them vulnerable to being denied recognition as women and men. The type of disability, its visibility, its severity, and whether it is physical or mental in origin

mediate the degree to which the body of a person with a disability is socially compromised. (p.1264)

While men and women report similar experiences of “devaluation, isolation, marginalization, and discrimination,” they experience two identified positions differently (Gerschick, 2000, p.1265). Women with disabilities still experience sexism, but men no longer idealize them. Asch and Fine (1997) write:

Women with disabilities have not been “trapped” by many of the social expectations feminists have challenged. They have not been forced to get married or to subordinate paid work to childrearing or housekeeping. Instead, they have been warned by parents that men only “take advantage”; they have been sterilized by force or “choice,” rejected by disabled and non-disabled heterosexual and lesbian partners, abandoned by spouses after onset of disability, and thwarted when they seek to mother. (p.254)

In fact, Hannaford (1985, Cited in Gerschick, 2000) reports that women are more than four times more likely than a man to be divorced after developing a disability; they are also only one-third to one-fourth as likely to marry. Men with disabilities lose most masculine privilege, but not all. Still, men do not lose social esteem from others to the degree that women do. Until ability to perform masculine or feminine roles to satisfy gendered expectations becomes compromised, individuals with concealed disabilities may not experience external pressures related to disability.

Often sexual orientation is presented as a problem. Of course, most people do not even think about heterosexual people when they hear the term “sexual orientation.” Gay, lesbian, and bisexual people have often been objects of inquiry. Like disability, orientation has been constructed as a medical condition – sometimes as a curable impairment, an untreatable tragedy, or a maintainable condition. The DSM III diagnosed homosexuality as a psychological disorder.

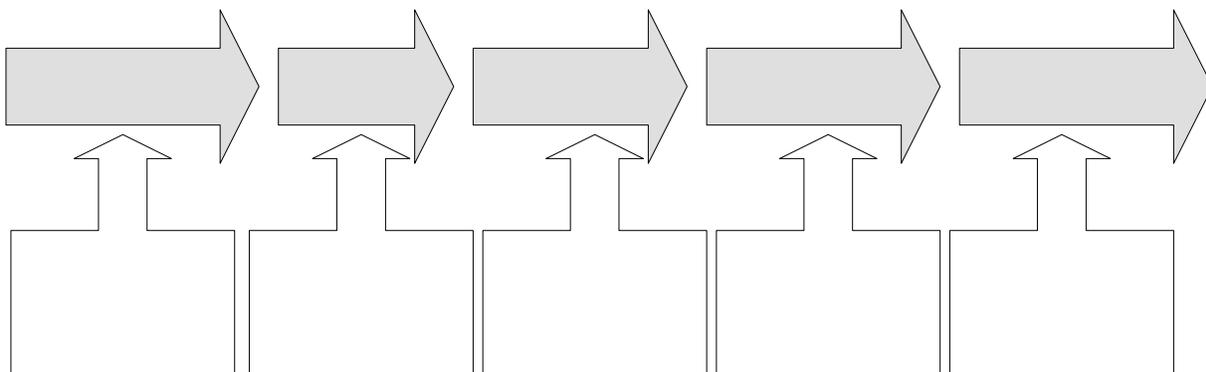
Race and Ethnicity

Race and ethnicity also play an important role in the outcomes of identification for individuals who self-identify as disabled. Historically, people of color have been labeled and prejudged to suit the ideology of the privileged Caucasian majority, in much the same way individuals with disabilities have been oppressed by the “abled” community. In an unusual convergence of race and “disability,” nineteenth-century society constructed two forms of mental illness associated with slavery. African slaves exhibited signs of this epidemic syndrome involving “drapatomania” and “dysathesia aethiopica,” the act of running away and the expression of resistance to forced servitude (Bronstein & Quina, 1988). Even more recently, Herrnstein and Murray’s (1994) suggested inherent intellectual differences between White and Black individuals’ demonstrated by scores on standardized tests. As many critics have noted, The Bell Curve bases many assumptions on unfounded racial beliefs regarding causation (Nisbett, 1995). Among other differences among the subjects, beyond race, were socioeconomic status and cultural variety. Still, they aimed toward an oppressive audience whose belief perseverance and confirmation biases allowed them to negate these confounding variables. Of course, society persists in prejudgment and discrimination.

These attempts to label individuals and their abilities according to race illustrate the oppressive discourse centered on race and disability. As Jordan (1994) explained, “White and Black connoted purity and filthiness, virginity and sin, virtue and baseness, beauty and ugliness, beneficence and evil, God and the devil” (p.42). This can become sublimated and affect one’s self-concept and self-esteem. In a related manner, Asian-Americans have been shown to be strongly affected by the discourse of European-Americans (Uba, 1994). They have a tendency to have much lower self-esteem regarding their appearances than their European American counterparts. Of course, conflicting orientations to racial identity, attitudes, and values exist within any racial group (Cornell & Hartman, 1997). As Robinson and Ward (1995) point out, African-American adolescents show high levels of self-esteem, even though there are some variation based on the darkness or lightness of their skin tone. Those with an average skin color describe more satisfaction with their appearance than adolescents with darker or lighter than average skin tones describe. This is positive in the sense that these adolescents are basing self-concept on their assimilation into a group of their own race, rather than privileging the dominant culture’s appearance. Perhaps, this demonstrates a type of identity development achieved by these young individuals.

Several theories of racial and ethnic identity development compete and supplement each other (Cross, 1991; Helms, 1990, 1995; Posten, 1990; Smith, 1991; Sue & Sue, 1990). Cross (1991), in the developmental theory he proposes, presents a maturation process toward a healthy Black racial identity. This growth centers on the movement from dominant-culture discourse to salience with one’s race and determination to transcend and eradicate racism for all individuals. Most interesting is the stage of immersion and emersion, which serve as a transition to maturity. In this stage, a person’s sole focus becomes race, to the exclusion of any other race. individuals in this stage may withdraw from interaction with any other race. They may vilify anyone who does not solely promote the interests of their racial group. If Cross’ (1991) model accurately describes identity development among Black individuals, exclusion from services and concealment of needs may be a natural sign of individual growth (Figure 5). Dependence on a White-dominated system, which imposes labels and requires perpetual disclosures to continue services, would become antithetical to self-esteem and growth.

Figure 5. Theory of racial identity development (Cross, 1991).



Researchers have argued that racial classification is somewhat arbitrary, based on social constructs and cultural agendas (Zuckerman, 1990). When individuals are being classified according to race, apparent phenotypes –skin color, hair type, hair color, eye color, stature– are used to make biological assumptions. This becomes a highly subjective exercise at best, especially in an era where multiracial backgrounds are becoming more common.

Ethnicity is an even more ethereal concept. Racial identity levels vary greatly among individuals. In fact, low racial identity levels lead to poor self-concepts (Poindexter-Cameron & Robinson, 1997). Identification with a particular ethnic group seems to be important to psychological health. This may have an impact on dominant groups that may have a low salience regarding ethnicity. The self-concept of such individuals may be otherwise compromised by its invisibility.

Passing as the dominant group may introduce additional problems. As Posten (1990) notes, biracial individuals have strong need to align themselves with one racial group over another. Being embedded within a culture seems to insulate individuals from numerous social and psychological impasses, creating a more solid self-concept and personal identity (Smith, 1991). Any group, passing or not passing as the dominant culture, becomes marginalized, in a situation where inclusion may be tentative and awkward (Anzaldúa, 1999). This is especially true among groups being actively oppressed with propaganda and stigmatization, as individuals of Arabic descent have been most recently. Of course, political pressures may single out particular groups to serve a purpose, and individuals with apparent differences, such as race, can be easily identified.

The recent removal of Affirmative Action at this university in regard to admissions and hiring subjugates minority students to an inequitable position. Representing a denial of the inequality among races, the university has taken the position that accommodations –in spite of social impairments inflicted on them, gives too great an advantage. This line of thought becomes especially troublesome, considering the likelihood it will eventually extend to attitudes about even more groups. It is not a far jump to assume individuals with disabilities should gain admission or employment by proving, in essence, that they are not disabled or that they can, with profound effort but no accommodation, compete with privileged and advantaged others.

Class and Economic Situation

Lack of transportation, phone service, nearby neighbors, employment, support services, educational opportunities, nearby medical facilities, safe water supplies, electricity, sewage connections, and other amenities that many individuals take for granted, serve to isolate and complicate the lives of some individuals. For some individuals, these stereotypical deficits are realities that individuals do face. A lack of access to medical support grows from more than geographical location. With an increase in number of older adult survivors of impairment or illness, the need for additional programs and funding continually increases. Keigher and Jurkowski (2001) explain:

Today 10 percent to 15 percent of people living with AIDS are ages 50 and over; 75 percent of people who diagnosed with cancer as children now survive, and 1.5 to 2 million people per year sustain traumatic brain injuries. Sensory losses during adulthood

require substantial psychosocial adjustments, including sometimes relocating from one's life-long home. People living with severe depression at any given time typically require social support and environmental adjustment. (p.213)

The increasing needs represented here indicate a growing percentage of individuals who will require increased efforts to find support and treatment. Medical successes increase the number of living older-adults with age-related complications who are no longer self-supporting. In some ways, the traditional multigenerational families, which share a domicile, may relieve some of the support and care-giving deficit in a region. However, this will not resolve all of the issues. As long as medical services are not universalized, a disproportionate number of individuals in more impoverished areas will suffer from a lack of care and resources.

Montgomery (2001), a writer with a concealable disability, adds, "Because 'the invisibly disabled,' like all who defy expectation, are suspect, people ask us why we need accommodation rather than what accommodation we need" (par. 12). The suspicion directed toward individuals who claim to have disabilities but do not have stereotypical signs to match may be impairing itself. Hugh McCaslin reflects:

Sometimes I wonder what goes on in the heads of those doctors. They look you right in the eye, and they're wearing a straight face on, and they tell you you're sick, you've been hurt digging out coal, and you'll never be the same, but your really not so bad off, because your back isn't so bad you can't be a judge, or a professor, or the president of the coal company or something like that you know. (Coles, 1998, p.50).

Unrealistic expectations punish individuals who rely on services and support for survival. Many impoverished young women have no husbands, two or more children, and a requirement to apply for jobs in order to keep getting financial support. The irony of their situation has to do with feasibility of getting work. They could not expect higher than minimum wage, if they could secure a job, and that it would cost more than that per hour to afford childcare for their children. Even if they were offered a job, which was often disastrous for them, most were in an isolated area of the county without transportation. Still, as a disenfranchised minority, these women's difficulties were not addressed in legislation regarding support. The same sort of situation occurs for many impoverished individuals who have no real means of escaping bureaucratic circles that prevent them from self-improvement. In fact, current legislation seems to guarantee these individuals remain dependent on external support.

In the same manner, individuals with disabilities often encounter similar makeshift "solutions" and accommodations. A handicap entrance may be added, but is it in a reasonable location? Oftentimes, a person with a disability may find they have to make their way to an obscured entrance much further away than the entrance others can use. Still, as in classes, they are often expected to get to destinations at the same time as others. A wheelchair accessible stall may be built, but are there wheelchair accessible sinks? Can the paper towels be reached? Moreover, there are the laws and regulations that define disability as far as services and support are concerned. Needs may be met only tentatively. Provided services may be limited or restricted to short-term, solution-focused remedies that only address symptoms and the short-term issues. In the end, some of these quick solutions may only compound problems. This has been debated recently with concerns about over-prescribing medications to make behavioral modifications

without the necessary component of counseling, or coaching, to help the individuals develop new habits.

As M. Jones (1997), a deaf-blind writer complains in *Ragged Edge Magazine*, “Apparently, I am only legitimately special if I look that way” (par. 20). *Ragged Edge Magazine*, a popular online periodical for individuals with disabilities, serves as a sounding board and information center for this community. It continually documents the stigma felt by individuals with disabilities, concealed or not. Too often, potential solutions offered by society present no meaningful, long-term answers. They are simply bandages that attempt to hide the wounds. As Charlton (1998) explains, “Hope is useful only when it is not illusory, and help is useful only when it leads to empowerment” (p.5). Still, our government at all levels tends to opt for services that create further dependence, rather than providing skills and resources that would empower individuals to escape medical, psychological, and economic hardship. Of course, within the context of a larger society, dependence guarantees privilege for certain members. Wealth, prestige, and position describe a relative situation, a situation requiring a reference group. Still, we are all harmed at many levels by inequity. Even at the most basic level, the greater the income inequalities in a society, the shorter the lifespan expectancy for everyone, not just the poor and oppressed (Kawachi, Kennedy, Wilkinson, & Kawachi, 1999; Lynch et al., 1998; Lynch, Smith, Kaplan, & House, 2000; Marmot & Wilkinson, 1999).

Policy, Law, and Legal Definitions

Early in the 1960’s, concerns about unfair employment discrimination coincided with other concerns about civil rights. The first measure, the Equal Pay Act (EPA) of 1963, mandated that pay needed to be set according to what job was being done, rather than who was doing it. All employees doing the same job would be given the same pay. Of course, an employer could argue that not every employee does the same job. What if someone cannot lift as much? What if they cannot communicate as effectively? Some proposed that “same work” did not mean identical work; it meant comparable work. Work involving the same level of effort and skill deserve the same level of pay (Taylor, 1989).

The next year, the Civil Rights Act of 1964 was passed. Title VII, a mandate against the use of race, color, religion, sex, or national origin in hiring practices, was included in this legislation. It became illegal to use these specific characteristics in decisions that might adversely affect a person’s employment status. The Age Discrimination in Employment Act (ADEA) of 1967 followed with provisions to add age to the list of protected characteristics.

In 1972, Title VII of the Civil Rights Act was revised, providing for the establishment of the Equal Employment Opportunity Commission (EEOC). This commission would monitor hiring and employment practices. The EEOC developed interpretations of Title VII that it would use in assessing employment practices. Other agencies, such as the Office of Federal Contract Compliance (OFCC), developed their own set of interpretations. Unfortunately, these different sets of interpretations disagreed about acceptable policies and practices. This led to the government publication of the *Uniform Guidelines of Employment Section Procedures*, which would inform all employers with a consistent standard for employment practices.

It wasn't until the Rehabilitation Act of 1973 and the American with Disabilities Act (ADA) of 1990 that protection was extended to qualified employees with disabilities. There are five titles making up the ADA: Title I, 42 U.S.C. §§12111-12117; Title II, 42 U.S.C. §§12131-12165; Title III, U.S.C. §§12181-12189; Title IV, 47 U.S.C. §§225,611; and Title V, 42 U.S.C. §§12201-12213. Even though these titles present succinct and direct outlines for conveyance of these disability rights, there has been significant interpretation and debate in the courts shaping how they have been administered (Parry, 1999).

Title I serves as a protection from employment discrimination for individuals with federally-acknowledged disabilities. It requires compulsory adherence from all employers with fifteen or more employees. It is under this title that nondiscriminatory guidelines for faculty and staff appointments have been mandated. As a protected minority, individuals with disabilities must demonstrate competence for the employment they seek, but at the same time sufficient impairment to justify disability status. This fine line may be difficult to define, especially when combined with the question of what degree of accommodations are reasonable and does the number of accommodations needed to create equity fall within a reasonable range. If the accommodations necessary constitute undue burden, organizations may plead to be excused from sanctions as a result of ignored mandates (A. J. Jones, 1995). Usually, claims of undue burden are rejected, and only a few are accepted.

Title II protects individuals with federally-acknowledged disabilities from discrimination by organizations providing services to the public, such as state or local governments or modes of public transportation. Federal agencies and airlines are not obligated to comply, but in most circumstance tend to follow the titles' mandates. Under this title, colleges and universities must design buildings and curriculum to allow accessibility to a diverse group of individuals with differences.

Title III protects individuals with federally-acknowledged disabilities from discrimination by privately-owned providers of public services and accommodations. Title IV establishes services and accessibility for individuals dealing with telecommunications. Title V mandates additional miscellaneous provisions.

The burden of establishing disability falls on individuals with disabilities, which involves diagnosis, legal petitioning, and disclosure (Parry, 1999). This creates a paradoxical situation in many cases. Individuals with disabilities demonstrate their markable differences in order to receive accommodations to help them conform. Opportunities to participate become contingent on presenting diagnostic labels that individuals with disabilities must eradicate or overcome in order to adapt to mainstream society. ADA helps to integrate individuals with disabilities into society in that it requires institutions to change in order to accommodate them, rather than placing full burden on them to adapt. Still, until institutions change enough to acknowledge the wide range of diversity, individuals with disabilities who do not meet federal qualifications may be excluded from resources and opportunities.

Under ADA regulations, individuals with disabilities must self-disclose in order to receive protection from discrimination, but providing personal information to others may not be an easy task. They must decide if the benefits of disclosure outweigh the negative consequences and surrender of privacy (Rocco, 2001). Upon disclosure, others may change their attitudes

toward the disclosers, attach negative stereotypes, dismiss their needs, take the position that even with accommodations they are unsuited for opportunities, attribute negative characteristics, or use the knowledge of the disabilities as leverage or a manipulation tool. To a degree, this remains an option only for individuals with invisible disabilities and hidden disabilities who can pass as individuals without disabilities. Timing can be a significant consideration, especially in an educational setting. Procrastination and avoidance of making a decision to disclose may result in receiving accommodations too late (accommodations are not required retroactively), not giving the instructor time to modify materials or procedures, and intensify stigma felt when accommodations are received.

The need to legally identify and document disabilities in order to allocate accommodations and aid creates a number of issues regarding the definition of disability. Even though advocates for individuals with disabilities recognize that the medical model of disability only addresses the impairment in a vacuum, a social model is too complex for categorization. If the discrimination and social oppression, not a documented impairment, qualifies individuals to be labeled as “disabled,” then all minority groups and unprivileged populations qualify as disabled (Harris, 2000). Still, when defined as a minority, individuals with disabilities have a unifying difference, not a handicap or impairment. In some cases, this makes more sense. The deaf community, which often serves as a counter-example of the norm, tends to frown upon suggestions of a “cure.” As a cultural group, many deaf individuals view changing or preventing their difference would be as unethical as trying to “cure” people of their race, ethnicity, sexual orientation, religion, or gender. This also presents issues regarding eugenic stances, such as those wanting to make abortion illegal except in special cases, including impairment, disability, and deformity (Harris, 2000). If disability labels inscribe a protected status, then the individual differences individuals with disabilities present do not imply “substantial limitations.” They may represent substantial differences, such as modes of mobility, learning, access, and communication. They become limitations only when society privileges a particular group of characteristics and designs its institutions to cater primarily to them.

The ADA tries to guarantee equity, but –to create a society that presents opportunity for equity and equality– government needs to dismantle the binary of abled/disabled and recognize a continuum of differences across society and ensure just recognition of all individuals based on what they can contribute and not their inabilities. Of course, prevention of discrimination is a necessary start, but it is also important to expand society’s ability to accept diversity; mandating tolerance and accommodation is not enough, especially if the result is normalization and assimilation.

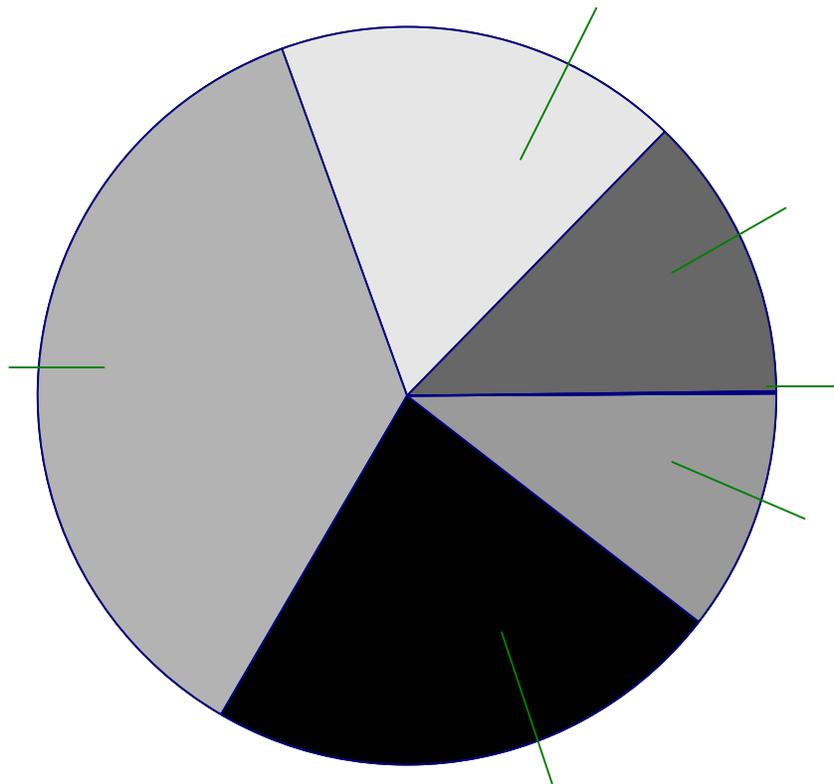
Higher Education and Human Development

The role of being a student brings with it a multitude of factors that would have an impact on individuals with disabilities. Erikson (1964) points out that adolescence and young adulthood are marginalized positions where individuals are caught between childhood and adulthood expectations, privileges, and attitudes. This certainly describes the majority of students in higher education, if not all, since even nontraditional students step into an adolescent/young adult culture at least on a peripheral level. Older students are marginalized in an educational culture where the norm is adolescence and early adulthood. There are several theories, which describe

the development of college students. A few seem especially salient concerning individuals with disabilities.

Only 10.6% of individuals identified and receiving Social Security disability benefits in 1998 had four or more years of postsecondary schooling (Darnay, 2003, p.240). This includes vocational and other types of training as well as college (Figure 6). Six percent of students in higher education disclose disability in the last national poll in 1996 (Horn, Berkold, & Bobbitt, 1999). Compared to students without disabilities, students with disabilities in higher education were more likely to be male, over twenty-four, and white. Female students with disclosed disabilities are much less likely to pursue higher education. Individuals with disabilities are much less likely to attend a four-year, public institution, and they are equally likely to attend a four-year, private institution. Most opt for public, two-year institutions, such as community colleges. Even though the majority of these students report an intent to transfer to a four-year program, most never transfer. Many do not qualify for admission or are unprepared to undertake college-level courses. Only 53% have gained a degree or credential within five years, more than a third never complete a degree or credential program.

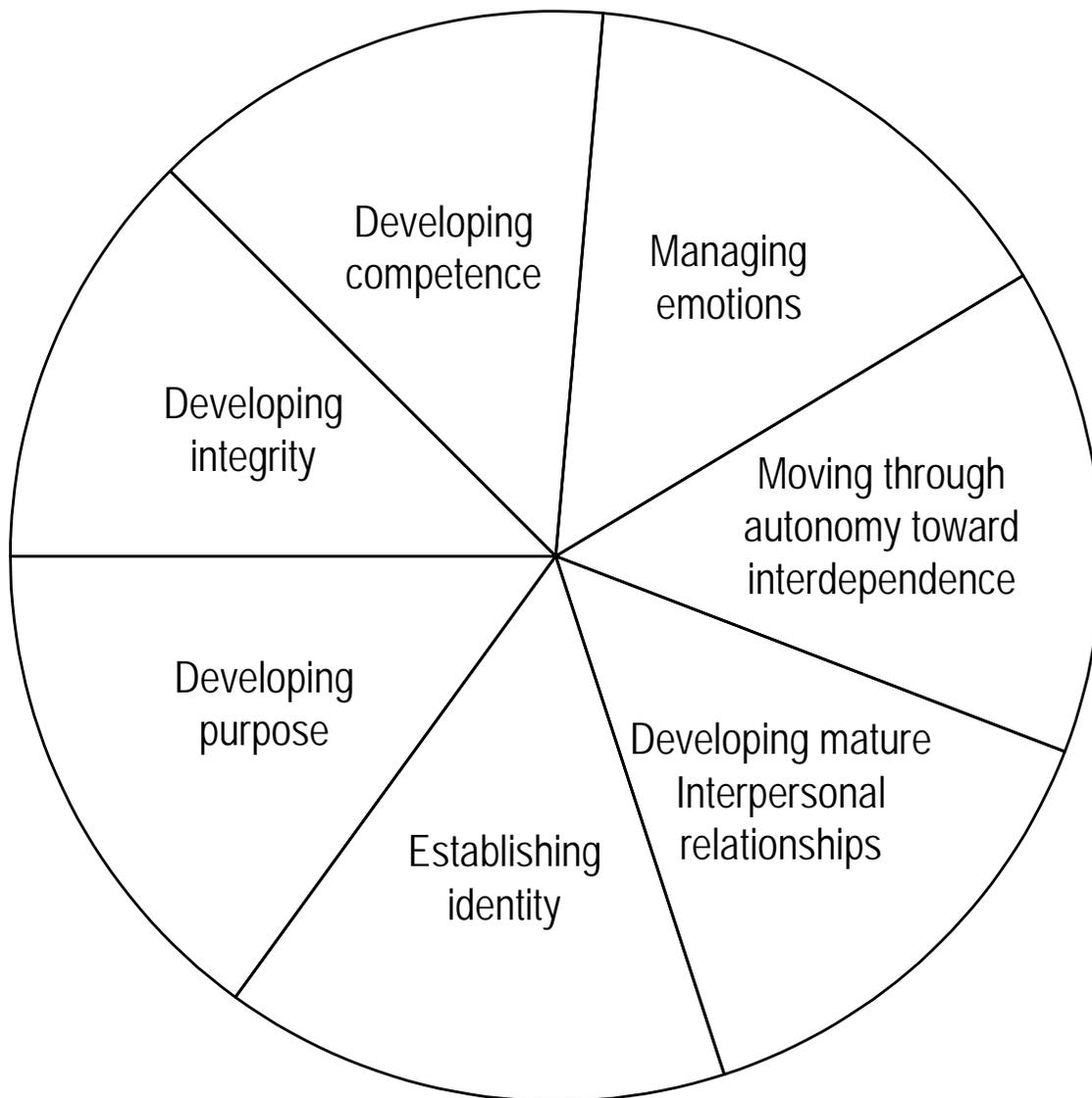
Figure 6. Disability beneficiaries by highest level of education attained, 1998 (Darnay, 2003, p.240).



Even though students with disabilities are less likely to complete their programs, those who do finish tend to get equally satisfactory jobs. However, eleven percent of individuals with disabilities tend to be unemployed a year after completing their degree, compared to the four percent that are not disabled (Horn et al., 1999).

Within the past three decades, numerous theories of development have been suggested within higher education. Chickering and Reisser (1993) present seven vectors of human development that are critical to college students: *Developing competence*, *Managing emotions*, *Moving through autonomy toward interdependence*, *Developing mature interpersonal relationships*, *Establishing identity*, *Developing purpose*, and *Developing integrity* (Figure 7). Unlike a stage theory, these vectors represent a holistic, simultaneous process of growth in all areas. As a template, this theory offers an excellent framework for discussing college student issues.

Figure 7. Seven vectors of college student development (Chickering & Reisser, 1993).



Developing competence is a vector of growth along a continuum between lack of confidence in one's abilities and a strong sense of competence (Chickering & Reisser, 1993). This may be an especially significant vector for students with disabilities, who may question their competence because of perceived impairments and differences. Psychological differences within the cognitive and emotional realm may generate hardships for the students whose perspectives do not match those of their peers. Competence cannot feel attainable when tasks take longer or require more effort for an individual than it does for peers.

Stigma may also play a negative role among individuals with disabilities. Development along this vector may be stifled, especially within the context of a stigmatized position. Marginalized students with disabilities may feel like imposters, only passing as real scholars. Of course, these students may have a chance for equitable potential through accommodations and resources provided on their campus, but that requires disclosure to at least a small audience. Students with concealed disabilities may deprive themselves of such opportunities, resigning themselves to failure.

While coaching students with ADHD, I discovered that it is all too common for students with ADHD and learning differences to feign apathy and immaturity rather than honestly dealing with their condition. Perhaps, markability as someone with a "disorder" who achieves with accommodations is more threatening than failure as a "normal," albeit lazy, student. Of course, excessive "partying" behaviors, which ironically earn an undercurrent of praise within places of higher education and scholarship, may represent something more than rebellion and pressure for approval. This may represent an extension of the same retreat from markability seen among a few of my former clients. Potential failures as committed students actually striving for success may be more difficult to deal with than failures resulting from indulgence.

Managing emotions describes another vector of development. Emotions sometimes play the role of presenting what may be considered impairment or disability. Some diagnoses, such as clinical depression, bipolarity, anxiety disorders, and post-traumatic stress disorder, are carried out using signs that are primarily emotionally motivated behaviors. Mental illness remains stigmatized in our society, more so than other types impairment. This may become motivation for concealment of disabilities that are psychological in nature. Students with disabilities are more likely to use counseling services provided on campus –27% compared to 22% (Horn et al., 1999). Individuals with learning disabilities and speech impairments made up the largest group of individuals with disabilities to use these services with around 74% of individuals with disabilities using counseling services.

The vector referred to as *Moving through autonomy toward interdependence* may be especially salient to individuals with physical disabilities, since they often must accept help and accommodations from others, which illuminates the fact of their differences. In order to conceal impairment, a person may forego resources that would help guarantee successful experiences. Ideally, this vector would represent growth from fearful self-neglecting independence to an ability to accept help, collaborate, and recognize the importance of external input without lowering self-esteem.

Within this dynamic vector, there also exists a continuum between emotional dependence and self-efficacy. Perpetual need of acceptance reassurance from others is replaced with self-actualized self-esteem.

Developing mature interpersonal relationships is the fourth vector of college student development. This vector presents a continuum from intolerance and ignorance of differences to acceptance and appreciation of differences. The eventual outcome of development along this vector is the capacity for intimacy. Individuals with disabilities may exclude others because of the fear of rejection, especially within a discourse community that perpetuates negative stereotypes and stigma directed toward disability. Bridging the gap of difference involves self-acceptance, as well as trust of others. Individuals with disabilities, who have not accepted their own differences, enter into relationships questioning whether another could care for someone with their impairments, appearances, inabilities, or behavior.

Interpersonal relationships demanding heterogeneity ultimately fail, since any person's self-serving biases will guarantee prejudice. As long as differences cannot be accepted and valued, even personal attributes that fail to conform to the average will incite denial or self-loathing, vilifying or degrading others who share the same condition. Some interesting differences between students without disabilities and students with disabilities may be attributed to the average age of each group (Horn et al., 1999). Among students with disabilities, there is a greater likelihood to be married or have children or other dependents. They are also much less likely to be a dependent on their parents. In some ways, these students may have had more opportunity to develop successful relationships, or at least existing relationships.

Vector five, *Establishing identity*, measures a range of self-concepts. It is central to the question of why a person might conceal a disability label or belief. Even though disability serves as a measure of otherness and exclusion for society, it can resonate as part of one's self-schema as central to identity or merely one peripheral element. This difference and otherness may become an object of loathing or a subject of pride (Thomson, 1997a).

Vector six, *Developing purpose*, is the continuum between lack of life goals and commitment to meaningful responsibilities and outcomes. The impact of disability and the social stigma and expectations associated with it may influence individuals with disabilities to feel useless or unmotivated. According to the 2000 census, only 56.6% of individuals with disabilities from the ages of twenty-one to sixty-four are employed; this is compared to same age group of individuals without disabilities with 77.2% gainfully employed ("Profile of selected social characteristics, U.S. summary 2000," 2002). Faced with a much lower level of employability, life goals may diminish.

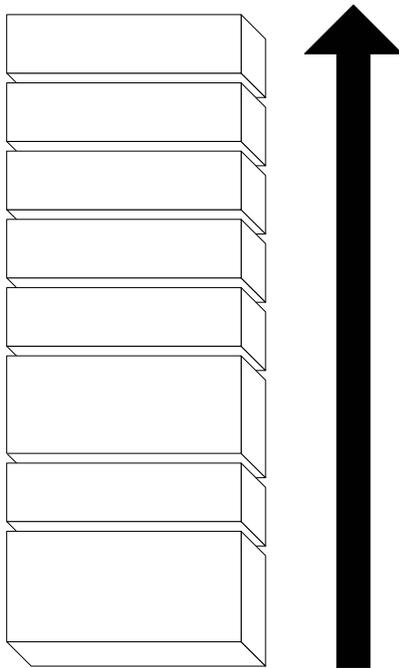
The seventh and final vector is *Developing integrity*. Developing integrity involves a range of personal values and beliefs. On the low end of the scale are rigid, dualistic beliefs, conflict between values and actions, and personal values with no experiential basis. This may involve being a blind follower. On the high end of this scale are humanizing values, respect for the beliefs and values of others, and authenticity.

Perry's (1970) college development theory seems to echo the same time of growth. The theory looks at intellectual and ethical development, moving from a dualistic understand of

values and others to a relativistic stance (King, 1978). Like both Kohlberg's (1976) and Gilligan's (1982) theories of moral development, Perry (1970) and Chickering and Reisser (1993) impose some problematic assumptions in their theories by valuing certain behaviors and attitudes as more ethical, moral, or mature. At one level, the privileging of a contextual relative ideology over unquestioned rigid beliefs seems common sense. Even though I have been socialized to agree with the premise of their value assignments, I must recognize that they presuppose the inferiority of some cultures, religions, and individuals who assign values differently.

The Loevinger model of development may important to consider as well (Knefelcamp, Parker, & Widick, 1978). Unlike many of the other theories, this focused on a wide range of ages (Figure 8). At first, it focused primarily on women, but later it was extended and adapted to include men. The stages in this theory include Presocial/Symbiotic, Impulsive, Self-protective, Conformist, Self-aware, Conscientious, Individualistic, and Integrated. Within her theory, one might suppose that individuals with concealed-disability statuses may have found an impasse somewhere during the Self-protective or Conformist stages, assuming that the choice to conceal is never a positive outcome.

Figure 8. Model of development (Knefelcamp et al., 1978).



In the Self-protective stage, individuals with disabilities may recognize the potential for stigmatization and the stereotypes generated in social discourse.

Likewise, the Conformist stage represents a time when individuals feel pressure and desire to belong. Assimilation into a peer group involves hiding non-homogenous attributes. This may mean concealing a disability, pretending to share values and beliefs, changing appearance, and a multitude of other types of conformity. Of course, disability has come to mean “difference” as much as anything else, once we dispose of a diagnostic, prescriptive definition.

During this stage, individuals are especially vulnerable to groups or individuals who present acceptance, understanding, and positive labels. The media clearly demonstrates manipulation of this audience, a trick mimicked by organizations, advertisers, proselytes, and perceptive peers.

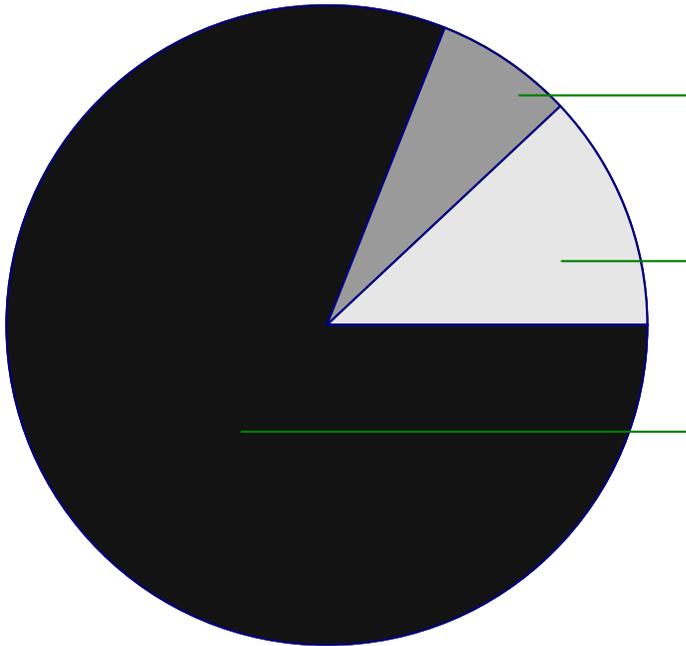
In addition to these developmental theories, it is important to note that many elements of our traditional education system is oppressive in nature, promoting conformity to prescribed standards instead of free thought (Friere, 1993; Manning, 1994; Mercer, 1972). Teacher-student relationships have been hierarchical, rather than dialogic (Komives & Woodard, 1996). Students have been expected to remain silent and absorb information presented by a teacher. Higher education has improved these practices on many fronts with initiatives such as professional development opportunities for faculty. Still, many instructors have never been taught empowering pedagogical practices, relying solely on knowledge of a content area for instruction. Continuing the bad example of Standards of Learning centered evaluation, too often students are expected to regurgitate information.

Further oppression by turning the educational experience into a norming process leaves individuals with disabilities in an even more precarious position. Higher education serves as a bridge for students into a professional career. Yet some students may not aim for their ideal career. Super (Komives & Woodard, 1996) asserted that career choices are directly associated with self-concept. Individuals with disabilities may underestimate their abilities, buy into negative discourse, and select less challenging options.

Demographics

Nineteen percent of the population qualify as disabled according to the Americans with Disabilities Act of 1990 (Darnay, 2003, p.224). This is almost one-fifth of the population (Figure 9). Also, as I have argued, a significant number of others would also self-identify as disabled, but choose not to disclose, seek diagnosis, or pursue legal identification as individuals with disabilities. The attempts at collecting accurate data regarding actual percentages have not been able to account for high rates of nondisclosure (Burkhauser, Daly, Houtenville, & Nargis, 2002). Even so, 19% is a significant proportion of the overall population. And, as Thomson (2002) explains, "Disability is an identity category that anyone can enter at any time, and we will all join it if we live long enough" (p.10).

Figure 9. Americans with disabilities as a percentage of the population, 1997 (Darnay, 2003, p.224)

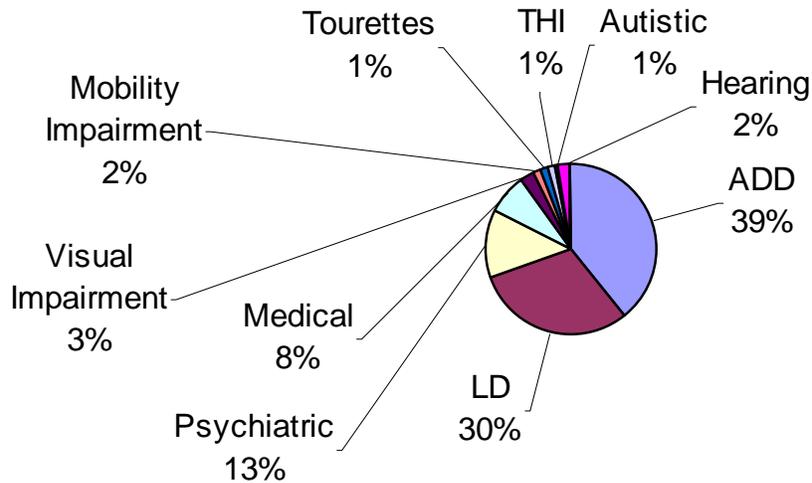


Disabilities, such as mental illness, appear in already oppressed populations. This insult to injury is no surprise, according to Nicki (2001):

[T]he reason that members of oppressed groups form a high percentage of mentally ill people is no mystery. Mental illness is found predominately among such groups as women, homosexuals, the poor, unemployed, or homeless, the physically disabled, the racially marginalized, or the elderly. In societies with rampant prejudice and discrimination, social inequalities, violence against women and children, unequal access to health care, low-paying jobs, unsafe working conditions, technological domination, chemically compromised natural environments, waste, greed, egoism, and so on, members of oppressed groups will be more likely to become chronically or perpetually physically and/or psychiatrically disabled, with their minds overwhelmed with the negative realities in their lives. (p.91)

In a survey of students conducted by the university's disability services office, a total of 423 students seeking accommodations during the Fall 2003 semester reported information regarding their disabilities. Disability labels were divided into eleven categories, speech impairments being less than .5% of the total (See Figure 10).

Figure 10. Student disabilities at Virginia Tech (SSD, 2003).

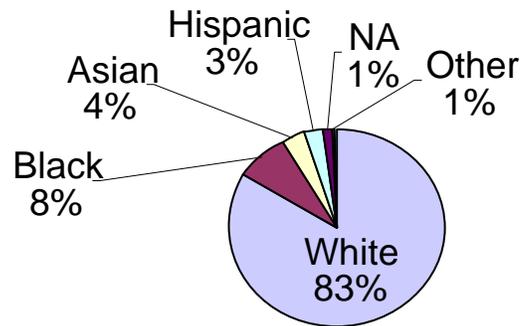


In a larger population, less common conditions are reported. Tourettes, traumatic head injury (THI), and autism is disclosed. Attention deficit (ADD), learning disabilities (LD), and psychiatric disorders make up more than three fourths of the disabilities disclosed to the university. Perhaps, this can be attributed to more than the number of actual disabilities. Certainly, these disability would be much more salient when considering academic needs. Many of the other disabilities would not gain any advantages from disclosure. The explosion of acknowledged needs have prompted some to question the validity of diagnosis, assuming that the higher numbers of individuals seeking services suggests that professionals and the college service providers are dispensing unwarranted diagnoses. The increase probably has more to do with increased accessibility and awareness of services that would make college attendance a possibility.

Medical disabilities are only 8% of those reported. In an academic environment, a medical disability may not be easily accommodated. Many medical types of disabilities may also be temporary conditions or conditions that vary over time. The obvious nature of these conditions—for example a cast, crutches, stitches, and other visible signs of disability—may not require interventions from service providers. Faculty members may agree to accommodate this visible signs more readily than less visible differences. Skepticism may be diminished by the obvious embodiment of a temporal disability.

Only seventeen percent of the total population of students receiving services at Virginia Tech reported a race other than white (Figure 11). Seventy-six percent of the college enrollment is white, slightly less than the percentage of individuals with reported disabilities. International students generally perform well in academic situations, which has made possible their attendance at the university.

Figure 11. Racial diversity among students at Virginia Tech (SSD, 2003).



Summary

Individuals with disabilities experience a dynamic group of factors that influence how they view themselves and what they disclose about themselves to others. The long list of factors include, but are not limited to issues of disability, ability, impairment, stigma, marginalization, gender, sexuality, race, ethnicity, class, economy, policy, law, development, psychology, and sociology. Some individuals can disguise the fact they have differences that may be considered disabilities, legally or personally, while others must wear their conditions like a badge for all to see. Individuals with concealable disabilities may disclose disabilities to others for a variety of reasons. Laws force disclosure in order to obtain protections and accommodations; however, that is only one area of disclosure. In various other contexts, choices regarding identity are made. Some individuals find salience with their differences, participate in activities and support groups with others who share their differences, comfortably admit their differences, and readily talk about them. This may be limited to particular situations. Other individuals or other situations may result in denial of differences, evasiveness, and attempts to conceal. If educators and administrators recognized the dynamics behind self-perceptions and choices in relation to disabilities, they could begin to explore possibilities of positive change on college campuses. They would have an opportunity to create a context in which prejudices and stigma attached to disability could be confronted with knowledge and input from a more visible and empowered population of individuals with disabilities.

CHAPTER 3: METHODOLOGY

Working with individuals with concealed disabilities required particular prudence. A text has the potential to empower and acknowledge individuals or to leave them bound and further establish stereotypes. As Moser (2000) explained:

It is important to make visible and describe the lives of disabled people, but a naïve faith in the innocence of description and representation is party to reproducing the conditions for the marginalisation [sic] and the differences that we want to draw attention to. Descriptions of reality constitute, order and mobilise [sic] reality, discursively. To make change possible, we have to describe how differences are constituted and how they work. (p.210)

Taking into account my responsibility to my subjects and the population I explored, I needed to become sensitive to the traps of areas of discourse that reinforce stigmatization, while presenting an accurate picture of the landscape my subjects exposed and not negating norms they associated with group membership. The scope and depth of the questions I addressed made a qualitative/cultural study hybrid a suitable means for exploration and discussion.. “The defect of quantification is that it does not always support, as well as qualitative work, the understanding of complex, dynamic, and multi-dimensional ‘wholes’” (Sofaer, 1999, p.1102).

I developed life stories in a series of profiles, which helped to illuminate the dynamics of these issues in relation to concealed disabilities. Oyserman and Swim (2001) reported that the majority of research looking at stigmatized groups has focused on an outsider perspective, meaning from the point of view of the stigmatizer. They voiced a need for more research focusing on an insider perspective, which, among other things, helped me “to understand how their life experiences and worldviews may differ from nonstigmatized people” (, p.11).

The methodology for this research consisted of collecting and analyzing life story narratives. As Benjamin (1988) suggested, intrapsychic and intersubjective approaches should be viewed as both complementary and necessary, especially in the context of motivation among individuals to either conceal or disclose their disabilities. I collected data from interviews, observations during the interviews, and texts, as well as published dialogs and contexts. In addition, I planned to observe and collect any available artifacts that may help in the exploration of individual experiences. Each life story was to be presented in hopes to answer my questions about what experiences helped to create the participants’ attitudes about disabilities.

Selection of Participants

The selection of participants involved several steps: solicitation of volunteers, selection of individuals meeting criteria, screening interviews, and final selection. A pool of twenty-seven individuals volunteered, responding to E-Mails to students on the Services for Students with Disabilities Office’s database, advertisements, messages from listservs, referrals, and announcements in several large sections of university courses. Selection of volunteers for the initial screening was based on four criteria:

- Self-identification as an individual with a disability.

- Status as a full-time, enrolled student at Virginia Tech's Blacksburg campus.
- Reported concealment of disabilities in at least one context or situation, including at school work, with family or friends, in the community.
- Optimal diversity of participants in regard to age, sex, race, orientation, and disability type.

Seventeen of the twenty-six volunteers met the criteria and were invited to attend a screening session. The researcher gained a signed informed consent from each participant before proceeding with the screening. The researcher conducted screening interviews in the manner most convenient to volunteers, whether via E-Mail, telephone, or face-to-face communication.

After the screening interviews, nine of the screened volunteers were finally selected for the study. The researcher used a process of elimination to select the nine participants. Deciding factors included:

- similarities to other participants who seemed to have more to share,
- expressed discomfort and unwillingness to openly discuss his or her disability,
- inability to meet for interviews,
- dual relationships (I knew them in other contexts),
- lack of material to add,
- conflicting schedules,
- and no response to invitations to participate.

After selection was made, all volunteers received notification regarding whether or not they were selected to participate. The resulting nine participants in this study included students enrolled at Virginia Tech during the Fall 2003 semester who self-identified as individuals with concealed disabilities. They were each contacted in order to schedule an interview.

Benefits and Risks

This research had both benefits and risks. Cotterill and Letherby (1993) wrote about qualitative research, "Due to the research experience, all participants are likely to have increased knowledge, both of the research topic and of the life of the other person they have spent such a long time with" (p.8). While Merriam (2001) warns against data collection becoming therapeutic, I am skeptical about any disclosure of personal information to an unbiased party offering unconditional positive regard not being cathartic, psycho-educational, and therapeutic. As Ozer (1990) reflected, "In the course of the last two years I have also found a voice to express my situation as a woman with a hidden disability. Writing about it transforms the pain from a prison into poetry" (p.632). I expect this will happen in the telling of life stories as well. Polkinghorne (1988, cited in Reid, 2001) explains:

We achieve our personal identities and self-concept through the use of the narrative configuration, and it is an expression of a single unfolding and developing story. We are in the middle of our stories and cannot be sure how they will end; we are constantly having to revise the plot as new events are added to our lives. Self, then, is not a static thing or a substance, but a configuring of personal events into an historical unity which includes not only what one has been but also anticipations of what one will be. (p.103)

The element that researchers should avoid is not descriptive of a therapeutic relationship, but rather a medical model, where diagnoses and treatments are presented, either as advice or prescriptively. My goal was description –not prescription– and creating a common vocabulary for exploration, without judgment. This in mind, I refrained from offering commentary or projecting assumptions onto the participants, making interactions during the interview-phase centered on summarizing, paraphrasing, and inquiring. Of course, I am not assuming that I could approach any subject as a blank, objective recorder. I could not erase the fact of my values, biases, and even motives in the choice of this topic. I believe that social change is necessary and hope to create an impetus for social revision by illuminating the problems and issues that exist and exposing the dynamics of disability for scrutiny.

Data Collection

Pilot Study

The first three interviews, including screening interviews, completed during the pilot study phase, illuminated several categories. These served as an initial means to approach the data I collected. Of course, there was overlap, since the participants were free to express their stories however they chose in as nondirective a situation as possible. The pilot interviewees were contacted again and asked additional questions to allow for utilization of some of their input in the actual study, since they seemed to add valuable content. Some of the questions that were generated in the process of the pilots were grouped beneath the initially identified categories. (See Appendix C).

Interviews

After the pilot study and revision of the interview questions, the data collection for the remaining participants began. An interview involved open-ended questions selected from the list of questions above and prompts for additional salient information. It was not my intent to ask every question listed, and it did not become necessary. I was much more interested in what the participants considered important and desired to voice. The questions were only some of the possible prompts that I used to facilitate the flow of the interviews. For the most part, I used as much non-directive, active listening as possible. All meetings were individual and private, as explained in the Informed Consent Form. After participants had signed the consent form, the interview involved the collection of demographic data and exploring the participants' experiences with disability.

The participants were invited to share any artifacts they felt further illuminated their situation. As Sofaer (1999) pointed out, “One of the great advantages of qualitative methods is that they enhance the capacity not only to describe events but to understand how and why the ‘same’ events are often interpreted in a different, sometimes even conflicting manner, by different stakeholders” (p.1106). One collection of journals was volunteered, which led to the focus on the interviews alone..

Concealed disability, being a highly politicized topic, presented many potential concerns regarding how it has been defined, embodied, and represented in our society by different agents. Cotterill and Letherby (1993) explain:

Under the general rubric of the life history method, oral narratives can include an account of one person’s life as told by her to another, or indeed multiple biographies, generated using semi-structured interviews and focusing on one or more aspects of many people’s lives. The narrative technique allows respondents to ‘tell the story’ in whichever way they choose and, importantly, validates individual experience and provides a vehicle through which this experience can be expressed to a wider audience. [...] They [life histories] are invaluable because they do not fracture life experiences, but provide a means of evaluating the present, re-evaluating the past, and anticipating the future. (p.6)

This in mind, the lived experiences of the narrator provided complex details of interrelationships and the narrator’s involvement in communities and groups. The expression of experiences was dynamic; it involved changing perspectives, attitudes, and understandings as participants explored events and experiences within the framework of the data collection. The interaction between the researcher and the participant added to the context and understanding of what the participant shared. As a researcher, I explored several questions throughout the collection process:

- How has the context of the interviews influenced the narratives?
- How much are the participants’ responses affected by my presence as the researcher?
- How much is not being disclosed or being edited?
- Have I led the participants to view or express their stories in particular ways? Are the questions leading?
- What degree of trust and rapport has been established between researcher and participant?
- How much do I project my own understandings and experiences onto the participants?

In the final text, I envisioned a series of narratives. I constructed the data I gathered into portraits of these individuals. I did not quantify the results in the portraits. I reserved

identification of themes for the analysis that followed. Of course, it is impossible to erase the fact that this information was filtered through the observer, limiting the results to perspectives I am able to take as an individual. I tried to be honest in the presentation of myself and the biases and paradigms to which I subscribe, when I am aware of them. Still, like all other qualitative research, there was value in exploration. It allowed me to learn not only about the participants, but it also taught me about myself as an observer. Of course, this produced a temporal snapshot, a moment in a participant's evolving understanding of experience.

Analysis

I continually asked myself through the whole process, what have I “learned from doing the interviews, studying the transcripts, marking and labeling them, crafting profiles, and organizing categories of excerpts” (Seidman, 1998, p.110). This ended up being a recursive process of analysis and reflection, where I continually moved between data collection, transcription, reflecting, observing, and exploring. My background in composition from my first masters degree allowed me to develop a process that worked for me.

As Pope, Ziebland, and Mays (2000) suggested, I used sequential, or interim, analysis, which allowed me to shape my questions and explore avenues of inquiry that presented themselves throughout. In this manner, I was given more opportunity to develop hypotheses and a grounded theory. Pope, et al. (2000) offer the definition:

The term grounded theory is used to describe the inductive process of identifying analytical categories as they emerge from data (developing hypotheses from the ground or research field upwards rather than defining them a priori). (p.111)

I hoped to explore my findings with a blank slate, which would permit me to discover important themes without imposing a template. Still, I did have expectations based on personal experiences, the experiences described by clients and students, and study.

Seidman (1998) presented the process of creating and analyzing that I worked with as I studied the transcripts of the interviews. The first step involved locating and marking selections of the texts that were interesting. Using the same close reading skills I used analyzing texts as an instructor and scholar of English, I exercised my best judgment to distill the text to significant passages that contributed to the study. From these condensed passages, I planned to develop profiles of the participants with metatextual observations of context, behavior, and affect. I aimed for a lucid, accessible text designed through a recursive revision process that omitted most idiosyncrasies of oral speech and repetitions that would distract from the overall flow and presentation (H. S. Becker, 1986).

Categories of interview responses identified after the pilot study served as a starting place for the analysis. Further interviews helped in the development of a more precise and condensed set of categories, which encompassed and better described the factors I noticed. I revised the original list and created more succinct and specific categories. These were used in my analysis of the texts. The first version of the revised list included:

- History and early memories

- Labels
- Home and community
- Work
- Education
- Religion and spirituality
- Personal relationships
- Others with disabilities
- Contexts for concealment and disclosure
- Social expectations and treatment
- Therapy and treatments
- Stigma and shame

I addressed these individually, pointing out the specifics from the data I collected. I used an informal process of rereading, listing, and marking the text in MSWord with commentary and symbols using the built in reviewing functions. This helped me to note and mark emerging themes, as I copied excerpts to individual documents for additional review. I gave traditional inductive approaches a chance, before I moved on to a more comfortable deductive approach. I experimented initially with NVivo 1.2 and Atlas.ti 4.2 software, but I found the software did not work well for my learning style at this time. After coding a few documents and looking at the models, I realized that the software pointed out connections that I had already recognized. I have worked previously with other forms of qualitative software, and while I find them interesting, they do not seem appropriate for this task. Instead, I have opted for a more deductive approach to analysis. The result of this analysis resulted in a third revision of the categories identified. A number of the previously identified categories were rejected or combined under more descriptive terms. The final list was divided into three categories. They included *experiences*, *labels and discourse*, and *outcomes*.

Using and revising terms as I sorted particular instances, I included quotes from interviews and observations. Oftentimes, the context of the conversation is important; so, I often opted for longer quotations to assure complete understanding of the participant's words.

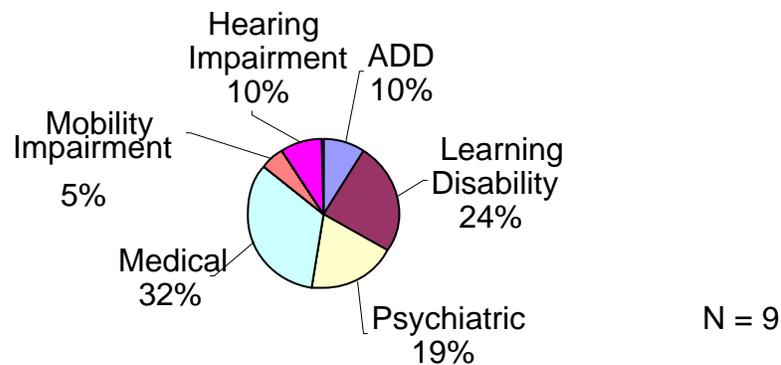
CHAPTER 4: RESULTS AND DISCUSSION

This study involved nine individuals with diverse backgrounds, differences, and experiences. Their unique perspectives, as well as the factors they seem to share, offer insight into the issues surrounding concealed disability. Exploration of the demographics among participants, the thematic factors they share, and the overlap of these specific situations with existing literature and theory culminated in a composite profile of an individual with a concealed disability, a snapshot of one possible prototype of the common experience of having a concealed disability.

Demographics and profiles

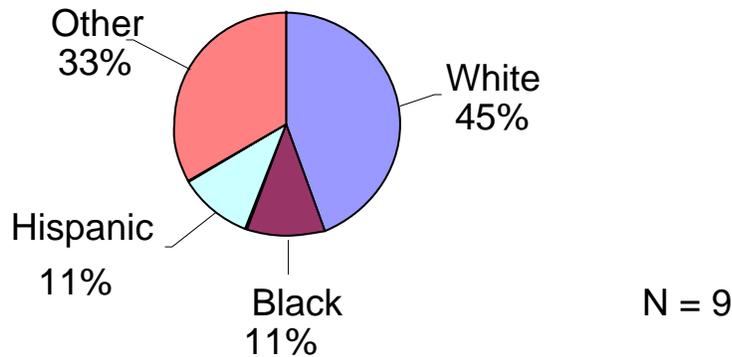
The participants in the study had a variety of differences. Most notable among the percentages of these differences was the large number of students with a medical condition reporting a disability among participants in this study (Figure 12). This suggests that medical conditions may be a more salient issue among students with concealed disabilities, since only eight percent of students reporting a disability at Virginia Tech had a medical disability (SSD, 2003). Of course, without necessitating documentation and without the need for accommodation, a greater number of disabilities are likely to be reported. This seems to hold true, with most participants reporting a larger number of disabling differences than were mentioned by students in the survey. It would be of no advantage to claim a disability identity, if individuals do not believe that their condition can be alleviated by personnel as a result of disclosure. Within the group of participants in this study, it is not surprising that these less common conditions did not get reported. The resulting selection generally represents a reasonable sample of possible participants.

Figure 12. Disabilities among participants.



The participants also represented greater diversity than was reported to Services for Students with Disabilities by students seeking services (Figure 13). This grew from an attempt to select the most diverse group possible from volunteers. Still, the largest pool of participants are white.

Figure 13. Racial diversity among participants.



The nine participants in this study chose the pseudonyms *Adam, Calvin, Caroline, Erin, Kevin, Portia, Elizabeth, Robin,* and *Ryan* (See Table 1). In order to better differentiate between these participants, a brief profile of each, addressing some of their personal qualities, will be presented. Some details had to be omitted to protect the privacy of these individuals, guaranteeing that their identities remain hidden.

Table 1: Selected Volunteers and Demographics Used in Selection Process

Participant	Sex	Age	Ethnicity	Disability	College Year
“Adam”	Male	42	White/Other	Affective disorders, Social anxiety, a skin disorder, ADHD	Doctoral
“Calvin”	Male	23	Black	HIV Positive, Alcoholism, Chronic migraines	Senior
“Caroline”	Female	36	White	Learning Disability, Anxiety, Irritable Bowel Syndrome (IBS),	Masters
“Elizabeth”	Female	54	White	Fibromyalgia, Learning Disability, Chronic Fatigue (CFS)	Masters
“Erin”	Female	19	Hispanic	Hearing Impaired	Freshman
“Kevin”	Male	18	White	<i>Arthrogryposis multiplex congenita</i>	Freshman
“Portia”	Female	21	White/Other	ADHD, Learning Disability	Freshman
“Robin”	Female	28	Other	Epilepsy, polymyalgia, dyslexia, learning disability	Junior
“Ryan”	Male	25	White	Learning Disability, Alcoholism, Depersonalization Disorder	Senior

Adam, a forty-two year old doctoral student, complained primarily about his social anxiety. Comorbid conditions added to his level of anxiety. Depression, a skin condition, and ADHD were described as contributing factors to his disability. He describes himself as someone with mixed heritage, but says he blends in as a White person. I never had opportunity to meet him in person. Adam keeps a hectic schedule and needed to participate via an E-mail dialog. He describes himself as lonely, and laments the fact that his social anxiety prevents him from approaching or dating members of the opposite sex. He hides himself and isolates himself, preventing himself from any degree of intimacy or friendship. He no longer uses accommodations.

Calvin, a twenty-three year old Black senior, explains that his disability is his HIV-positive status. He notes that he does have a problem with alcohol and chronic migraines, but he has sought help for both of those concerns. It is the HIV status that disables him and that he attempts to hide. Calvin presents himself as extremely extroverted, creative, and caring. He is tall and thin. He dresses stylishly and has pale highlights in his dark, loosely curled hair. His emotions rise to surface quickly, making him blush and his eyes moist at various times in conversation. He has experienced rejection and stigma from family and friends.

Caroline, a thirty-six year old White graduate student working on her masters degree, primarily has problems related to Irritable Bowel Syndrome (IBS). She also has a learning disability and anxiety. Caroline has light brown, wavy hair, which she pulled back on our second interview. Her skin is pale and freckled, and her eyes, a light-olive color, seemed weak and sensitive to light. She complained about allergies on the days of our interviews. She personifies nervousness, biting her thin lips and wringing her hands constantly as she talks. She resigned as a teacher, when her IBS created difficulty and embarrassment for her in the school where she worked. She does not use any accommodations, since she fears the outcomes of disclosure. Numerous social situations have conditioned her to dread the potential response from others.

Erin, a nineteen year old Hispanic freshman, explains that she has a hearing impairment. She has thought of it more as a difference than a disability until more recently. As a college student, she has experienced confrontations from a faculty member who resents her use of accommodations. This has made her more concerned about disclosure. She is tall and thin, an athlete's build. Her long dark hair and honey complexion accents her dark eyes and extremely white teeth. She smiles and seems very animated. I would not guess that she had a hearing impairment, except for occasional omissions of sibilance. She responds without hesitation, giving no clue that she is reading lips. Throughout the interview she seemed happy and upbeat, until conversation turned to her teacher who had resisted her accommodations. At that point, she looked as if she were going to cry.

Kevin, an eighteen year old White freshman, has a physical disability, *Arthrogryposis multiplex congenita*. This is a muscular-skeletal disorder which involves paralysis and immobility of limbs and joints. Kevin assumes that this is less noticeable than it probably would be. Still, he has attempted to conceal it in various contexts, and he believes that he has been successful in some instances. He is about five foot and six inches tall with short dark hair and slate-blue eyes. His shoulders and arms are proportionally much shorter than those of the majority. Kevin has high self-esteem and self-efficacy, but reports past problems with both. He describes himself as popular (his classes prom king) and outgoing. He thinks of himself a part of

the popular crowd and insists that he is not a “mascot.” He uses some accommodations, but he finds that the physical nature of his disability makes going through a disability services office unnecessary. Most instructors volunteer more accommodations than he would receive officially anyhow.

Portia, a twenty-one year old freshman, describes herself as White and mixed. ADHD and a learning disability serves as her primary obstacle to success. She has shoulder-length, dark curly hair and has a compact, muscular build. Every occasion I saw her, she was dressed in gym clothes. She is talkative and tends to digress quickly from one idea to another. She receives accommodations, but has chosen at times to avoid disclosing to faculty. Her fear of misunderstanding, suspicion, or stigma prevents her from using accommodations until they are absolutely necessary.

Elizabeth, a fifty-four year old White female, has fibromyalgia, chronic fatigue syndrome, and a learning disability. She has red, wavy hair, green eyes, and pale peach-colored skin. She is slender and tall. At our interview, she had her hair plaited and hanging down her back and wore long copper earrings that looked like leaves or feathers. Her hands constantly move while she talks, her long thin fingers drawing in the air. I visited her in her home for the interview. It is full of her artwork –paintings, quilts, and pottery. Her house smells like apples and the wood burning in her fireplace. She shows a wide range of emotions as she talks, everything from laughter to tears.

Robin, a twenty-eight year old, light-skinned junior who prefers to identify racially as “other,” described herself as “a multifaceted person who doesn’t fit neatly into any group.” She did not volunteer much without prompting at first. She seems introverted and shy. She is petite and, unlike many of the others, moves very little during conversation. She has several complaints, including epilepsy, polymyalgia, dyslexia, and a learning disability. Because of a recent seizure, she has lost driving privileges, which has made getting to and from school difficult. She has received accommodations for her learning disability and dyslexia, but she finds most of her difficulties come from her polymyalgia and epilepsy. She has found that the fewer people that know about her problems the less problems she must deal with.

Ryan, a twenty-five year old senior, was tall and broad shouldered with short, dark hair and dark blue eyes. He complains about a learning disability, alcoholism, and a depersonalization disorder. His eyebrow had a small gold ring piercing it. His unconventional clothing and jewelry seemed representative of an alternative subculture. He seemed pleased to have a guest to disclose to, even though he explains that he would never disclose a disability to anyone at the college. He describes a series of negative outcomes when he has disclosed in the past. Stigma related to mental illness has been a particularly salient issue for Ryan. He also volunteered his journals, which I have included in the appendices.

The interviews and writings presented several common topics, which help to illuminate more of the specifics of experiences and served as categories to organize the data. The final list of categories addressed included:

- Experiences

- Education
- Invasions of privacy
- Personal relationships
- Religion and spirituality
- Therapy, treatments, and accommodations
- Work experiences
- Labels and discourse
 - Attributions toward others
 - Social expectations and treatment
 - Learned helplessness
- Outcomes
 - Anxiety and depression
 - Awareness of condition
 - Contexts for concealment and disclosure
 - Limitations and advantages
 - Stigma and shame

I hope that readers will gain some insight into the personalities and emotions of voices represented. The salience of this topic created opportunity for these individuals to disclose, sharing experiences that they have long repressed or hid from others. The experience of sharing seemed to liberating and powerful for many of the participants. Caroline, Elizabeth, Calvin, Adam, and Robin even showed affect, such as tears, blushing, and crying. As these events are analyzed, it is important to note the degree of emotion that is associated with disability experiences, differences, labels, and stigma.

Experiences

The experience of disabled embodiment has often been neglected within the field of disability studies, in an attempt to redefine disability outside the realm of a medical model; as Snyder and Mitchell (2001) explain:

Although recently disability criticism has been calling for a return to a phenomenology of the disabled body, this return has been slow in coming. Like feminized, raced, and queered bodies, the disabled body became situated in definitive contrast to the

articulation of what amounted to a hegemonic aesthetic premised on biology. Within this cultural belief system, the “normal” body provided the baseline for determinations of desirability and human value. (pp.368-369)

Even the nonvisible disability experience focuses on appearances. Individuals with invisible disabilities make reflected appraisals of themselves, wondering what others see in them. By concealment, they hope to render nonvisible and visible disabilities invisible. The concern is perception –*Will I look stupid? Will I look competent? Will I look weak? Will I look foolish?* It all eventually boils down to a question of embodiment. Individuals, with or without disabilities, attempt to manage the manner in which they are perceived. Experiences inform them as they calculate and perform behaviors to gain the recognition and approval they hope to attain. Some resign themselves to stigmatized roles, while others attempt to construct identities that disguise stigmatized differences. Even in the retelling of personal experiences, I am acutely aware that identity management is involved and at best I am privy to well-crafted inventions based on memory and need.

As I listened to participants describe the situations they have encountered, I began to wonder what experiences actually led to the definitions and attitudes they were exhibiting in those particular contexts. I wondered if these individuals would consider themselves to be disabled, if they had experienced different situations in their development. It was interesting to hear how these individuals framed their own experiences. “Disabled bodies have long been cultural signifiers whose meaning has been largely determined by nondisabled people; today people with disabilities are ‘signifying’ on their bodies in their own ways with their own voices” (Couser, 2000, pp.309-310). Themes of learned helplessness, ostracism, invasions of privacy, overprotectiveness, abuse, embarrassment, and failed attempts at treatment suggest that opportunity to acquire negative self-perceptions and beliefs regarding limitations and inability has been a constant in most of these individuals’ lives. As Thomson (2002) writes:

Disability –like gender– is a concept that pervades all aspects of culture: its structuring institutions, social identities, cultural practices, political positions, historical communities, and shared human experience of embodiment. (p.4)

Balanced against some of the exceptional situations reported by a few of the participants, it would not be difficult to recognize the potential for a range of themes to emerge among individuals with similar conditions.

Education

This study looked at student experiences of disability. As a common thread among all participants, the importance of school, does not surprise me. Recognizing that this group of participants not only are individuals with disabilities who chose to attend college, but they specifically chose to attend Virginia Tech. For some, it was just a matter of convenience, but Erin, Kevin, and Portia selected Virginia Tech because of the services and accommodations that the university offered. Among participants receiving services, a unanimous report of good experiences with the service providers on staff at Virginia Tech accompanied a variety of reports regarding experiences with faculty, which is discussed in more detail later.

One theme that emerged involved how academic experiences influenced participants' understandings of disability. K-12 schools play a major role in shaping attitudes and beliefs about disability, where students with disabilities are often framed as pitiful, heroic, tragic, or shameful (Ware, 2002). The resulting pessimism has a causal relationship with academic failure (Peterson & Barrett, 1987). However, students who view a learning disability in more optimistic ways, as something that should not create stigma and can be overcome, had higher self-esteem and better academic prospects (Heyman, 1990). Relying almost entirely on the biomedical and psychiatric models of disability, schools too often shape "students with disabilities" into becoming synonymous with the impaired –the lame, crazy, or slow. Freshmen tending to use negative explanations to describe experiences were discovered to make less use academic support services (Peterson & Barrett, 1987). While most of the participants reported positive experiences, the negative experiences seemed most salient and often evoked a powerful emotional response. While all of the participants agreed that most faculty and staff providing accommodation agreements and services were helpful and understanding, many had some disparaging experiences with faculty members.

For Adam, college offered an opportunity self-discovery and escape from oppressive feelings at home. He writes:

Despite the problems of side effects of medications, I was happiest when I was away from home, living at the University. I think that it was specifically because of the feeling of control in my life for the first time and the freedom from worrying about what others will think about my friends, my dates, and my life in general. [...] For whatever reason, I have a deep-rooted, disabling, traumatic fear of being myself, having friends, dating, and other such social actions when I am living with my family. I think that I fear being judged or fear the embarrassment of my friends being judged either face to face or in secret. I am afraid of having a social life or a life of my own in the presence of my family. Realistically, I know that this doesn't make sense and is not founded in actual experiences or rational anxiety, but it exists. Whenever I am at home, I enjoy my family, but I shutdown my social life and give up on any hopes of satisfying social needs.

Adam, finding in college an escape, had socially isolated himself, fearing judgment of his friends. This, in a sense, may be a projection of his fear of personal rejection or embarrassment. In front of his family, he becomes a recluse, perhaps conforming to their expectations for him to be asexual, innocent, and introverted. As the disabled child, he may be thrust into the role of the "good" child. Disability becomes an excuse for caregivers to perpetually baby him. An individual with disabilities may feel resentment from family members, especially other siblings, who crave the attention given to the sibling with a disability. Parents may also resent becoming perpetual caregivers, in spite of reticence to allow a child to mature. As with Adam, the desire to please prevents him from claiming autonomy and adult privilege while in the presence of his family. This partially grows from habit. It is difficult to break lifelong patterns of behavior, and the act of "babying" is actually a form of control. An individual who has been deprived of self-efficacy may find breaking free of oppressive and stifling situations difficult. This probably also grows from an undermined self-confidence. Only when forced to assume responsibility, an individual may commit to personal decisions rather than depending on parental direction. This may be part of the concern about talking with faculty and staff about disability-related needs. Some individuals with disabilities may find it difficult to assert the requirement for

accommodations. They may wait, hoping a parent or someone in the “parent” role will assert direction.

When students disclose a disability to an instructor, they put themselves in a position where they risk denial of access on the premise of incompatibility and inability or negative assessment by an instructor who attributes the disclosure to attempts to avoid responsibility and equitable work in a course (Rocco, 2001). This type of experience was reiterated as a theme among the participants. Erin described being singled out by a teacher, who seems to think accommodations give her an unfair advantage over other students. She explains:

I use C-Print here. It may be just a fear of their words being recorded. They are not too excited, like my [science] teacher. My [science] teacher hates it. He thinks that it's not fair, it's making me have more of, it's not equal, that is how he thinks. He thinks, if I'm not physically able to do something without help, I should just get out. He says that there is no fair competition, if students who can't cut it just get extra advantages given to them. [...] He thinks it's an advantage, and you know it's not what accommodations are for. They just give a fair chance. And, it makes me feel awful sometimes, because then the other students look at me, thinking they have been cheated after what he says. It's wrong when a teacher makes you feel bad about needing them, but.... So, my [...] teacher and I don't get along very well. But most of my teachers are okay with it.

The teacher Erin described lacked an understanding of what purpose accommodations serve. This instructor brought beliefs from a cultural paradigm where competition is highly valued. His beliefs reflect a position that education should weed out those who cannot compete as aggressively for achievement and high evaluation. Transposed onto a system that values diversity and focuses on facilitation of success for all students, his attitudes hinder equitable chances for success among individuals with disabilities. A student attending the same class as Erin would be much less likely to request needed accommodations after seeing her put into a potentially humiliating position in front of her peers. This would be especially true among students with nonphysical impairments, if this instructor responds so negatively to a physical disability. Of course, assimilation into the Virginia Tech community does not depend upon conversion to standard educational goals and beliefs. Training and reinforcing information may help faculty to conform to policies, but this may not eradicate more subtle expressions of resentment toward individuals with disabilities who use accommodations.

Ryan described situations where faculty members showed resentment about his using accommodations. He states:

The reaction I have gotten from the professors, I would tell them [others with disabilities] to just keep it to themselves and make do and forget about telling anyone unless they really, really needed help. If it was that important, that they needed help, then I would go to the professor and try to speak to them one-on-one and try to work out something with the professor where you can work with that professor maybe during office hours or on your own time or whatever instead of you know going through the disabilities office and making arrangements with the professors for an outside note taker or you know some outside, like if you arrange for a special classroom and then you got to go with an outside source, it's just too many groups of people trying to factor into it. With the way the

professors treat it that I have noticed, I would not really want to deal with them unless I had to. [...] You know, to be honest with you, I think the best thing to do is go through the students disabilities office, get your accommodation letters, but don't take them to your professors until, like when you get your first test back or you are going through the class and you find that its really hard to keep up or you are finding that you are having trouble. Then, go to the professor and say look you know I didn't come to you about this at first because I didn't want to bother you or make it a big deal, but I am having some trouble, and I do need some help, and I do have this, and then I think it would be ok. But, I would not recommend it because the professors, for the most part, treat you really badly, and they factor in that you got extra time and such and grade you even harder.

As in Erin's situation, Ryan voices concern that instructors will create barriers as a result of being forced to provide accommodations. As with Erin, his concern is not necessarily unfounded. Hopefully, that type situation is not common. However, it may be a fallacy to assume that instructor attitudes do not have an effect on how they perceive and evaluate student work. The subjectivity involved in much assessment and interpretation of participation may be influenced by primary impressions and attitudes.

Faculty are placed in an interesting situation regarding the provision of accommodations. They are forced to depend on documentation for verification of a student's need. This means students must disclose to both service providers in a disability office and to instructors before they can access services and support. For some students, this asks too much. Caroline describes her teacher's insistence on documentation before acknowledging her health problems, thus creating a impasse for Caroline. She discusses how she decided not to disclose in order to get accommodations:

My history teacher started taking off points every time I had to leave the classroom, and I had to withdraw. I told him I had a health problem, but he wanted an accommodation letter from the Dean of Students. Of course, I wasn't going to go there and tell the school about having IBS. It's embarrassing as it is already. And, you never know who will tell who at a college. Can you imagine carrying a note to your teachers that said you can control your stomach, you might run to the bathroom at any time, and you can't stop to ask or you'll have an accident?

Her fear of embarrassment prevented her from successfully completing a course. The number of students who leave classes rather than risking disclosure can only be guessed at. In my own teaching, I have noticed a few students leaving classes when I announced a presentation or other social activities would be part of the class. Rarely will these students communicate their fear or concern; they simply leave and show up a few days later asking me to sign a withdrawal form. Some just discontinue attendance and do not bother to withdraw.

Instructors have also gotten praise for their understanding. Elizabeth notes:

I have had some that are really, really nice, and I have had others that have treated me as though I could do better or that I have no excuse for like days I have to call in. They think that it's just someone who has been out partying all night or they have so many students in the classroom for one thing. I think that when someone calls in and says they

are not going to be able to come in that they are sick, that they just automatically put these things together you know that maybe I went to the party last night or I am just one of the other students. I don't think they stop and realize that I have a disability that keeps me from coming in lots of times when there are no parties or anything you know I don't think they have time to investigate all of that or look into it. I think it would be too hard and difficult.

She admits that instructors are not always able to discern what is going on with students, especially when they do not disclose their needs. When disabilities are more readily noticed, instructors are often more aware and ready to facilitate success. Kevin describes a good experience at college where this has happened:

Everyone's been real nice, professors and all. Most are trying to accommodate me before I even give them a letter. It would probably be different, if I could hide my disability better. But, it's out there where they can see it, and they can't think I'm just like cheating or trying to get advantages.

The educational situations, in which concealment, disclosure, visibility, and invisibility are relevant, suggest inconsistent experiences make decisions about accommodations more complex than just need. Instructors may respond in a variety of ways, and students must weigh their chances for a good result before making decisions. Eligibility and need should be enough cause to guarantee that securing accommodations is the best choice always, but the reality is that the result may make a situation worse. Part of this may be due to the multiple purposes the university must consider:

Within the university, disability policies are part of the discursively elaborated process wherein human rights legislation impacts people's everyday lives to ensure that people with disabilities are not discriminated against. While disability policy is the textual means through which the university recognizes its moral and legal duty to provide accommodation, it is also designed to protect the university from unreasonable expense or "undue hardship" and from lowering or otherwise compromising academic standards. In other words, the formal rules and procedures of disability policy—which instruct students to 1) identify themselves as disabled, 2) supply appropriate medical documentation, and 3) negotiate accommodations with individual instructors—are intended to reconcile the interests of the law, of disabled students, faculty and staff, and of the academy. (Jung, 2002, p.184)

Balancing these duties may create, in a sense, a competitive stance among its subjects for limited resources. Students, faculty, and staff probably have not been formally trained to compromise and cooperate in mutually beneficial manner. Opportunity to develop mutually advantageous agreements may not happen without facilitation. Adolescents have been shown to have less self-efficacy when their self-perception of ability is lower (Ryan & Pintrich, 1997). They are much less likely to seek help, disclose needs, or admit limitations. Ironically, the individuals with the most need are the least likely to seek accommodations. Individuals who feel more confident about their abilities have been shown to seek out accommodations and support more aggressively, while their less confident peers are more likely to give up on or never attempt securing help (Karabenick & Knapp, 1991).

Education remains the best answer available to create an equitable agreement regarding accommodations. Instructors and staff need to be taught about the objectives of accommodations and the laws and policies governing their provision. I tend to believe that most problems faced by students who face resentful or uncooperative instructors can be resolved through better communication. Students may come across as too demanding, and some do try to take advantage of accommodations that they have not been given. Still, faculty do need to be informed of their responsibilities and role in this process.

Many instructors simply do not understand what their own legal responsibilities are. Providing accommodations to students who have been officially designated and assigned accommodations is not a choice. And, fairness does not allow self-reported needs from student to instructor. Disability must be validated with documentation of professional diagnoses. Also, accommodation letters are not created lightly. Highly trained staff have investigated a student's history and documentation to assess the student's needs. Even if services on campus may offer help to faculty by proctoring extended-time testing and other such services, it is ultimately the instructor's responsibility. The instructor should recognize that special arrangements such as this are a courtesy, and staff members are not obliged to provide this service. This may create hostility or resentment from faculty members who already invest a great amount of time and effort to provide quality instruction or who are trying to balance research goals with their teaching load. Accessibility to postsecondary education for students with differences involves additional work and time for instructors to make special arrangements and individualize class activities.

Invasions of privacy

Participants report repeated invasions of privacy in a variety of contexts. Even with the advent of new privacy legislation, participants report professional offices and a variety of additional locales have left them exposed against their wills. Ryan remembers an incident:

We were in therapy one time and the therapist was like, "You can talk about anything, no matter what you say, it's confidential." And, so we did, and I told them some stuff that was going on. I can't remember what it was now. We got in the car to come home, and my, not my mom, but I was living with my step mom. I didn't live with my mom growing up, but my step mom. She was like, "Why did you tell them this? You know that's not true! That is not how things are!" And, it really upset me, because I was like, "I thought this was confidential! I thought this was supposed to help me! But, here I am getting yelled at for it!" So, it was like I had to build up my wall and hold pain in and whatnot because nobody else could really help me with it.

This invasion of privacy would certainly circumvent a willingness to disclose. Often, as with Ryan's therapist, the individuals compromising privacy did so from a professional capacity, ignoring policy and legislation that guarantees privacy in those situations. Elizabeth talked about standing at windows in doctors' offices where she was asked, in the presence of a waiting room full of individuals, the reason for her visit, about her insurance, and other private matters she desired to keep silent. Elizabeth talks about how receptionists in those doctor's office demeaned her by compromising her privacy. She explains:

Over and over again especially at doctor's offices [privacy regarding disability has been compromised]. Their receptionist is not separate from the waiting room, and you go and you stand in line and they have to know your, they want your insurance cards and they ask you to produce that and then they ask you what you are there to see the doctor for that day. And you have to disclose that with a waiting room full of other students you know or don't know or may know you that you don't know. And sometimes there has even been another family member in the room, and sometimes there are the opposite sex in the room, and you have to disclose what your problem is at the window in order to get to see the doctor. And I feel like my privacy is very invaded on, and I have had people come up to me and say I didn't know that you had this problem or that problem and sometimes its very embarrassing. I hate to say this, but there have been instances where this has actually seemed to come after me and cause me to have very severe bouts of depression because of things I really didn't want to discuss with other people, that was my own business.

Waiting rooms are awkward spaces to inhabit already, without the unwanted additional exposure. The individuals waiting are assumed to be ill or impaired, because of their presence alone. They all hold a stigmatized position and are protected only by the degree of anonymity and privacy afforded by the staff and architecture.

Not only did Elizabeth have to disclose private medical matters, but she was also forced to produce financial information. I did not ask Elizabeth about the type of insurance she presented, but it is not a surprise that Medicaid, Medicare, and other forms of financial information disclose membership in stigmatized groups. Certainly, the need for services does not suggest anything about an individual's attributes. However, stereotypes abound which associate need with moral flaws –laziness, deficiency, maladaptation. Society, while it values and applauds the charitable, denigrates and stigmatizes the benefactors.

Illegal invasions of privacy continue, in spite of potential charges and fines. This is a form of control, a means of oppressing others, and power is rarely relinquished without a struggle. Juxtaposed against the threat of legal sanctions, the power to encroach on other's personal matters is diminished, but not extinguished. Burden of proof would fall on the complainant, and orchestrating such evidence and testimony would be unlikely. Also, those individuals most affected by exposure would probably be the most likely to avoid the additional exposure a complaint would invite.

Gatekeepers, often using these strategies, can make the process of gaining access to services to uncomfortable, daunting, or demeaning that many will opt out. Adam describes an issue concerning the "gatekeepers" at a counseling clinic he went to for services. He writes:

I had to seek out free or reduced rates for access to psychotherapy and psychiatric services. It is great that these types of services exist, but it sometimes felt demeaning to go there. The stress of trying to deal with front desk workers who looked down on me often outweighed any benefit that may have been derived from the services that they tried to play gatekeeper for.

Gatekeepers can be effective, making the application process both demeaning and public. Like a hospital waiting room, already an assumption is made in certain public spaces about the attributions of the inhabitants. Reception areas of places providing mental health services, economic aid, disability services, court services, social services, or “handouts” make inhabitants especially vulnerable to stigma. By compromising a feeling of anonymity and safety, a staff could easily exercise power over clients. This type of approach would reduce the number of individuals seeking services for any type of stigmatized role.

Too often, the services and supports that individuals with disabilities need to fit in are inaccessible without public disclosure and embarrassment. Even guaranteed anonymity may be compromised when one participant in a situation is not sensitive and ethical. Calvin remembers:

A guy in the support group was talking it up, telling all our private stuff. I went online in chat and put on another nick and asked about me. He started trying to pick me up because he didn't know it was me and telling me I don't want to go out me because I have HIV. I printed the log of the chat and showed it to everyone at support group. He doesn't come now. [...] It's not disability, but a professor told that he saw me going into the Park [a gay club] right in the middle of class one time. He wanted to talk about gay people and decided to out me right there in class. If he knew about my HIV, I'm sure he'd have said that too. I mean, a lot of people know that I do drag, but that doesn't mean I want my business thrown out in class.

As Calvin illustrates, promised confidentiality is not always a guarantee of privacy. And, unfortunately, without an explicit agreement to keep a matter private, an individual's personal life may be exposed in any context, even a classroom. Calvin's professor should know that our society stigmatizes some groups, and revealing others' membership or participation in one of those contexts could be damaging or even dangerous to them.

Gossip, like public “outing,” focuses on individuals with differences. Treated with suspicion and curiosity already, they become the targets of speculation and observation. Stigma begets stigma. Gossip dominates some offices and social gathering places, where private matters are published for others to hear. For Robin, even family publicizes her secrets. She explains:

My sister-in-law Rhonda is the worst. She's a big gossip, and lives across the road down a few houses. Every time I fart... oh, sorry...I shouldn't say that... every time I get out in the yard and do anything at all, the whole family knows.

Robin, who is a private person to begin with, faces constant exposure. Many individuals with disabilities are thought of as asexual, innocent, and reclusive. This may result in special notice, when they choose to date or even just pursue friendships. The gossip surrounding friendship with a member of the opposite sex, regardless of sexual orientation, may create social isolation, such as Adam describes. Unwanted attention may make such friendships uncomfortable. Match-making and match-breaking may feel demeaning. Such invasions of privacy are destructive on a variety of levels.

Related to invasions of privacy is the issue of staring. Staring seems to be primarily associated with visible, physical disabilities, but some of the participants speak of fear of being

noticed and watched. Thomson (1997a) writes, "If the male gaze makes the normative female a sexual spectacle, then the stare sculpts the disabled subject into a grotesque spectacle" (p. 26). In other words, the stare establishes otherness, making the individual with disability an *object* of scrutiny, a marginalized curiosity. Kevin talks about being stared at:

I had a few incidences when like people would say stuff to me and now it's more so like curious children just looking and staring, but that is about it. Sometimes you see adults too, but that is the extent of it.

Caroline, Elizabeth, and Adam also voice concerns about this type of notice. Kevin talks about others becoming embarrassed when caught staring:

But the only thing that really bothers me is when people just stare, which is funny sometimes is I will do an experiment and I will walk down the mall and watch people's eyes; so, when they stare up, they start from my arms and go up to my face and see I am looking at their eyes. So, they freak out after they see that so.

Implicit in staring is appraisal, and thus oppression. Objectifying others, making them objects of curiosity, dehumanizes and relegates them to masses of flesh, bodies to be scrutinized. Reminding me of Kevin's returned stare, Sandahl (1999) writes, "No longer compliant objects of the stare, people with disabilities are staring back, claiming the body as a legitimate part of identity, a body whose metaphors and physicality belong to us" (p.13). It is interesting that curiosity draws attention to any deviation from "normalcy." Yet, we are very selective in which deviations we notice. Considering the wide array of diversity, the characteristics that demand notice seems arbitrary and random.

A stare denotes evaluation, and the object of that stare must either ignore or acknowledge being objectified. For a person with multiple differences or hidden differences, the catalyst for the stare may be unknown. It may arouse self-consciousness and discomfort. It may publicize the most private and closely concealed secrets, or make the object of that stare wonder if they have been discovered. Clare (2003) writes about the power of the stare, as it dissects and dehumanizes:

Gawking, gaping, staring: I can't say when it first happened. When first a pair of eyes caught me, held me in their vise grip, tore skin from muscle, muscle from bone. Those eyes always shouted, "Freak, retard, cripple," demanding an answer for tremoring hands, a tomboy's bold and unsteady gait I never grew out of. It started young, anywhere I encountered humans. Gawking, gaping, staring seeped into my bones, became the marrow. I spent thirty years shutting it out, slamming the door. (p.257)

Clare (2003) finds the power to stare back and acknowledge her differences. Others, perhaps, shrink into the shadows, disappear from public view, walk with their heads down trying to be invisible. A stare is abusive and violent, a violation as oppressive and damaging as a racial slur or misogynistic gaze.

Ironically, several participants described the act of staring at others with disabilities. They discuss the awkwardness of being caught staring. Caroline states:

I get pretty uncomfortable around disabled people. I'm afraid to stare or they'll think I'm staring. So, I try not to look. Then, I feel like I'm noticeably trying not to look at them. I don't know what the PC term is for little people or midgets, but you know what I mean. There's one that works in the Wal-Mart where I get my groceries, and he stares at me and I'm afraid to look back, and it's awkward. [...] I mean I feel like people look at me that way too, but maybe there's nothing to do about it, because people are curious and they don't know how other people are thinking. I mean, you never know if someone's going to get all defensive and make a scene or something. If I was a midget, I think I would be a lot quieter than he is. Maybe it's a good thing. But, it would be a lot easier if someone just introduced me to him and then maybe I wouldn't feel as awkward if I could call him by name.

Having a disability does not erase the fact that most individuals with disabilities are raised into an "able-bodied" culture. They measure themselves and others against the yardstick of society's assumptions about "normalcy."

Calvin explains, "I'll take a peep, if they got something wrong with them I aint seen before. People just like that. They just curious, nothing mean meant of it." Calvin is honest, but the reality is that his stare may be as detrimental in the long run as any other affront to privacy. The message encoded in a stare may have little to do with the interpretation of that message as it is decoded. In other words, intent does not determine reception. Curiosity about the unusual is presented as just reason to stare at others. Kevin adds:

I mean my condition is a little different than that of a wheelchair and of course like sometimes you will stare at somebody in a wheelchair because that is different too, but like I am walking and I just have shorter arms and stuff like that so it's more different.

Kevin normalizes his condition, contrasting his differences with "more obvious" differences, such as the use of wheelchairs. He goes on to describe how others will grab his hands. He reports, "Personally I don't mind if people ask me about my disability, like what I can do and what I can't do. Some people will grab my hands after they ask to see the extent of it, which is kind of weird." Kevin becomes dehumanized, being scrutinized as a specimen or curiosity. Without discourse and assumptions regarding his identity, it would be unlikely that anyone would grab his hands to study them. Whether staring, gossiping, or invading space, violations of privacy create further stigmatization for individuals with disabilities.

Overprotection and overindulgence

Some common familial themes included overprotective parents, resentment from siblings, overindulgence, lowered expectations, and being compared with other family members. Of course, a parent with a child that has a physical disability may treat that child as if fragile. Even later discovery of a disability may incite more protective treatment. A parent may usurp adult responsibilities of their children, hoping to further protect and nurture them. It is worth noting that the childhood experiences of most participants predated diagnosis.

Caroline speaks about her father's treatment of her and her brother. The disparity in treatment in this case grows from sex, not ability.

Since I was a kid, he hadn't hit me or anything until in middle school he caught me putting on some lip gloss. He hit me across the jaw so hard one of my teeth was loose. It eventually came out, but lucky it was on the side. I guess I was self-conscious then too, because I was afraid to smile big or open my mouth too much to keep people from seeing my missing tooth. Don't thank Dad was abusive or anything. He was just too protective and that one time got too rough. I think his sisters got knocked up and had to get married early, and he didn't want that to happen to us. Now, my brother could get away with anything. He'd come home after midnight drunk as a skunk and they'd just ignore him.

In Caroline's case, overprotection grew into physical abuse, not unlike the abuse described by Ryan. Even with her rationalization that he was not "too abusive," we see her father's violent reaction to her wearing lip gloss as both cruel and extreme. Siblings may further compound the problems associated with disability with jealousy over the attention from parents and others. Chores and responsibilities may exceed those given to siblings with disabilities. Freedoms may also be given, as with Caroline's brother, who was not disciplined, while she was to the degree of abuse. Calvin explains:

When I go out, I don't tell friends that know I'm [HIV] positive, since they make a deal out of it. And, they expect me sick and in bed, but I still go party and all. I hate to be mothered by friends! They push too much, and I avoid hanging with them when they like that.

The question of who exactly is being protected is ambiguous in this case. They, perhaps, fear being stigmatized themselves, and as Calvin also explained, they tend to referee his relationships with others. They seem to think that Calvin would subject a partner to undue risk of contracting HIV. He self-reports that he would not under any circumstance, but as an interviewer I am only privy to his life from his self-report. I do not know what may motivate his friends concerns.

Robin talks about feeling forced to be weak, "I have a bad day and have to stay in bed, and they all blame me for trying to get out a little bit. Like I'm supposed to stay in bed twenty-four-seven." In Robin's case, overprotection means being forced to comply with expectations of family members, who want her to stay in bed and rest, avoiding any type of physical activity. This is an old theme, hearkening back to stories like "The Yellow Wall-paper" by Charlotte Perkins Gillman. In the story, the protagonist's husband isolates and stifles her with a prescription for bed rest to combat her "hysteria." In the course of the story, Gillman illustrates the universal nature of such oppression for all women, whereby their voices, creativity, joy, and even health is diminished by external projection of frailty that in a Pygmalion-like manner comes to be. Although written in 1892, the story creates a familiar image of oppression under the guise of help and protectiveness. Whether applied to the experiences of women or individuals with disabilities, the rationalization or manipulation taking place in the story continues away from fiction.

Overindulgence also may play a role in the differences in treatment between individuals with and without disabilities. Parents and family may see the individuals with disabilities as irrevocably damaged and attempt to “make up” for their misfortune. Certainly a child with disabilities would learn to play the role with tantrums, learned helplessness, and complaints until adults give in. The result may be obesity, poor health, delayed intellectual progress, muscular atrophy, and poor social skills. Kevin discusses the role his grandmother played as an overprotective and overindulgent adult, which resulted in social isolation and weight gain. He explains:

So, when I was in middle school I was a little bit obese too, because I went to my grandmother’s house mostly, that is part of the isolation because she loved me and everything so I stayed with her because I felt more I belonged there I guess rather than with interaction with other kids, and I ate a lot so I got obese.

Gestures of concern and a desire to help may further impair individuals with disabilities. Challenge and self-efficacy must be developed in order for these individuals to meet challenges on their own. While working for Services for Students with Disabilities at Virginia Tech, I was surprised by the number of parents still trying to conduct all of their children’s business, even when those children were adult college students. Numerous students, bending to their parents’ wishes, would waive their rights to privacy, giving parents permission to discuss and receive reports on their progress. Of course, IDEA guidelines, which allow for three more years of public education may feed into this dependency, since parents typically remain involved in IEP conferences, even when the student no longer requires their signatures to make transition and education decisions.

Personal relationships

Personal relationships with others influences the presenting-self that was employed by the participants. Again, there was a range of experiences, but the outcomes were similar. The early memories of relationships seemed typical in most cases. Disability was not a salient feature of these individuals’ experiences in most cases. Relationships generally suffered because the participants wanted to conceal major aspects of themselves, resulting in retreat from the degree of intimacy that would compromise their secrets.

It is probably for these reasons that participants reported feelings of isolation and loneliness. We know that physical independence, social skills, and social anxiety related to disability has a positive causal relationship with loneliness (Hopps, Pepin, Arseneau, Frechette, & Begin, 2001). Some, if not all, of the attitudes and behaviors that lead to loneliness were nurtured through childhood experiences. As LaCom (2002) writes, “The discursive representation of the ‘sexless invalid’ and deformed sexual deviant further complicates issues of isolation and shame” (p. 192). Related to this, Sandahl (2003) writes:

Queers and cripples often experience profound isolation while growing up, since they are rarely born into queer or crip families, much less communities. To cope with this isolation, and to resist the negative interpellations of being queer or crippled (not to mention queer and crippled), members of both groups have developed a wry critique of

hegemonic norms. In queer communities, the application of this critique has been given its own verb: to queer. Queering describes the practices of putting a spin on mainstream representations to reveal latent queer subtexts; of appropriating a representation for one's own purposes, forcing it to signify differently; or of deconstructing a representation's heterosexism. Similarly, some disabled people practice "cripping." Crippling spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects. Both queering and crippling expose the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity, and both disarm what is painful with wicked humor, including camp. (p.37)

While participants did not employ these tactics often in the interviews, it would be expected that they would not include the researcher in this type of joking, which involves a message encoded and decoded among members of a group. Outsiders, likely to misinterpret these messages as hostile, may not recognize the power gained when discourse is appropriated and diminished through use in this way.

Able-bodied assumptions include compulsory abled embodiment. By this I mean the requirement to "appear" abled in order to gain societal privilege. Those who do not fit this social expectation become ostracized by default. Whether last to be chosen for a softball team, a study group, or employment, individuals who do not meet societal expectations for performance get rejected and discarded. The message "You are not wanted" resounds clearly. The reason for a lower performance does not influence the outcome. Rarely does someone ask if the cause of a "poor" performance is due to impairment or another difference. Sometimes there isn't readily available answers anyhow. A team captain picking players for a softball game will not select the player who cannot catch or hit a ball, regardless of whether the player's eyesight, attention, coordination, mobility, or training is to blame. And, regardless, this outcome sends the message that the player is least valuable, not worthy of inclusion, a loser.

Isolation also grows from discourse. The language we use to convey our social attitudes about ability and disability become the impetus for social isolation and selected confinement. Kafer (2003) explains:

Compulsory able-bodiedness is also instituted and maintained through less physical—although no less coercive—means, through "verbal and nonverbal messages." Perhaps the most basic manifestation of this system is the cultural presumption of able-bodiedness. Unless someone identifies herself as disabled, or is visually marked as disabled (for example, using a wheelchair or other mobility aid; carrying a white cane or accompanied by a service dog; or missing a limb or other body part), she is assumed not to be disabled. This assumption serves to isolate people with disabilities by masking the pervasiveness of disability throughout society. It has a particular effect on those with non-apparent disabilities, in that their (incorrectly) assumed able-bodiedness often blocks their access to needed services, denies them the support of friends and family, and hinders their inclusion within disability communities. (p.80)

Kevin and Erin, whose conditions are both physical and congenital, shared more early memories regarding disability than the others. Their differences had more salience and demanded more attention because of their visibility. The same is true of Calvin in regard to race,

when he notes, “Growing up was hell for me. We was one of the only Black families in my town.” Early experiences delineated their differences and the cause, being more obvious, may have in some ways insulated their self-esteem by moving the root of their problems away from disposition and into the realm of physical diversity, a condition shared by others.

Ryan places blame on his experiences in childhood for his disability, which adds another dimension for consideration. The isolation and exclusion he experienced under the authority of a controlling father shaped a lack of social competencies that would follow him. Adam blames himself for his isolation. His loneliness clearly stems from disability and privacy issues. Self-esteem, diminished because of experiences, causes Adam to question his social competency and to manufacture a negative reflected appraisal of himself. He writes:

My mood swings are often hard for others to accommodate. People often misinterpret this as evidence of a secret underlying dispute or problem with a relationship. I am also limited in the number of places where I can take a date because I am unable to hear in places where there is a lot of background noise, I am allergic to cigarette smoke, and if I am living with family, I never want to bring them home with me. [...] Personal relationships are often difficult because of my central auditory processing disorder. Actually, I am not sure if this is the actual problem that I have. What I know is the extent of what an audiologist could diagnose. He was able to trace the problem to my brainstem or above. It would be the job of some type of brain specialist to get a more specific diagnosis. He found that in background noise, my comprehension of speech is reduced severely. All people experience this to some extent, but my dip in understanding is disproportionate and makes it virtually impossible for me to accurately understand spoken conversation in nightclubs, loud restaurants, noisy classrooms, malls, public transportation, meetings and other places where people usually meet and make friends. I suspect that this may have contributed to my social anxiety, since I am constantly thrust into embarrassing social situations because I did not understand what was being said.

Like Adam, Caroline notes that without her disability, she feels like she “would be a lot less shy.” Reflecting on her reports of treatment from her father, it seems likely that she would have developed a similar personality regardless of the presence or absence of a particular condition. Her concerns has to do more perceptions of others than outcomes of impairment. This is unlike Calvin, who actually could become a threat to others, if he chooses to practice unsafe activities. He talks about his problems in relationships, comparing himself to a character in a story:

Ever read “Rappacini’s Daughter” by Nathaniel Hawthorne? We read it in literature and it’s this girl whose father makes her poisonous, like a flower in the garden. She grew up around poison and got poison herself. Then she poisons anyone who gets close to her. But the poison and her are the same. So to kill the poison would kill her, because she is the poison and you can’t separate it. I feel like her. I am poisonous to the ones I would like to love and afraid for them to get close. Even though I know how to be safe, when I am in love I get all tense and afraid. And, I usually push them away instead of risking it.

In his allusion to “Rappacini’s Daughter,” Calvin reveals a great deal about himself. Describing himself as a poisonous flower, he conjures an image of something delicate, fragile, forbidden, beautiful, and dangerous—a juxtaposition of both negative and positive qualities. His

self-imposed isolation grows from a conscientious concern for others and fear of transmitting his “poison.” To risk love is to risk killing a loved one. Calvin’s understanding of his illness and its role in his life creates a bleak picture in the social realm. He fears the outcome he creates for himself. He explains:

I never really date anymore. It scares people, but I’m honest. Don’t want it on my conscience. I went through a time being angry when I thought it their own fault if they don’t want protection. But, I got past that. I met guys on chat and hit it off, then I say I’m HIV positive and they are gone. If they’re going to run, I’d rather them do it before I get to like and feel hurt. I may end up being alone, but I still have friends. There are also weirdos that will hear that you have HIV and want to sleep with you. I have nothing to do with them. They are tedious. There aint enough Black guys around, gay guys. I go out with white guys some, but people stare at you like they going to kill us or something. It’s not like that back home, but around here even the other gay guys get flustered about it. And, they all freak out if I date a guy who is healthy, like they think sick people should only date sick people. And, they all try to break you up. They’ll all ignore some guy until you go out with him, then they all start flirting with him and hitting on him. Even my friends don’t trust me to be safe with a guy or to date somebody. I don’t want to just be alone.

Disability also served as filter for Calvin. He explains that his disability helped him to discern who his real friends were:

You find out who real friends are when you get told you have HIV. A lot of them just disappear or act whacked or something when they find out you HIV positive. You see who sticks by. They real friends, and they worth it. It hurt me a lot, some close friends that just act like I’m a stranger now.

Ostracism by his former “friends” demonstrated for Calvin the stigma attached to HIV. As many individuals retreated from him, he was able to recognize true friendship in the supporters that remained. Still, not all of those that stayed around have proven to be good friends. Calvin complains that some of these allies seem to distrust him, questioning and monitoring him when he initiates ties with others without HIV. This duplicity brings to question their friendship. Calvin also mentions individuals who seek out individuals with HIV, presumably to contract the virus. Regardless of their motives, their intent is to use the carrier of the disease, and have based their attention on the fact of the illness. Prejudices also limit social interaction. Race, as well as HIV, incites reaction. Calvin has found intolerance regarding biracial relationships, noting the hate-filled stares from others.

Relationships may also be diminished by attempts to avoid responsibility. Not knowing or being open to the problems another faces may relieve family members of feeling a need to acknowledge problems and deal with them. Elizabeth explains:

Well my family chooses not to accept that I have a disability because if they know it they will feel compelled to help in some way and they don’t want that. My friends think, like I told you before, that I am avoiding them just because sometimes I am making excuses just because I don’t want to be with them for some reason, and they take it sometimes

offensively because they don't understand the depth of my pain. And then as far as relationships are concerned, I have shied away from getting close to anybody. I have really liked some people before, and I got into a relationship that really turned bad because I am not able to physically do sports and different things that people like to do, and I just shy away from it although I am a very lonely person because of it. I would rather be by myself than have to explain the depth of my disabilities to someone.

Elizabeth avoids telling friends about the problems she encounters, probably assuming they will respond in the same way her family has. Her friends end up attributing her behavior to apathy, disrespect for them, or desire to avoid them. This compounds her issues of loneliness and creates low self-esteem for her, since she imagines that others are viewing her in negative ways. Counter to this experience, Kevin describes how his relationships with others changed with increased self-esteem and self-efficacy:

I have improved that a whole lot since ninth grade. Beginning in ninth grade that was probably one of the turning points, around tenth grade and latter part of ninth grade, because I became a manager of the wrestling team at tenth grade, and I had nothing to do really after school which is 1:40 until about 3:30; so, I started working out and running and everything, and I slimmed down a little bit and started feeling better about myself and started talking to people more, and I started associating with people more. That just really hit off. I have always had like pretty good friends, really good best friends, and I am like outgoing, but up until then I didn't really like try to push for like trying to be in the social realm. Up until, my best year was actually last year. I got a girlfriend, and I have had her since March so yeah, but I have just gotten really good friends through the years and I have met a lot of people and I am more social with everybody now. I got to the point where my high school like everybody knew me, and I was prom king so I mean.

Families and peers know that disappointment and failure abounds when a significant other has profound differences (Colman, 2003). Family and peer relations often get reinvented by individuals with disabilities, who do not fit into traditional relationships (Rapp & Ginsburg, 2001). In most cases, individuals with disabilities are not born to parents with the same disabilities. Ignorance and lack of empathy may not diminish the sympathy afforded these individuals, but sympathy without understanding can be as disempowering as intolerance, relegating individuals to dependent and pitied roles.

Many participants talked about feelings of incompetence. Others seem to have a tendency to overcompensate for the problems experienced by others. This results in, as discussed earlier, overindulgence and overprotection. These reactions have a negative effect. As Nicki (2001) writes, "Social arrangements which do not accommodate people with disabilities intensify their disabilities" (p.93). They become merely a means of publicizing differences without remedies. An individual faced with disclosure of deficits without a means for achieving equity may become resigned to eminent failure or loss.

When faced with a bad event, some individuals may tend to blame the situation on some cause rather than chance, and they are more likely to experience depression-related problems as a result (Abramson, Seligman, & Teasdale, 1978). This cause often is attributed to something external to and beyond the control of the individual. Adam writes:

As a child, I was often confused. I did not have a grasp on the concept of schedule. All of my early childhood memories revolve around being randomly moved from place to place such as daycare, back home, to relatives, or whatever. I felt like I had no control or influence on the course of my life and that I was incapable of making plans. I also learned to not cherish anything or get too involved or satisfied with any one thing because I had to be prepared to be randomly taken away from that activity at any moment.

Adam became withdrawn and emotionally shut down as a defense against lack of self-efficacy. Random movement from location to location and lack of structure made him feel out of control.

Performance ability has been shown to diminish when individuals' achievements have been presented to them in a negative manner (Seligman, Nolen-Hoeksema, Thornton, & Thornton, 1990). Individuals will attribute failure to who they are rather than the situation they were in, and will attribute successes to situations with little prompting. The result is conformity to the lowered expectations they create for themselves.

More pessimistic explanatory styles have been shown to result in an impaired immune system and illnesses (Kamen-Siegel, Rodin, Seligman, & Dwyer, 1991; Peterson, Seligman, & Vaillant, 1988). Unfortunately, many of the participants report treatment which supports a negative explanation for their situations. Individuals with disabilities have a strong positive correlation between degree of self-efficacy and degree of self-esteem (Barnwell & Kavanagh, 1997). The act of taking away another's self-efficacy undermines self-esteem. Robin explains:

Well, they treat me like a baby, make me feel weak, or like I'm pretending or something. And, they always have advice. They can't just listen or show sympathy. They have to give me some advice about what I shouldn't have done or what I need to do.

This oppressive attitude can become systemic. Caroline shares:

My Mom and aunts get together and you have a complaint fest of the century. They all start telling about where they hurt and what's wrong with them. It's really depressing, makes you wonder how any of them are still alive. Now, my Mom and other two aunts don't really have anything major wrong with them I know of, but they can complain with the best of them.

These three sisters have learned to glorify their weaknesses, making the negative attention of pity from others their primary mode of interaction. This leads to cognitive fallacies, such as catastrophizing and fallacies of perfection, approval, and helplessness. Of course, misplaced sympathy may lead to resignation among students with disabilities. Teacher expectations can have a powerful influence on student performance. Landfried (1989) warns against "educational enabling," the process of making learning tasks easier for students with disabilities. When these students are not challenged in the manner they see other students challenged, they conform to the lowered expectations, assuming that they are less capable than they really are. Kevin explains:

I used to, when I tried to do stuff sometimes like the easier route was just to ask my brother or sister or somebody to help me do something, and I just knew I could do it, but it would take such a long time that I would just ask them to get it out of the way quick, and that kind of bothered them.

Religion and spirituality

Certainly, social discourse suggests that religion and spirituality would be salient topics for the disabled. Society often frames disabled individuals in the martyr role, picturing them relying heavily on beliefs to overcome the existential factors they are forced to endure. However, the interviews revealed that when questioned the participants had little to say about the topic. It is the absence of commentary that I find interesting and thematic. I do not doubt the spirituality of the participants, but the interviews do illuminate the stereotype of the infirmed individual who must rely on faith and future hopes in order to survive emotionally, if not physically. Of course, the question of what constitutes spirituality and mental illness and how they might be differentiated has been a topic of debate (Jackson & Fulford, 1997). We have seen the ever-optimistic Christopher Reeves who promises he will once again enjoy full mobility. Is his optimism a healthy expression? His faith in scientific progress motivates him to strive for his former condition. This is not unlike others in society who try to recreate their youth. Media advertises a plethora of products making promises of renewed youth. In the case of Reeves, it may be surmised that he has reached an emotional impasse at the bargaining stage of the grief process. He has become the antithesis of his *Superman* role. The social interest in his experience has been a juxtaposition of wholeness and “ability” with disability. Of course, he may once again gain his mobility, but he is unlikely to be satisfied. He probably wants lost youth and beauty, but he combines all of these ideas into his illusion of completeness and healing.

On an archetypal level, society seems intrigued with poignant representations of the beautiful and perfect body being marred or destroyed. Consider the social preoccupation with the Christ figure, not to mention the adorable children selected for telethons and other pleas for money. Countless films and plays present the once beautiful now scarred, aged, or insane representation of the marred body –the religious promise of healing, of the human leprosy washing away in the flood of spiritual re-creation. On this level, however, the difference may be equated with sin. In this way, religious influences are not always uplifting and empowering. In fact, Calvin describes a disturbing example of withheld acceptance on the part of his grandmother’s religious affiliates. He talks about his grandmother’s beliefs and his experiences:

Grandma never gets sick, just complains of rheumatism and arthritis all the time. She’s the type that gets healed at church every week, whether she needs it or not. She got “slain in the spirit” again every week she talks about it again. I’m not into that stuff. I’d go when I was younger, but it’s not a place where I fit in. I stay away from grandma too. I don’t need elders from her church coming to pray over me and stuff. They came in on me when I was in high school, her and a bunch of elders and held me down and laid hands on my and prayed. Tried to heal me of being gay.

His response to this was running away from these individuals. Of course, the church members are most likely motivated with a desire to help, but they are communicating to Calvin and others that his sexual orientation is in itself a disability that requires a cure. Implicit in this situation is the traditional Manicheistic premise of baseness and sin causing or creating disability. Calvin continues to complain:

My grandmother tries to church everybody. Kept telling me, “You burn in hell, if you don’t get Jesus. You get AIDS and die. God will punish you.” Don’t tell her that I’m HIV, she’d think that proved her right.

Calvin feels compelled to hide his disability from his grandmother, since doing so would justify her belief that having an HIV-positive status is a punishment from God. A number of vocal conservative religious zealots have announced that AIDS, as well as other oppressive conditions, comes from a judgment. This attribution of impairment to sin blames the person with the condition. It suggests that impairment is a deserved punishment, and as thus, just. The resulting conclusion is less than humane –“They made their beds; let them lie in them.” From this perspective, intervention contradicts a heavenly ordained sentence. It is an interference with God’s intention regarding these culpable objects of wrath.

Still, in spite of his negative experiences, Calvin finds spiritual outlets. He explains:

And, I used to sing at church, but when people found out I had HIV and was gay they let it be known I wasn’t welcome anymore. They didn’t out-and-out throw me out, but I was told I wouldn’t be needed to sing or do anything again –sit back and just listen and keep your mouth shut deal. I stopped going after that. I’m not comfortable where they all think I’m going to hell and a heathen. I am spiritual though, but in my own way. I find my spirit in dance and music and friends and enjoying life and not taking life for granted.

Spirituality and religion does not need to be self-debasing. Through religion and spirituality, some find self-worth and value. Central to this form of faith may not be rhetoric about bodily perfection and implicit ideals of ablism. Instead, focus may shift toward compassion and acceptance of differences. Religious organizations may create the inclusive environments that individuals with disabilities may need in order to develop socially. Whether genuine or pretense, gestures of acceptance and compassion serves to establish self-esteem and self-identity that extends beyond the socially prescribed stereotypes.

Caroline shares similar attitudes about religion. She expresses concern about the extortion of money from an elderly aunt. Her aunt practices religion in order to gain a propitiation for her failures, thinking perfection will lead to wholeness. Like Calvin, Caroline describes a degree skepticism. She talks about her aunt’s beliefs:

She’s real religious and keeps thinking she’ll be healed if she’s good enough. It’s kind of sad. She doesn’t have much money and sends who knows what to TV preachers and all. She drove down to Charlotte one time to get that Benny Hinn guy to heal her, but he never called her up. I think he’s a wacko. I’ve seen him on TV and he’s a nut making a dollar, but don’t dare tell my aunt that. She thinks the guy walks on water. It makes me mad, her barely scraping by and sending him all that for him to vacation on and buy drugs or whatever. Now if you talk about her performing disability, she puts on a show.

Caroline seems acutely aware of the religious rhetoric and discourse used to solicit money from individuals with disabilities. Faith, even if misplaced, seems to motivate her aunt to persevere. Even taking into account the lack of resources due to her contributions, the aunt may in fact have a stronger will to survive and have more hope. This does not change the fact that some groups

will attempt to take advantage of desperate individuals. I do not know specifics about the evangelist that Caroline describes, but I know that charlatans abound in our society. Even so, outside the realm of perpetuation of scams and fraud, Caroline's aunt may benefit more from the hope she gains than the financial resources she loses.

Regardless of the specific beliefs, the support found in religion or spirituality may serve to create a means of gaining strength in spite of hardship. Individuals with disabilities may find strength and motivation to persevere in their beliefs. As Calvin explained, for him becoming aware of his illness gave him a new appreciation and perspective. It opened doors to more deliberate and meaningful living. Still, my data did not support a strong salience for this topic among the participants.

Therapy, treatments, and accommodations

Many of the participants discussed a variety of therapeutic, medicinal, and medical attempts to alleviate their conditions. Calvin explains:

I go to a support group, let me make good friends. I don't get any special treatment. I get some medicine through my home state, and I don't know if it will stop. I don't worry. Nothing but see what happens.

Therapeutic approaches, occasionally assuming a maintenance program should be applied, may perpetuate dependence rather than empowering individuals to change. It is not uncommon for parents and caregivers to make decisions about treatment without consulting young clients. Low self-efficacy may contribute to docile acceptance of unwanted treatments. Caroline talks about taking Lithium for depression:

We needed to just be sad for a while. But I got on lithium for my depression, because they thought we would all commit suicide because those boys accidentally did. They kept telling us that might happen. I knew a girl that pretended like she would so her parents let her go on a senior trip. It was really messed up.

Treatments and interventions can be as painful as the initial condition. Disability has many modes of concealment and repair –pharmaceutical, prosthetic, cosmetic, behavioral. Of course, medicine offers more treatments than cures. The limits of HIV medications gain publicity, but psychotropic drugs are also long-term maintenance. Side effects, such as weight gain, irritability, nausea, and fatigue, may serve to heighten the degree of stigma. Drugs may decrease clinical depression, but increase situational anxiety and depression. Skepticism about the number of individuals using stimulants to treat attention deficits has prompted some to deny the existence of the disorder at all, making individuals with attention deficits suspect and judged as fakers. Of course, this would limit the freedom an individual might feel to disclose a need for accommodations or other services.

Caroline's experiences with antidepressants were negative. Her depression seemed to be situational, in that she describes comorbid issues with self-esteem and social anxiety. The side-effects of the medication fed her low self-esteem. She explains:

Lithium made me gain a lot of weight and made me more depressed really. I take Prozac now, but I still can't lose the amount of weight I want to. Lithium made me feel like I was starving all the time though. You know, like being dehydrated or with a flu or something. It kept me sick at my stomach and I'd nibble on food all the time. I felt sleepy and groggy all the time.

Adam, like Caroline, suffered from the side-effects of the medications he was given. It sounds as if he was used as a guinea pig, being given a variety of psychotropic medications which had no beneficial effects. Perhaps, this points to the fact that psychotropic therapy is still in its infancy. Still, the failure of these medications proved to further impair him and made his educational progress even more difficult. He writes:

About six years ago I was diagnosed with depression, bipolar disorder, social anxiety, attention deficit disorder, and a number of other psychological problems. All of this was made possible when I became a full time student and gained access to free psychological and psychiatric services at the university. I am sure that these problems had a tremendous impact on my life since I was a child, however, the series of medications that I was prescribed was probably more disabling than the original symptoms of my disorders. [...] I am unfortunate that I do not respond well to psychotropic medications. I seem to get most of the side effects without the benefits. I have taken dozens of antidepressants, stimulants, anti-anxiety pills, and mood stabilizers, with little or no success. I can remember times when I was taking stimulants and benzodiazepines at the same time, under the advice and prescription of a licensed psychiatrist of course.

Medication was not the only form of therapy that failed Adam. Psychotherapy may also present problems as Adam explains. Too often therapists may doggedly rely on a particular counseling model. Adam describes his experiences in therapy:

I went for psychotherapy and psychiatrist services at the university. I was often disappointed in the psychotherapy because they seemed to presume that by making me aware of my problems, that I would magically resolve them, when in fact, the constant reminders had a depressing effect on me. I tried to explain this to them on several occasions, but they still resorted to the same strategies that were already proven ineffective with me. I knew what they were thinking and could predict their next question before they uttered it. I had memorized the script, and they were not very tolerant of deviations from my role.

Unfortunately, there is no universal panacea. The inability or unwillingness to vary approaches for Adam may have been a symptom of inexperience or cognitive conservatism. Perhaps, they had not mastered other approaches and, rather than referring him to another counselor, ignored his request and attempted to force him into the role they desired. The outcome being convincing the client that psychotherapy has nothing to offer.

Erin, Kevin, and Portia selected Virginia Tech because of the services and accommodations that the university offered. Among participants receiving services, a unanimous report of good experiences with the service providers on staff at Virginia Tech accompanied a variety of reports regarding experiences with faculty, which is discussed in more detail later.

Adolescents have been shown to have less self-efficacy when their self-perception of ability is lower (Ryan & Pintrich, 1997). They are much less likely to seek help, disclose needs, or admit limitations. Ironically, the individuals with the most need are the least likely to seek accommodations. Individuals who feel more confident about their abilities have been shown to seek out accommodations and support more aggressively, while their less confident peers are more likely to give up on or never attempt securing help (Karabenick & Knapp, 1991). Freshmen tending to use negative explanations were discovered to make less use academic support services (Peterson & Barrett, 1987). Kevin describes how others in high school reacted to his accommodations. Still, in spite of some negative response from peers, accommodations made it possible for him to participate in the classroom. He explains:

In high school I had two sets of books so I didn't have to carry one and sometimes like, I don't think it was the accommodations, but my ability to get those things is what kind of bothered other people sometimes. That made them a little bit jealous I had them. I could leave class five minutes early, if I needed to, just to walk. I never took that luxury because I didn't really need it all that much, but just things like that, little things. People are more jealous because I could get those things rather than me having those things because I didn't really take them all. I had a laptop at one point that the school provided, but that didn't work out too well because I would have to get it out, plug it into the wall and that would take too much time; so, I just stuck with the notebook, and I can write well. So, it wasn't that big of a problem and people were jealous of that, that I could get that, but it wasn't too big of a problem.

Even his living skills can be augmented with architectural conformity to him, rather than expecting him to conform completely to his environment. In this way, making tools that work serves to make Kevin completely functional. He explains:

I have a sink in my dorm room that instead of twisting like a knob you pull a lever, and I have this sock thing that helps me, but I didn't get it from the campus. Another too is the door handle is a little bit different. Instead of a knob you push it down, and I can work the key pretty well with that so everything is accommodated for me except for my hangers, where I put my hangers up, but I found a way to get through that so. It's just a little high at first, but they brought it down a little lower so pretty much everything is all right. [...] If I need anything, I just go to the Student Services. They are really good about that.

Of course, as we have noted before. Accommodations may not be readily accessible to all students who need them. Caroline's fear of embarrassment all but immobilizes her. The simple courtesy of not requiring excuses every time an adult student leaves the room would allow her a moderately comfortable classroom experience. She notes that she makes do without accommodations to avoid stigma:

My history teacher started taking off points every time I had to leave the classroom, and I had to withdraw. I told him I had a health problem, but he wanted an accommodation letter from the Dean of Students. Of course, I wasn't going to go there and tell the school about having IBS. It's embarrassing as it is already. And, you never know who will tell who at a college. Can you imagine carrying a note to your teachers that said you can't

control your stomach, you might run to the bathroom at any time, and you can't stop to ask or you'll have an accident? I always go though that. I'd throw up sometimes too, but you can't stop and chat when you have to throw up either.

Of course, not all modes of treatment fail, but those treatments that have failed seemed especially salient to the participants in this research. The degree of dissatisfaction with current modes of treatment was not expected. In many cases, the cure became as devastating as the problem, introducing additional impairments. Hopefully, research will bring about better approaches to addressing impairments and deficits in less intrusive, less damaging ways.

Work experiences

Experiences and issues regarding work ranged from positive empowering situations to negative oppressive situations. Employment opportunities often change with disability. Transition to work can be a difficult process for individuals with diagnosed disabilities (Sitlington, 1996). Federal and state benefits may be withdrawn and be difficult to get reinstated if the work transition is unsuccessful. This may make individuals reluctant to risk rehabilitation. Also, decisions regarding disclosure at initial interviews and in the application process may raise many issues (Huvelle et al., 1984). Individuals with special needs may be stigmatized enough to prevent hiring. Expenses for the employer to accommodate their needs may be prohibitive as well. Acquired impairments may also limit abilities related to career paths that are no longer as accessible. College sometimes serves as part of a career change and vocational rehabilitation.

Schools, of course may not fairly recognize and accommodate disability. Breckenridge and Vogler (2001) discuss the treatment of teachers:

In the sphere of education considerable attention has been paid to the well-being of the child who is disabled; however, this same sphere has been unfriendly to the idea of giving equal access to teachers who are disabled. An elementary school student with impaired cognitive ability who cannot walk is likely to have greater access to services in school than is a teacher who has full cognitive ability but uses a wheelchair. The hiring of teachers who are disabled is a remote possibility in the first place; even if they are hired, securing the legally required accessible bathrooms is likely to be a major struggle that can and often does put their jobs on the line. The stubborn politics of localities frequently trump legally mandated obligations. (pp.352-353)

This is unfortunate, since exceptional role models with disabilities would decrease the amount of stigma in our society by creating more familiarity. While ongoing budget cuts, under funded programs, and aging buildings not designed to accommodate differences is the norm, hiring instructors with special needs would be prohibitive, perhaps creating an undue hardship by absorbing already limited resources. Schools are put in an awkward position. The absence of groups among educators sends a clear message, intended or not.

Of course, there are instructors with differences everywhere. Many individuals, if not most, manage to effectively hide their differences from employers and clients. Concealment may

decrease opportunities for understanding, but it may increase the likelihood of initial hiring. Adam writes:

I receive no accommodations at work because I have not alerted anyone to my problems other than mentioning to one or two colleagues that I don't hear as well when there is a lot of noise. This only occurred in specific situations where I had to ask them to repeat themselves, or turn off a radio, TV, or whatever so that I could understand them.

For some, work represented the opportunity to demonstrate competence and ability. In fact, a substantial number of individuals with serious impairments do not report any type of work limitation, a conundrum for disability definitions posited by service agencies (Burkhauser et al., 2002). Kevin described his experience working at McDonalds. Erin also talks about her job at a historical park. Ryan mentions a variety of jobs where he excelled and his disability remained irrelevant. Calvin echoes Ryan's sentiment, when he states:

I'm a work study for [a place of employment on campus]. They don't know. None of their business. I have a card in my wallet in case I get hurt for the hospital and emergency people.

For others, work represented something destructive. For Caroline, it was a place where she felt embarrassment and shame. For Elizabeth, it was a place where she suffered. Elizabeth talked about forcing herself to go to work when she didn't feel well. She ignored her physical pain out of necessity:

It was bad at work too. I would go to work and I would try to do the very best I could, but sometimes I would just get really ill, and I made mistakes that I was called on in the office several times you were given warnings about things I was expected to do and didn't do or things I tried to do and didn't do them quite right. And I didn't want to use my disability as an excuse although that was the reasoning because I always put myself in everything I did or tried to do my very best at everything, and I really thought, I felt like I had done something and not really well. [...] They knew I had a disability, but they didn't seem to be concerned about it I guess because if you get there and you are not in a wheelchair or not in braces or at that time and you look really well, that they don't understand. [...] When I applied, I told them I had some impairments and I told them what they were, and I told them that there would be certain things I might not be able to do, but I tried so hard to keep up my work in spite of my disabilities that I think they wanted to always see me as the whole person and then the days I didn't feel like doing no work, they didn't quite understand even though they knew, they chose to think if I made it there I was fine. And they had some people that weren't disabled that really didn't carry their weight so I sometimes had extra work to do and that sort of dependent on that, and I don't think they really ever realized how much pain I was in. But that was probably my fault because I didn't want pity or I didn't want to be different, and I wanted to keep my job.

Elizabeth notes that the invisibility of a difference results in supervisors ignoring the possibility of a person having an impairment. Even though she had disclosed her disability to her employer, it only served to increase their expectations of her. She felt compelled to pick up any

slack, because she had disclosed a disability, while others, who presumably had no impairments, did not contribute their fair share of work. Elizabeth's disability did not make her work as difficult as her desire to please and unwillingness to confront others. Of course, many individuals with disabilities end up being relegated to menial tasks and difficult manual labor, since society tends to make assumptions about abilities based on stereotypes and labels.

Not all experiences are bad. Portia describes a great experience with work. She has earned a managerial position in three years and enjoys her work. She exclaims:

Well, I started working in community theatre the summer before I was diagnosed with ADD. I did that for three years or something. I am the manager. It's so much fun, and one thing at work is I can't take my medication at work, I always avoid my meds since they make me come down and not function well, because it's a lot for craziness, but my co-workers can tell when I have taken my medication or not.

Of course, this all occurred prior to Portia's becoming labeled. The outcome of her labeling on her work success may have been profound. Without knowing, we can only guess at the results of diagnosis on initial job experiences and what her disclosure of such a disability would have done to upward mobility.

Labels and Discourse

As Lane (2002) explained, "disability is not something you have; it's a label you acquire" (p.368). As a result of interpersonal, clinical, or personal appraisal, the participants have acquired the label of disabled for themselves. Diagnoses and other labels have been acquired by all of the participants as well. The discourse that these labels grow from generally served to reinforce the domination and oppression exercised by "normal" individuals. Of course, not all labels were medical. A few participants listed derogatory names others used to abuse them. Labeling an individual as disabled has multiple outcomes:

The disability/ability system produces subjects by differentiating and marking bodies. Although this comparison of bodies is ideological rather than biological, it nevertheless penetrates into the formation of culture, legitimizing an unequal distribution of resources, status, and power within a biased social and architectural environment. [...] Disability is a broad term within which cluster ideological categories as varied as sick, deformed, crazy, ugly, old, maimed, afflicted, mad, abnormal, or debilitated—all of which disadvantage people by devaluing bodies that do not conform to social standards. Thus, the disability system functions to preserve and validate such privileged designations as beautiful, healthy, normal, fit, competent, intelligent—all of which provide cultural capital to those who can claim such statuses, who can reside within these subject positions. It is, then, the various interactions between bodies and world that materialize disability from the stuff of human variation and precariousness. (Thomson, 2002, p.4)

Like most marginalized positions, the position of being labeled as disabled has implications for students in a college setting. The positions of the labeler, and the relationship of the labeler to the subject, influence the power of that label. For example, an individual may easily dismiss labels assigned by insignificant others, but labels assigned by others with power or

regard may determine issues such as self-esteem and autonomy. The key seems to be the degree to which an individual adopts a label. The label itself may define an individual, influence decisions, regulate functioning, impair or increase opportunity, become an excuse for failure or neglected responsibility, represent nothing more than a challenge, or be totally disregarded. This adoption process seems dynamic. While a label exerts control over an individual's experiences, that individual may simultaneously profess to disagree with the label, become enmeshed in the outcomes of that label and try to conceal or hide that label, all at once. This results in a dissonance of sorts, a multilayered definition of self, which tries to construct an identity with and without disability, with and without stigma, with and without impairment, and with and without normalcy. In the case of some participants, this meant trying to be "unusually normal" and "exceptionally average" – oxymoronic identities wrestling for a meaningful way to accommodate or assimilate the fact of labels and diagnoses.

Diagnoses and general labels denote various degrees of insult. Kevin admits, "I think I use all of them the same," as he talks about terms such as impaired, handicapped, and disabled. He explains, "Of course there is like the offensive terms like crippled; I would not like that." Caroline notes, "I just went crazy when they labeled me disabled. Even though it meant getting help, I felt like I was being made stupid." Of course, labels range from legitimate diagnoses – "fibromyalgia," "clinical depression," "*Arthrogryposis multiplex congenita*" – to outright attacks. Portia says of ADHD, "I thought it meant that you were just wild and out of control, couldn't sit still."

One common theme regarding labeling has to do with the association with prostheses and designation of a person as disabled, as seen in the participants descriptions of what they picture when they hear the term disability. Of course, society presents a clear bias when describing a tool as prosthetic. For example, a cosmetic prosthesis like a wig for a person receiving chemotherapy serves the same function as a baseball cap for an individual with pattern baldness. We may easily associate the wig with a disability, but not a cap. The validity of these items as viable needs is based on social values. A faculty member would not be likely to demand the wig be removed in class, but may not hesitate to demand a cap be removed. Social assumptions are made about the degree of stigma perceived by individuals and the validity of needs based on the observers' beliefs and values. Still, the degree of stigma felt by the individual in the baseball hat may rival or exceed the stigma felt by the individual in the wig. In the same manner, individuals like Kevin, would not need to worry about being questioned if using a specially designated parking space, an automatic door, or other tools and facilities. Without appliances and appearances that designate a disability, another person may risk being challenged for using those resources.

Official diagnoses are not the only labels that represent disability, even though they may validate eligibility for accommodation at an institutional level. Removal of homosexuality as a pathology from the DSM IV did not change the fact that society still stigmatizes gay men and lesbians, as has Calvin clearly experienced. The factors that oppressed this population did not vanish with the official label. Accessibility to accommodations does not need to be dependent on an assumption of pathology.

Our society has become flooded with new types of prostheses on which many depend. While some are cosmetic, such as wigs, make-up, and sprayed-on tans, others augment functioning. A former algebra teacher complained that students depend on calculators now.

Actually, calculators have possibly been replaced by computers, which have been the channel for much communication, socialization, and information dissemination, not to mention the medium for diverse online cultures. Televisions, automobiles, skateboards, cell phones, and compact disc players have also emerged as common extensions of individuals. The only significant difference between these devices is often the popular acceptance of them. Society easily normalizes the use of tools without necessity, signifying ownership designates choice and economic accessibility. When a tool is employed as the necessary means of conveyance or functioning, it becomes stigmatized.

I have seen classes at the university using wheelchairs for a day or going blindfolded. Again, the experience was far from disabling, even if impairing. While this type of playing disability might create opportunity for recognizing physical constraints or afford a fun diversion from the norm, the social stigma of a disabled status may be even more obscured by superficiality of pretended impairments and the assumption that frustrations about physical limitations are the central factors at play. The Vygotsian rehearsal of disabled roles will not create empathy. If anything, they may generate sympathy, or outrage about policies and access issues. Learning to perform disability is definitely taught, but in the same covert manner that other stigmatized roles are taught. Wearing the disability label involves self-concept, self-esteem, self-efficacy, and reflected appraisal stemming from the social discourses that address difference, impairment, and limitations of functioning. Artificially simulating the limitations of a physical impairment does not begin to create the overall experience of having a disability.

This study has reinforced the ideas of privilege and its dynamics in relation to differences. The privileged characteristics created within our society include being White, male, “abled,” Christian, heterosexual, and “attractive.” The list is indefinite, including an impossible combination of what society hails as ideals. It is unlikely, if not impossible, that anyone meets all of the criteria for privilege. Everyone lives at some degree outside the realm of this ideal, the outside being a much larger collection of attributes—everyone not White, not male, not “abled,” not Christian, not heterosexual, and not “attractive.” It is this collection of outside, unprivileged characteristics that one is most likely to try to conceal to avoid stigma, feign homogeneity with the in-group, and gain privileges that these characteristics earn.

What is true of the set of characteristics that are privileged? They are arbitrary. Privileged characteristics change with the context and era when they are expressed. The waif-like models of the recent turn of the century would not be nearly as appealing at the turn of the previous century. Within a homogenous group, sharing features from either outside or inside the set of privileges the traditional, patriarchal, white discourse creates, the shared characteristics will become the privileged characteristics within that particular group. In this way, individuals are assimilated into an identity, and that identity has the potential to be resignified with new labels created to express affiliations (Stocker, 2001).

This is clearly seen within subcultures and ethnic groups, who learn to value their group identity more than they fear the results of prejudicial discourses. Within hereditary communities, this is not surprising. Familial identities are central to self-concept; so, traditions, religion, ethnicity, and other acculturated characteristics may not be hidden. It is, however, interesting to note that non-hereditary communities may create valued group identities as well. Homosexuality, acquired differences, and societal assimilation, all of which have no familial connection, may

become central to a positive self-concept, regardless of discourse. This does come at a cost of privilege and acceptance, because of transgressing the norm. Individuals with disabilities within “normal” society may have good reason to conceal their disabilities in the face of possible stigmatization; however, when within a homogenous community, may value their difference and attribute their identity to that difference. For example, a strong deaf culture has emerged in American society, which departs from the medical and impairment models of disability. Within the deaf community, deafness becomes as salient as ethnicity or gender in positive identity formation. The same is true of individuals with dwarfism, who may also identify as a community rather than victims of an impairment.

When we think of these individuals in terms of marginalization, we must come to realize that laws and political reforms will not help them become functional participants in society in a true sense. At most, it may reinforce tolerance and accommodation, but it will not result in acceptance of them as they are. Melting-pot philosophies have created the assumption that assimilation will foster acceptance, but assimilation involves changing them to meet the preexisting social values and, in essence, preserving the marginalization and stigma. Of course, changing social values, developing a much wider array of valued characteristics is much more difficult. Suggesting reweaving the social fabric of society and its hegemonic reinforcement of traditions is much easier than facilitating the process. Nicki (2001) writes:

The case of psychiatric disability is complex because a variety of beliefs inform a social understanding of mental illness and thus attitudes toward those who are mentally ill: that mentally ill people are irrational and dominated by emotion; that emotion lacks directive, cognitive content and is inferior to calm reason; and that negative behavioral or ideational components of mental illness can be easily suppressed or overcome. Also, norms of mental health are different for men and women. For instance, a woman who displays aggression and ambition, and is not feminine, risks being labeled "mentally ill" or, if genuinely mentally ill, having her illness seen purely in terms of her transgression against her gender. Cultural concepts of irrationality and sexist norms of mental health marginalize people with mental illnesses in attacking their personhood. (p. 81)

Public schools and colleges have taken divergent routes in the provision of accommodations (Kincaid, 1997; Sitlington, Clark, & Kolstoe, 2000). While public schools have tried to remove the categories of classification and to focus more on curriculum-based assessments, colleges tend more toward making categories more specific and relying on standardized achievement tests.

Outright attacks, such as negative attributions and labels, seem to be common. Caroline describes her father’s calling her names. She explains, “He’d call me ‘fat ass’ and ‘ugly.’” Calvin echoes her with, “People called me queer and faggot and sissy and stuff....” Other labels denigrated the participants by relegating them to the status of someone to be pitied. Robin explains, “I’ll always be ‘Poor Little Robin’ to them, like I am stupid or something.” Robin also explains, “Disabled people are disabled. Something is wrong with them.” Caroline echoes this sentiment, when she addresses the term disability as applied to learning disabilities:

I think learning disabilities should have another name instead of disabilities. People get the wrong picture. I mean, I picture totally the wrong thing when I hear the word

disability. Disabled people can't get around and do stuff like I can. I mean, I'm just a little slow in math, but I can still do stuff. My stomach problem, now that's a disability.

The definition of disability seems to be a salient issue. While some distance themselves from the label, others argue to include themselves, even if privately. Calvin redefines disability:

You might think I'm not disabled because I can do most of the stuff I used to, but I am because of what I go through. I'm not so much sick right now, but I know it's coming, and I'm contagious. I have to be careful not to get sick, since it may be hard for me to get well again.

For Calvin, impending disability is disability. He has been limited by a need to be cautious to prevent the onset of physical limitations, not the immediate conditions he now experiences. Even successful prevention brings him closer to a day when his immune system will fail. Yet, Calvin seems to be relieved that he does know about his illness.

A diagnosis often results in a huge relief for an adult who realizes that deficits are a result of a real condition and not simply failure or inept behaviors (Rocco, 2001). The inability to justify deficits, inabilities, and "nonstandard" behaviors further marks an individual by creating negative assumptions in others. When differences cannot be explained with a simple diagnosis, an individual may become suspect. Adam writes:

I have several problems that have been diagnosed by professionals and a few others that I have noticed myself over the years. Each one is difficult to deal with on its own, but the combination seems to be worse than the sum of the parts. These include affective disorders, vision problems, a central auditory processing disorder, social anxiety, a skin disorder, and various other health related issues. [...] I can't really refer to my disability because it is a unique combination of things. This has made it virtually impossible to give it a label. If I try to name any one thing, then it doesn't seem to be severe enough to warrant any special attention because it is so common and so many people seem to either adapt well or respond to treatment which I often cannot even afford. [...] I often refer to my disability as "problems", because I have a combination of disorders and I normally discuss them one at a time.

By addressing his differences as "problems," not "disabilities," Adam loses justification for his perceived deficits. In a sense, disability labels position many individuals into a similar situation. A medical diagnosis, as discussed earlier, does not fully illuminate a person's life experiences and social issues.

Not only do individuals have a variety of differences, which create a cumulative experience, but they also experience temporal changes. Many types of illnesses, impairments, and disorders limit functioning at different levels at different times. Elizabeth explains:

There have been times when I would get in my car and feel okay and then I would go to a class, and I could not get out of the car the pain would be so bad or I would be in the middle of a meeting or a church service and have to get up and leave because I could not sit for the length of it. I hesitate to put myself in that situation so I lead a very lonely life. I won't want people to see me that way or to, its degrading enough to be that way without

on top of it having feelings of insecurity in front of crowds of falling or not being able to get up out of your seat or not being able to sit back down or not being able to take a step without hesitation. And I never know where those moments are going to be with this illness, its just so debilitating.

Elizabeth prefers to hide herself during periods of high dysfunction at the high cost of loneliness. Social isolation serves to protect her social standing—a dynamic that makes little sense. It is not clear what is gained when interpersonal relationships are forfeited.

Societal definitions of disability and the labels that accompany them grow directly from political agendas. Society believes it cannot provide for all people who do not work, and thus it must devise a plan to limit the number of individuals considered worthy of accommodation. This differentiation forces the creation of an arbitrary line dividing disabled and abled, or more precisely unable to work and lazy. Both designations bringing with it oppressive labels and stigma. Lane (2002) writes:

In the United States at present, we designate some forms of human variation as functional limitation arising from an impairment—therefore, a disability—whereas we consider other forms of human variation normal and not a disability at all. Thus we accept as normal human variation—and not disability—wide differences among people in height, but we consider very short people to have a disability; we accept differences in weight as normal, but gross obesity is a disability; we accept differences in skin color as normal variation, but we consider albinos to have a disability. Differing degrees of alcohol consumption are not a disability, but alcoholism is. We all learn at different rates—that's normal human variation—but mental retardation is a disability. The following are not considered disabilities in the United States today: baldness, nearsightedness, halitosis, and addiction to cigarettes. Mood variation is normal, but we consider mania and depression as mental illnesses. An addiction to pipe smoking is not a disability, but an addiction to crack smoking is. Not only is it hard to tell disabilities from normal variation, but today's disability may be tomorrow's normal variation and vice versa. Alcoholism has gone from moral flaw to disability. Homosexuality from moral flaw to disability to minority rights. Child abuse from moral flaw to disability. Mild mental retardation from normal human variation to disability. (p.359)

Attributions toward individuals with disabilities

The exact definition of disability cannot be easily pinpointed, even within a context. It is no surprise that individuals with disabilities so quickly dismiss membership in a disabled community. Apart from the forfeited empowerment that dismissing a group identity fosters, onlookers must recognize that, at the least, disability is broad term. One critic writes:

Similar to the label "woman," the term "disabled" cannot easily be accepted as a self-evident phrase referring to a discrete group of particular people with certain similar essential qualities. "We" is a particularly unstable term when speaking of disability; it is very difficult to decide definitively whom the term does and does not include. Should it encompass all kinds of impairments—cognitive, psychiatric, sensory, and physical? Do

people with chronic illnesses fit under the rubric of disability? Is an asymptomatic HIV+ person disabled? What about people with some forms of multiple sclerosis (MS) who experience different temporary impairments—from vision loss to mobility difficulties—during each recurrence of the disease, but are without functional limitations once the MS moves back into remission? Or people with large birthmarks or other visible differences that have no bearing on their physical capabilities, but that often prompt discriminatory treatment? Government and non-governmental organizations alike frequently issue definitions of who is disabled and thus eligible for certain programs and protections. Such groups, ranging from the World Health Organization to the U.S. Social Security Administration, would not have to be so precise in defining "disability" if such definitions were without controversy; the very fact that so much energy is funneled into defining disability and impairment suggests the fundamental instability of the terms. If it is this difficult to ascertain who is "disabled," then it is likely equally difficult to determine who is "nondisabled" or "able-bodied." (Kafer, 2003, p.78)

Beliefs about oneself, others, and the world can be central to how one copes with disability or difference (Boswell, Knight, & Hamer, 2001). Not everyone copes. All individuals suffer through existential factors, such as illness, pain, and inability. When these conditions take on a pervasive and impairing degree of expression, they can intrude upon personal identity and self-concept. While some individuals remain autonomous, resignation to the stereotypes and failure has been the option for many. Having liberating, positive beliefs about oneself may be difficult when confronted with negative stereotypes. As Boler (1999) writes, "Some perspectives, particularly those I feel are reiterated throughout the dominant culture in harmful ways, are difficult, even dangerous for me to hear" (p.179).

Most participants noted a discomfort around individuals with disabilities and unwillingness to categorize themselves with these individuals. Individuals with disabilities often assure others that they do not think of themselves as disabled; our culture offers powerful incentives to hide and negate any disabled identity (Thomson, 2002). Historically, such an identification represented dependence on charity, legitimate claim to alms, and earned pity as a victim of undeserved impairment (Iezzoni, 2000). Of course, some of our discourse has suggested that disability is just reward for moral shortcomings. Caroline explains:

When I think of disability, I guess I picture people with wheelchairs or hooks for hands or blind or something. Things that are easy to notice. I don't really think of sickness or having a hard time in math or writing. My first memories of people with disabilities was when I was a kid, and there was this black guy that sat on the old safe outside the drugstore every day. He had only one leg, and he'd ask people coming out of the store if they could spare change. When he got enough together, he'd go in and buy alcohol. I didn't like him. If you didn't give him change, he'd harass you, call you names and stuff. I guess I grew up thinking about beggars when I thought of disabled people, like that old man. My granddad got Alzheimer's disease, but that was after he retired from the plant and had his stroke. We tried to keep him with my family for a few years, but he got so far gone he had to be put in a nursing home. One day he wrestled Mom in the kitchen floor and liked to have killed her. Who knows who he thought he was fighting or why.

A prevalent disassociation with other individuals with disabilities prevents an idea of group identity and perpetuates the desire to conceal a disability label. A person's identity is a social construct, created mostly from our assumptions of what others see in us (Mruk, 1995). And, of course, how we frame a group has everything to do with how it will be described. Calvin sums up a problem with asking what someone "pictures" when they think of disability:

I get in my mind crutches and canes and wheelchairs and things like that, but that's just because those are things I can see. If you tell somebody to picture something, they going to describe something they can see.

Disassociation of others with characteristics an individual devalues, would make esteem maintenance an easier task (Nosek & Hughes, 2001). A number of individuals with disabilities demonstrated a tendency to present themselves as exceptions, unlike the others with more stereotypical positions. Kevin explains:

I never really like hung out with or acquainted myself with any other handicapped people. I have seen others and I have met a kid before who had a weaker version of my condition, and I talked to him a little bit just to tell him like its okay and everything, but other than that I don't really associate with other handicapped people. And when I do see them, it's just different. Of course I look too, because I am curious at what they have and how they do things too like anybody else so it's not like I feel on the same level or on different level them. I just don't seek them out. [...] Like if somebody is trying to help me too much if they think I can hardly do anything like I am kind of, "I can do this! Can you chill out a little bit? Yeah." So, don't go to extremes. People in wheelchairs experience people talking slower or doing things like that a lot. It's unusual, people talking louder or talking slower, but that is, then again that is more extreme disabilities. They've done that to me before, but like I say, not so much as with people who are in wheelchairs and such. [...] I would not say they say anything to me, but sometimes they look at me like I might have lower intelligence or something like that. I don't think some people expect me to be so smart sometimes and do act in a way like I am not sometimes so.[...] Sometimes I get angry. Like I am looked at too differently with that and like they don't understand and they are trying to make their own assumptions it's kind of aggravating.

Perhaps, this is common to any stigmatized identity. Individuals may acknowledge stereotypes regarding any group to which they belong, and believe themselves to be the anomaly, the individuals who have somehow escaped the stigmatized roles exhibited by the group. In-group trends, which emerge in any subculture, may help to establish these stereotypical assumptions, creating associations with the group and particular styles, behaviors, and attitudes. Thomson (2002) writes:

By disavowing disability identity, many of us learned to save ourselves from devaluation by a complicity that perpetuates oppressive notions about ostensibly real disabled people. Thus, together we help make the alternatively menacing and pathetic cultural figures who rattle tin cups or rave on street corners, ones we with impairments often flee from more surely than those who imagine themselves as nondisabled. (p.22)

This type of thinking leads to denial of diversity and hegemonic rationalizations for the continued oppression of these groups. If, as participants suggested, the stereotypes of individuals with disabilities include perpetual anger, hopelessness, complaining dispositions, negativity, and unwillingness to work with others, acceptance of these stereotypes will result in continued justifications for oppressive attitudes. Of course, empathizing with others with disabilities may be difficult, since perceptions and understanding of life events may be quite different in each individual (Clegg & Lansdall-Welfare, 2003).

Robin describes her perceptions of herself as unique, and in spite of her own disability, employs stereotypical attributions in her understanding of others with disabilities. She says:

Most disabled people just sit around and do nothing and collect welfare or disability. I'm making something of myself. [...]. Most of them just hang around waiting for other people to do things for them. It pisses me off when I see people with disabilities begging for money and stuff, instead of just doing what they need to get along. It's not fair to be born with a disability, but, if you are, you might as well just deal with it and move on. Everybody has something wrong with them, you know. I have pain and learning problems, but I get up and go to school whether I feel like it or not. And, I have to study longer than other people and all, but I just do it. If I sat at home and complained all the time, I'd never get anywhere.

This interesting projection of negative appraisals hinges on the assumption that others do not have a degree of impairment that would make success more difficult or impossible for them to attain by perseverance. Calvin reports similar attitudes. He discusses individuals with disabilities that he feels are not meeting their responsibilities:

Some people just sorry, and they use problems for an excuse. They act helpless to get out of work and doing stuff. Most disabled people just like everyone else, good days and bad days, sometimes feeling good and some days laid up in bed or dragging. [...] Now, I can't tolerate sorry-assed people who don't try to take care of themselves. You don't have to be disabled to be nasty though. There's a guy that walks around downtown here all the time, got some nasty dreds and smells ripe all the time, like something dead. I can't stand that, ashy skin and rotten breath. People have to take care of themselves. I don't care what's wrong with them. I can tell that guy has something mental wrong with him, but that's no excuse for filthiness. If he can't take care of himself, somebody needs to step in and help with it, the government or family or something. Doesn't social services or somebody do that, check up on people like that? That has to be a health hazard or something. I don't want to walk into that.

Hygiene seems especially salient for Calvin, who has difficulty understanding why anyone would forego the level of cleanliness he expects from himself and others. He mentions mental illness as an invalid excuse for these behaviors. Personal health concerns may also motivate some of his attitudes about hygiene. Still, he humanizes others with disabilities, stating:

I don't know anybody that don't got something wrong with them. Hey, we take care of each other. That's what family is. You take care of your friends and your family. If they can't do something, you just got to do it for them and then they can do something else. I

don't feel sorry for people, because we all got our own problems. No, I don't feel bad about them or nothing. I don't feel sorry for myself either.

Recognition of the value of affiliation with others who have disabilities was rare among the participants. Most preferred to dissociate. Adam writes:

If someone has a similar problem, it seems to benefit me to talk to them about it. I feel better about the whole thing in a sadistic sort of way; because it sometimes seems comforting to know that others are suffering too.

Perhaps, presented in a dark manner, Adam voices a need for affiliation and verification that he is not unique or unusual in his experiences. Whether we think of this as catharsis or identity management, the obvious contribution to self-esteem is obvious.

Another theme that emerged involved reported advantages to having a disability. This is often discounted from a traditional perspective. Still, participants voiced what they perceived to be positive outcomes of having a disability. Of course, some of these statements may be rationalizations, but that does not diminish the power of these statements as they disrupt the hegemony that establishes our traditional perspective. Approaching disability as a form of transgressive power allows us to deconstruct the paradigm of disability as tragedy, and it opens up the possibility of seeing disability as a difference with potential to transcend or revise cultural norms (LaCom, 2002). Kevin describes advantages of his condition:

Some people ask do you wish you would normal, that is what sometimes, its like what way do you mean normal you have to ask them. But I always say no. I don't think, if I think it happened earlier that I got changed over like my disability was gone, I don't think I would have become the same person I am today. I think a lot of things I developed are because of my handicap. Like I have a good imagination, and my ability to, I am good with advice and stuff. When I was little I used to watch, like because I could not participate in those activities, sometimes I would just watch people interact and that is kind of why I want to be a psychologist is because I like watching other people and seeing how they do things so. I think if I wasn't some of those aspects of my life would be different.

Calvin adds, "Sounds messed up, but HIV made me more in control. It made me grow up and settle down some. Taught me to enjoy stuff. It helped me to make real friends." In a sense, Calvin describes a spiritual awakening, a learned ability to appreciate life and examine values. This, of course, has come at a great cost and with a variety of doubts and fears. Even Kevin's successes were accompanied by doubts. His concerns about functioning ended up being unnecessary, but they were anxiety provoking. He explains:

I have had to learn to do a lot of stuff like putting on clothes, and I don't think I could have done so well in college with a lot of that. Actually, I was pretty stressed out during the summer trying to get everything ready, so I knew how to do stuff when I got here, so I would not have any real problem, and I had to figure things out like buttoning my pants. I could not do that too well. So, I would get a belt and tighten it over so it looked like it was buttoned, and I didn't really have any problem with that. I could zip it up ok. It's just

I think if I was hindered a little bit more it could cause a little bit more problem with getting around and things like that. I think I still would have been as social later on, but still it might have been harder. If like I was a lot worse off, I might not have believed a girl could really like me. I have been alone a lot more, not because people wouldn't hang out, but because I'd think they must not really want to. But, I probably do about as well as anybody really as far as college goes.

In many ways, Kevin, with his visible and extreme appearing disability, is much less impaired than others with no visible signs. Kevin has no pain, no on-going treatment, and no skepticism from others. Elizabeth, on the other hand, fits the societal expectations for a healthy appearance, but has profound limitations. She explains:

I have a whole lot of pain all over my body especially my legs and arms. I have suffered from severe depression because of my physical pain and not being able to do things that I used to do or want to do. I pretty much lived a life full of pain.

She continues describing how her pain limits her ability to function:

I have trouble just living normally at times. That is really bad because I like to keep a clean home, and I like to do the things I have always done with cleaning, and it's really hard, and I get really upset because I can't do everything that I want to do. I can't keep it the way I used to keep it, and it gets on my nerves, and I get really sick, and I don't want to ask for help and things starting piling up and then it's really hard to get things back in order. And it brings me down mentally and physically at that point.

Personal reports of how disability affects oneself may not conform to the societal expectations that may be imposed on an individual. Appearances may not reveal the degree of discomfort or difficulty faced by an individual. This must be considered when assumptions are made about a student's ability to perform in particular ways in the classroom, especially since instructors may not know the degree of disability and difficulty that may be concealed. School creates a situation where individuals with disabilities may be forced to push themselves to a degree of self harm and suffering. Elizabeth talks about the mental and physical outcomes of "living normally" with her pain. Robin also describes a similar type of situation, which resulted in an epileptic seizure. She explains:

I have pushed myself too hard in the past. I had a seizure driving once. I'd been pulling all-nighters trying to finish some designs for a class. I just got too tired and wasn't eating right. It'll be two more years before I'm eligible for a license again, but I've moved onto the bus route and have gotten used to it.

The limitations faced by individuals with disabilities are not always the direct result of the diagnosed disability. Caroline illustrates this as she describes her experiences in a variety of contexts, and it becomes clear that what impairs her is stigma and the social anxiety it provokes. In similar manner, Adam writes about what would be different, if he didn't have his problems:

I think that I would have a lot more friends and be involved in more social activities. I would not be as ashamed or afraid of social situations because there would be no

impediments to successful communication or things to hide. Then again, the damage may have already be done and I might be unable to escape from old habits.

When negative existential factors such as impairment, illness, and inability occur, the overall attitude behind how these events are explained can have a major influence on the quality of a person's life (Seligman, 1990). A belief that these events are circumstantial anomalies that can be overcome or accommodated with a reasonable amount of effort will promote a healthier general attitude. It is perhaps for this reason that students that do not have learning disability have fewer problems adjusting to college than their peers who have a learning disability (Reiff, Hatzes, Bramel, & Gibbon, 2001). On average, along with categories of ethnicity, sex, and socioeconomic status, students with disabilities rank with those at highest risk for academic failure (Lehr & Lange, 2003). As Elizabeth reports:

School has been especially hard because for one thing my pain is distracting, and I can't really go to class taking the medication I need to keep the pain away. And then I have always had this problem of being distracted very easily. I think I have had to deal with Attention Deficient Disorder plus my physical pain. And those two together are not a good combination when you are trying to get something in class that will enable you to have a better life as far as maybe being able to do some kind of work or maintain your future. And there is always that hope inside you that you may improve, if you lose that, you really have nothing. So you depend on what you learn and what you remember, and it's been very, very difficult because there are a lot of distractions for people like me in the classroom.

Caroline describes her thoughts about a man with achondroplasia:

I'm not nasty minded or anything, but I wonder how a person that small can get up on a toilet or wash their hands. A toilet would be up to this guys neck, and they put in these taller commodes for people with disabilities. He'd have to bring a stepstool or something. I'm a short woman, and I feel funny sitting on the tall toilets they have these days, since I can barely reach the ground. How does a guy half my height manage? [...] I wonder about how disabled people get along. There are a lot of places on this campus where people with disabilities just can't get to. One of my teachers is at the top of a lot of flights of stairs, and there is no elevator. Even people who can walk get pooped trying too climb them if they are healthy. Sometimes when my stomach is cramping, I don't think I can make it.

Even though most adults with disabilities could be successful in postsecondary level courses and could be gainfully employed with such training, many opt to reject opportunities to pursue these goals because of problems conforming to public school teaching methods, low self-esteem, undiagnosed learning disabilities, assumptions made by others about their abilities, and failure of the postsecondary institution to create a welcoming environment for those potential students (Gadbow & DuBois, 1998).

Taking into consideration the attributions projected onto individuals with disabilities, even from other individuals with disabilities, faculty and staff must recognize the fact that the degree of impairment, difficulty, and pain experienced by others may not be observable. The

baseball cap hiding pattern baldness may be concealing something much more salient and distressing than the wig that hides hair loss from cancer treatments. We cannot know, and our assumptions simply serve to impose personal values and beliefs.

Social expectations and treatment

An unexpected theme that emerged involved deep-seated resentment toward individuals who believe they are being conscientious when they repeatedly draw attention to disability. Many participants described a sense of dread when these altruistic individuals approached them, anxious to talk about the disability, offer help that is not needed, or awkwardly ignore the disability in a manner that makes them and individuals with disabilities uncomfortable. Impairments that individuals may have become aware of or easily notice may be impairments that individuals with disabilities are attempting to conceal. Attention and recognition regarding the impairment may be distressing for an individual:

The disabled body is a body whose variations or transformations have rendered it out of sync with its environment, both the physical and attitudinal environments. In other words, the body becomes disabled when it is incongruent both in space and in the milieu of expectations. (Thomson, 2002, p.20)

As disability transgresses social expectations for “normalcy,” it asserts a new set of expectations and discourse that can be just as constricting. Beliefs about disability may relegate individuals into roles that are not their only options because of physical or mental limitation, but instead impositions of social constructs and hegemony. Bhabha (1994) describes the manner in which this is maintained and reinforced in society, writing, “The work of hegemony is itself the process of iteration and differentiation [and] depends on the production of alternative or antagonistic images that are always produced side by side and in competition with each other” (p.29). This being true, concealment or other types of refusal to adhere to expectations may place individuals in dually stigmatized positions –dependent and adversarial. Recognizing this fact, may help individuals to understand the reticence of individuals with differences to encourage or enjoy gestures of kindness or acceptance that draws attention to their disabilities.

Understanding and sensitivity involves listening and watching for the cues, which others offer. Common courtesy generally seems to be appreciated –holding a door, facing individuals when talking to them, helping individuals pick up dropped items, not shoving or crowding, and other friendly gestures. There may be times when individuals with disabilities may show anger or resentment, but participants seemed to agree that courteous behavior that would be extended to anyone should be used without exception. Of course, many resentful or unappreciative responses probably grow from a belief that someone is being patronizing or highlighting their impairments as a form of control, especially in situations where these individuals feel aware of audience or conscious of an impairment they are trying to conceal or downplay. These individuals may never realize that a friendly, helping behavior is not solely offered to individuals with disabilities.

Identification as one who is different, remains a threat, even when the identifier attempts to aid or support the individual with differences in a discreet manner. Altruism is often greeted with a degree of suspicion. This is not surprising in light of our history:

Women, people with disabilities or appearance impairments, ethnic Others, gays and lesbians, and people of color are variously the objects of infanticide, selective abortion, eugenic programs, hate crimes, mercy killings, assisted suicide, lynching, bride burning, honor killings, forced conversion, coercive rehabilitation, domestic violence, genocide, normalizing surgical procedures, racial profiling, and neglect. All these discriminatory practices are legitimized by systems of representation, by collective cultural stories that shape the material world, underwrite exclusionary attitudes, inform human relations, and mold our senses of who we are. (Thomson, 2002, p.9)

Clare (2001) enumerates these types of encounters with societal norms:

Rebecca Wight, a lesbian, shot and killed as she hiked the Appalachian Trail with her lover. James Byrd Jr., an African American, dragged to death behind a pickup driven by white men. Tyra Hunter, a transgendered person living as a woman, left to bleed to death on the streets of D.C. because the EMT crew discovered she had a penis and stopped their work. Tracy Latimer, a twelve-year-old girl with severe cerebral palsy, killed by her father, who said he did it only to end her unbearable suffering. Bodies stolen for good. Other bodies live on--numb, abandoned, full of self-hate, trauma, grief, aftershock. The pernicious stereotypes, lies, and false images can haunt a body, stealing it away as surely as bullets do. (p.362)

Society has a tendency to attribute stereotypical characteristics to individuals identified as having a disability. With these stereotypes comes the attitudes, fears, and hates that infect society's understanding of diversity and difference. In a study by Schwartz (1988), students were asked to rate the intelligence and ability of individuals based on their photographs. When the individuals in the photographs were identified as "disabled," the students rated their intelligence and ability levels much lower than when they were identified as "abled." Assumptions cloud our discourse when we consider disability:

The dominant paradigms of disability –the medical, charity, supercrip, and moral models– all turn disability into problems faced by individual people, locate those problems in our bodies, and define those bodies as wrong. The medical model insists on disability as a disease or condition that is curable and/or treatable. The charity model declares disability to be a tragedy, a misfortune, that must be tempered or erased by generous giving. The supercrip model frames disability as a challenge to overcome and disabled people as superheroes just for living our daily lives. The moral model transforms disability into a sign of moral weakness. (Clare, 2001, pp.359-360)

These assumptions may dismiss or deny the impact of a disability on others. These assumptions present the individual with disabilities as someone who just refuses to work –someone who is lazy, manipulative, or freeloading. This can be especially true of disabilities that are not obvious. In the case of psychological disorders:

Those who have no familiarity with the world of psychiatric disability may not only be dismissive of explanations of psychiatric illness, not seeing it as real illness, but outright hostile toward these explanations, seeing an afflicted person as emotionally immature, self-centred and self-indulgent (focusing too much on her own problems), attention-seeking, or morally or spiritually weak (not able to cope with life). Of course a mentally ill person could be all these things, but such traits do not in themselves inform or reveal mental illness. There is no inherent correlation between these features and mental illness. A person who tells others she is suffering from a mental illness such as depression may be told, like a person suffering from a physical illness, that it is "all in her mind." (Nicki, 2001, pp.93-94)

This proves to be true among participants in this study. Adam complains, "In general, people don't know that I have problems, so they assume that manifestations of my disability are just examples of me being an idiot." He thinks that others are assuming he is incompetent, not disabled. Elizabeth has similar issues. She explains:

I feel like people expect things of me because I look like I can do them, and when I say that I can't or I don't or I don't have, I don't feel like it, it has, it really makes me feel bad about myself because I feel like they see me as very selfish or self centered person who just doesn't want to help others or doesn't want to socialize or anything like that. It makes me feel bad about myself, feel worse about myself.

Elizabeth finds herself in a position to either disclose her disability or leave her inabilities unexplained. Either way, she becomes stigmatized. She is left feeling like she has been judged as incompetent, unfriendly, or selfish.

Outcomes

Participants demonstrated a variety of outcomes of impairments or differences that may cause an individual to identify as a person with a disability. Some of the outcomes of these impairments and differences included affective disturbances and disorders, awareness of a condition that may lead to decisions about identity and ability, contexts which lead to concealment or disclosure, limitations, advantages, stigma, and shame. Of course, these responses to situations brought about by a condition they have chosen to label as a disability, are only a sampling of the possibilities. Still, the reoccurrence of them among the participants in this study suggest some significance among this particular set.

Ultimately, the question of how and when a label was assigned must be followed by an inquiry into what that has meant for the person labeled. Many of the experiences listed above could as easily fit into this category as well, but for the purpose of this study I have decided to categorize them with experiences that might have led to these outcomes. The dynamics are much more complex and an assumption of causality is tentative at best. Still, the twofold nature of many of these themes acknowledged, I have chosen to simplify the presentation of them.

Anxiety and depression

All of the participants addressed anxiety and depression. Situational mood change accounted for many of the symptoms of anxiety and depression among the participants. Concealment of disabilities served to increase the amount of stress (and sometimes distress) many of them felt. Sometimes the anxiety grew directly from questions of ability or acceptance. Depression, as a counterpart, resulted from ostracism and low self-esteem. This was true with Kevin, whose depression grew out of experiences related to his disability. He notes, "I really started going down the end of fifth grade and didn't come back out. I was in like kind of a depression set mood until around ninth or tenth grade or so."

People suffering from clinical depression risk becoming more depressed because of the hostile and confused attitudes of others regarding their illnesses. Those who insist that people suffering from depression be cheerful ignore the reality that depression, for those afflicted, is an undesirable state of unwelcome thoughts and doubts that fill every corner of the mind--the thought of death the worst intruder. If those afflicted could so easily overcome their conditions, they would. (Nicki, 2001, p.95)

Social fears have a powerful influence on individuals with disabilities. In fact, among chronically-ill individuals with depression or anxiety, the depression or anxiety often predated the illnesses (Cohen & Rodriguez, 1995). Depression and anxiety have been shown to have a causal relationship with susceptibility to illness (Anda et al., 1993; Frasure-Smith, Lesperance, & Talajik, 1995; Williams, 1993). Of course, individuals with disabilities who have higher motivation to conceal their disabilities may be more apt to experience anxiety and depression. This is especially salient among this group because there is a tendency to feel anxious because of the motivation to impress others juxtaposed against doubts about the ability to do so (Leary & Kowalksi, 1995; Schlenker & Leary, 1982, 1985). Unfortunately, research has suggested that anxiety over creating a good impression generally results in behaviors that create a negative impression (Meleshko & Alden, 1993). This may grow from the fact that individuals with self doubts, who behave in a shy or socially anxious manner, have a strong tendency to view incidental events as relevant to themselves (Fenigstein & Venable, 1992). Therefore, individuals with disabilities may appear incredibly sensitive about any behavior that could be construed as condescending. This can grow from social anxiety and the fear of social rejection, rather than feeling offended. The outward projection of anger or frustration may in fact result from a need for acceptance and worry about how others think about them (Asendorpf, 1987). It is interesting to note that, once these individuals allow individuals behind their facades, they tend to develop more intimate and long-lasting relationships (Paulhus & Morgan, 1997; Shepperd, Arkin, & Slaughter, 1995).

Some participants share stories of situations where social anxiety limited their ability to function. Caroline talks about the effects of nervousness on her classroom participation. She shares, "I know when I'd have to be in front of the class in college I'd get sick and have to run to the bathroom. Anything that makes me nervous." Like Caroline, Elizabeth has also experienced debilitating social anxiety. She explains:

I know once I was asked to work a problem at the board in front of the class, and I could not, my mind was just going here, there and everywhere, and I was having a lot of physical pain. And I got up to the board, and I got so nervous that I actually thought I was going to faint. It was just such a bad experience in front of the class that I never went back to that class again. I just could not make myself go in there again, I could not face the professor, I could not face the other students, I did not want to have eye contact with them when I saw them on campus or anything, and I just dropped the class. It just absolutely, I had to go to my counselor, and I had to talk to her about it. And I just hesitated after that to put myself in a situation where I had to stand before a class or anything again, and that has really, really hampered my education.

Not all symptoms of anxiety and depression resulted from situations. Ryan, Caroline, and Elizabeth all have been diagnosed with clinical anxiety. Caroline goes into detail about her diagnosis and treatment. She even discusses her fear that treatment would jeopardize her ability to avoid potentially embarrassing behaviors. She explains:

The doctor told me they use Paxil for Social Anxiety, and he wanted to switch me to that, but I wouldn't let him. I was afraid that I'd take it and not have common and make a fool of myself. I don't want to be nervous in public, but if I didn't care I might be a, make a real spectacle of myself. I don't know.

As in the discussion of experiences with staring, fear of appraisal motivates self-protective behaviors. In this case, Caroline gives up medicinal interventions instead of accommodations. The resulting limitations are similar. She also suffers through continued situational anxiety and depression. She discusses her experience in high school:

I got diagnosed with depression in high school. They sent me to the school nurse and to a counselor because I was down all the time and started losing a lot of weight because I wasn't eating. My English teacher thought I was suicidal because of some poems I turned in too, and she had called my parents to see if everything was okay at home. And, everyone got all worked up, which did make me feel suicidal, but I'd never hurt myself. I'm too big a coward.

Ryan contacted me several weeks after our interview. He reported that during the break he had been hospitalized after a suicide attempt brought on by depression and anxiety. He seemed to feel that his volatile emotions stemmed from a disorder rather than situational stimuli.

The outcome of stress and distress, as well as depression, may result in more than self-harm. Self-efficacy may also be impaired. Depression may create feelings of helplessness and resignation. The influence of this on concealment and disclosure would depend on individual factors. On one hand, an individual may choose not to disclose a disability because he or she lacks the motivation to pursue accommodations and support. However, another individual may disclose because resignation to stigma and acceptance of stereotyped roles. In such cases, a fight or flight response to a challenging situation may be preferable to stoic resignation.

The interviews did illuminate a variety of responses to anxiety. While anxiety motivated Caroline and Elizabeth to give up, it served to encourage Kevin to grow and change in a positive manner. His response involved practicing skills and exercise. Caroline later explains:

Prozac helps a lot though. Without it I get a sick, empty feeling all the time. You know that feeling like you're ready to cry all the time. I still tear up sometimes when I am talking to somebody. It's embarrassing. Just suddenly I get flushed and my eyes are wet and red for no reason at all. I always do that when I talk to my teachers, which makes me feel like an idiot. Like I am ready to cry because I am having trouble with a homework or something. And he must be thinking I'm a mess.

Research has shown a correlation between test anxiety and disability (Swanson & Howell, 1996). Perhaps, the discourse associated with disability undermines the confidence of individuals who have been labeled.

Awareness of condition

Much of the writing and discussion about disability centers on visible conditions (Samuels, 2003). This leaves awareness of nonvisible conditions less salient and more difficult to achieve. Samuels (2003) goes on to explain:

[W]hile disability studies has presented profound challenges to dominant cultural conceptions of the body, social identity, and independence, it has not provided the theoretical basis on which to critique and transform the equation of appearance with ability. Instead, its focus on the visual continues to render nonvisible disabilities invisible while reinforcing the exact cultural reliance on visibility that oppresses all of us. (p.248)

We look for and understand visible difference in terms of situation. Nonvisible differences are more easily blamed on disposition, personality, and weakness. Caroline explains, "I just went crazy when they labeled me disabled. Even though it meant getting help, I felt like I was being made stupid." A person with a nonvisible disability may assume that his or her impairments speak to failures instead of circumstances. As Adam writes:

When I was in middle school, I was diagnosed with severe near sightedness. Until that time, I always attributed my lack of visual acuity to lack of skill, effort, or intelligence. I thought that those blurry shapes and blobs that I saw on the blackboard at school were perceived the same way by all students and that I was an idiot because I was the only one in class who had difficulty deciphering them. I learned coping strategies that fooled the teachers into thinking that I could see well. I would listen for clues and make predictions.[...] About six years ago I was diagnosed with depression, bipolar disorder, social anxiety, attention deficit disorder, and a number of other psychological problems. All of this was made possible when I became a full time student and gained access to free psychological and psychiatric services at the university. I am sure that these problems had a tremendous impact on my life since I was a child, however, the series of medications that I was prescribed was probably more disabling than the original symptoms of my disorders.

Adam had assumed that his inability to read what was on the board was a result of him being an “idiot” instead of him having vision problems. When differences are not visible, how do we know that over are not experiencing the same stimuli? How do we know that difficulties are due to a disorder and not a failure of some other sort? As adults, we may suspect an impairment sooner than Adam did as child, but it is not uncommon to hear someone exhorting an individual with clinical depression to just cheer up or an individual with a learning disability to just try harder. Elizabeth explains:

I would say it was probably in my 20’s when I realized I had problems. I know that I began feeling like I couldn’t do several things at one time and keep my mind on just one. A part of it had to do with pain in my body and the other part had to do with my mind. It seemed as though I had some kind of an attention disorder, I could not keep my mind on things for a very long period. [...]When I finally became so ill that I had to go to the doctor, the doctor to see about it. But by that time, I had gotten extremely run down and was suffering a great deal, and I still really am not sure exactly what causes all the pain. They labeled it as maybe some kind of polymyalgia or fibromyalgia. And it covers so many different things that its really hard to describe. [...]Being told by a doctor that I did have something wrong with me changed a lot of things. I just felt like that everybody wants to feel like they are whole and able to do things that other people do. But with me it seemed to be that my family didn’t understand or chose not to understand. It seemed to change things about me personally, I wanted to sort of withdraw away from everybody and just go within inside myself and keep away from other people and so forth. [...] It was an empowering moment, when I found out there was really something wrong with me other than thinking it was something in my mind because I had had friends and family who made me feel like I was making excuses not to do this or not to do that and that I wasn’t really ill. My happiest times are when I pretend like there is nothing wrong with me because I want to be able to do things other people do.

Even after diagnosis, Elizabeth’s family chooses to treat her as if she chooses or fabricates her problems. In fact, she fabricates her wellness and finds pleasure in her successes at doing so. Robin, manages her identity as well, when she assures others that she is “not dumb,” only different. She shares:

I have epilepsy, which has gotten better a lot since middle school. Medicine helps control it, but I am supposed to be careful about caffeine and alcohol and a few other things. I have to take care of myself though. I found out that I have what’s called polymyalgia. I get muscle pains and chill and feel tired and sick a lot. And, I also have dyslexia and a learning disability with math, but a lot of that is the dyslexia too. I had trouble learning to read, but I’m not dumb. My brain works different and words and numbers get jumbled. I do better with reading now, but numbers sometimes gives me big problems, especially in my major. But I’ve learned ways to check myself, and I just have to double check every little thing.

Her multiple disabilities, like Adam’s, has a cumulative effect, perhaps making her appear more impaired than a single diagnosis might suggest she should be. She developed a means to accommodate and diminish her differences. In the same manner, Kevin’s differences ceased to be fully accommodated as her grew older and changed. He reports:

Like I said, that [ninth or tenth grade] was when I first started noticing my disability more and started feeling sorry for myself because of it and started questioning like why me, why was I made this way and how other people would perceive me and everything like that, and I just worried so much.

His report changes as he thinks about the question. Later, Kevin adds:

I have to say around like three because my balance is off. I broke my arm a lot, my left arm, and I started noticing that I was a little bit more fragile than most and that I was different in the way I walked and stuff like that and my arms. It didn't hit that hard, but I just started noticing it then at three to four, when I first started walking.

And, later Kevin explains:

I was always aware of it, like when I first started thinking. I used to play with the other kids. I was always pretty much aware of it, but it didn't really hit home until probably like the beginning of elementary school when I had to play with other kids and they would be riding bikes and I could not. That is when I started noticing I was different from everybody else. But that didn't really hinder me so much until like middle school when I had to do, perform some social aspects like more so, like more advanced stuff. It really hit me then, but I have come to terms with it so.

Of course, memories are constructed, and perhaps at each of these times in his life he developed a greater acuity and understanding of his situation. His main issue is social, but he does address being physically fragile and broken bones at an early age. Still, he frames it by coming back to the social impact of his middle school years.

Calvin's experience with awareness sounds very much like stages of grief. He experiences shock, anger, sadness, and eventually some degree of acceptance. Along with his awareness comes recognition of the communicability of his condition. More than just announcing his own stigmatized position, disclosure entails telling some others of their vulnerability and potential exposure and infection from previous sexual encounters. Calvin describes these feelings after being diagnosed:

I didn't believe it at first, like no way, it can't happen to me. Then, I'm pissed off and depressed and mad at the world. Not much has changed though. It's not made me sicker than I might get without it yet. I don't know when I got it from him, but I'd not been with him two years and I got tested, unless I got it from someone else. The hard thing was telling other guys I been with I was sick. I thought they'd freak on me, but most got real quiet like and sad. They in shock like I was.

There is no real danger of contagion without intimate contact in Calvin's case. This does not prevent irrational fears and the resulting treatment, as with his roommate's father. It is likely that many individuals react to disabilities with nosophobia due to ignorance. Awareness of disability seems to be an awareness of other's awareness and attitudes. The primary feature of awareness for these participants was the resulting reflected appraisal of themselves. This

measure of self-worth perhaps begins to determine the degree and context of disclosure or concealment an individual will employ.

Contexts for concealment and disclosure

Sometimes a late disclosure is due to the student's fear of rejection or shame because of the stigma still attached to disability. Another cause for a late disclosure is students internalizing the common but incorrect belief that an accommodation provides an advantage rather than leveling the field. So they wait until the last minute to disclose, believing they should be able to learn without the accommodation. In a study of women with chronic illness, the women often chose not to disclose disability in order to gain accommodations, citing the suspicion and skepticism individuals with nonvisible disabilities must face (Jung, 2002). The instructor has an opportunity to explain to the student that this is not a wise strategy, after all, an accommodation allows access to learning materials and methods. A challenge for adult educators will be to lessen the stigma felt by a student who hesitates to disclose (Rocco, 2001).

Collins and Miller (1994) discovered two interesting correlations: Individuals are more likely to share private information with individuals they like, and individuals are more likely to feel more compassion for individuals to whom they have disclosed private information. It becomes a cycle of disclosure and growing closeness. The act of disclosure creates intimacy, self-esteem, and a positive outlook. In addition, the potential for extended and subsequent interaction becomes a catalyst for more disclosure (Shaffer, Pegalis, & Bazzini, 1996). This involves trust. Before individuals disclose, they need to feel assured that the information will not be used against them. Some individuals have a secure attachment style, and may disclose easily (Keelan, Dion, & Dion, 1998). However, the expectation for disclosure may create an impasse for some individuals with disabilities who fear stigmatization and rejection. Trust grows when another reciprocates with disclosures, which increases the degree of disclosure returned (L. C. Miller, 1990). Concealment is not surprising when taking into consideration the history of discourse regarding individuals with disabilities, the stigma still attached to them, and marginalization they must face from various sources.

Even highly visible forms of difference may be “concealed.” Society confuses the label of disability with impairments and conditions associated with disability. Disability is a social construct, centered around assumptions about identities of people with socially devalued differences. In the same way individuals may wonder how an effeminate man believes he can hide his sexual orientation, individuals get caught in the trap of wondering how an “obviously impaired” person can presume to hide an identity as one with a disability. Certainly, behavior and socialized roles may have an impact in either situation, but only ignorance would result in equating these characteristics with an identity. Of course, the body must play a role in identity:

Disability coming-out narratives raise questions about the body's role in identity by asking how markers so conspicuous as crutches, wheelchairs, hearing aids, guide dogs, white canes, or empty sleeves [can] be closeted. (Thomson, 2002, p.22)

Of course, one participant had a highly visible disability that he “concealed.” Kevin explains, “I would walk somewhere I would try to conceal my hands sometimes, like people

couldn't tell if they couldn't see my hands, but I finally got over that." He assumes that his disability is not as noticeable as other disabilities. Whether true or not, the belief itself promotes self-assurance and diminishes felt stigma. His presentation of himself as one who overcomes an adverse situation builds his self-esteem and makes any stigma directed toward him another opportunity to feel pride in his ability to survive and excel. This is in sharp contrast to Elizabeth, who explains:

I don't want anybody to feel sorry for me, and I desperately want to be looked at like other people, but in my heart I know I am not. And that is just the way I feel about it. I just, I want to appear to be normal, but yet I have to accept the consequences sometimes that if I appear to be normal I am going to be treated normal.

Disclosure may also be motivated by anger, distress, or trauma (Stiles, Shuster, & Harrigan, 1992). In an interesting manner, some individuals who stand to lose the most through disclosure may become more likely to disclose because of the distress concealment may cause. Research suggests that women have a greater tendency to disclose personal information than men are (Cunningham, 1981). However, men with egalitarian gender-role attitudes who reject patriarchal stereotypes tend to disclose in a manner similar to women. Perhaps, they too react to the oppression of nonconformity. Sandahl (2003) writes:

If one cannot pass as nondisabled, then one must at least represent one's impairment as absolutely impeding (charity case) or relatively inconsequential (overcomer). The charity case will be cured and therefore will be rid of the impairment, and the overcomer disregards the impairment by achieving in spite of it. (p.41)

As discussed earlier, temporal variability of symptoms causes problems. Society likes to categorize, and those who do not conform to a category become an anomaly, which society will not tolerate. Keeping this in mind, disclosure may not be an innocuous task. As Kafer (2003) writes:

Physical violence against people with disabilities has been widespread and has often operated under the auspices of the state. Recent public acknowledgements of forced sterilization programs in North Carolina and California have offered evidence of the ways in which disabled people have been violated in order to ensure the able-bodiedness of the citizen (an endless and ultimately futile task). (p. 79-80)

While overt violence in the form of childhood abuse and verbal abuse was reported, the participants did not disclose any ongoing violence. Perhaps, the most extreme stigma was reported from Calvin, who is obviously stigmatized and ostracized even by his significant others. He finished our interview with a warning:

Share on a need-to-know basis only. Telling helps nobody. Don't say a word, unless you just have to, to get what you need. And, most of all, don't act like your dead until you die. If you're going to die, have some dignity. Let people remember a brave and optimistic person, not a whiney complainer.

Adam echoes Calvin's warning. He sees no value in sharing. For him, it would only invite trouble. When asked about disclosing, he writes:

No, I never disclose my disability because I do not know of any benefit that they could provide by knowing this. It seems that if anything, it could do more harm than good since my problems are not obvious to other people.

Still, he does not withhold information about his condition when being asked, unless he believes the person to be a gossip or he just doesn't like them. Perhaps, this gives him a sense of security in that he may feel he is controlling the amount of information about himself that is spread.

Adam continues:

If someone asks, I will usually tell them, unless they are a notorious gossip or I just don't like them. [...] If someone has a similar problem, it seems to benefit me to talk to them about it. I feel better about the whole thing in a sadistic sort of way; because it sometimes seems comforting to know that others are suffering too.

The therapeutic value of sharing experiences does not escape Adam, however. Unfortunately, Erin, Calvin, and Adam seem to be the only participants who regularly discuss their disabilities with others who have a shared experience or invested positive interest. Of course, Calvin's experience has not been a totally positive one. He talks about his support group:

The support group tries to get us to tell more. Openness will help other people be educated and less afraid. They tell us that, but the leader doesn't have HIV, and she doesn't know what it's like already with a few people knowing. Rumors go around. A lot of people think they know. I don't want to be treated like a leper everywhere I go.[...] I only tell people now if they are really close or in danger of getting it. Otherwise, it's nobody's business. I know I won't risk giving it to anybody. [...] I conceal it any chance I can. I don't tell anybody that don't need to know. It would only make people treat me worse. I already get whispered about and stuff.

Calvin is aware of the stigma and dangers of further disclosure. He does, however, have a choice about disclosure—at least, he did initially. Rumor and gossip may have usurped some his ability to protect his privacy. The classroom does not always allow for discretion. Sometimes the situations students are put in highlight their differences. Robin discusses group work:

I hate classes where I have to work in groups, because when I'm not in a group nobody knows or cares how long I take to do my work. In groups I have to either admit I'm disabled or let them think I'm stupid.

Caroline echoes a fear of being thought of as less intelligent. For her, however, another impairment trumps her learning disability for potential stigma. It seems to diminish the concerns associated with a learning disability by contrast, illustrating the relativity of these stigmatizing conditions. She explains:

I don't tell people I have a learning disability or anything, but I don't care. I mean, I don't want people to think I'm retarded or anything, but it's other stuff, like my bathroom problems I keep secret. That's why I had to come back to school. I couldn't teach school and maybe have to leave my class and run to the bathroom whenever.

Elizabeth simply goes without services or accommodations, rather than sharing her disability status. While she wonders about the benefits she could receive, she prefers her privacy. She explains:

I have never really checked into accommodations because I have been one that has tried to hide my disabilities, and I have always wondered about it. I have always looked at other students who are really more handicapped than I am and wondered if there were things they knew about, but its really difficult for me to talk about my problems because I am a very private person.

Elizabeth's children enable her concealment. She sees this as respect for her privacy, but ulterior motives are probably involved. At the same time, her children may be protecting themselves from stigma. "Covering up" for her may be at her request, but that may not be a service to her. She has described the loneliness she experiences as a result of her concealment. Fostering and enabling this harms her as much as it may help her. She notes:

My children do [encourage or enable concealment] because they know how much it hurts me to feel different and how much it hurts me to be alone so much, and they help me to conceal it out of their feelings for me, and they know how hard it is for me to interact with people and try to be as normal as I can and hide those things. They help me with that, sort of covering up for me in some situations. And I really appreciate that because I am a very private person.

She seems to have a similar philosophy to Calvin's, who boils the whole issue down to a question of functioning. Performance is key. Outside of necessity, privacy should be maintained and conditions should not be relevant. Calvin explains:

I don't go announce I got something wrong with me. Like I say, most everybody has something wrong, and you don't hear everybody saying they disabled. They just go on with it. If you can carry your share of the load, it don't matter to me if you tell me or not. That's personal.

His mother serves as an enabler for concealment by generating rumors about him and his roommates and other females. Friends also maintain his privacy. Calvin explains:

Friends keep my secret most the time. That's for me. My mother is ashamed and just tries to hide and ignore it. I can't talk about anything around her. Her motive is shame and embarrassed. She won't accept me for who I am, so she pretends I'm something else. She tells people about female friends like I'm dating them and about the girls I live with.

Calvin explains that he does disclose in situations where another person may be affected. He explains, "I'm in an intimate situation, I tell somebody right up that I'm HIV positive. I expect the same back."

Decisions to disclose a disability status is based on necessity to obtain materials or access to an environment, avoidance of the negative consequences of disclosure, the role of the discloser, and the attitude of the potential recipient of that disclosure (Rocco, 2001). The manner

in which an adult educator or peer responds to the disclosure of a difference in the classroom can determine whether a student persists and completes a program or surrenders. Caroline reports:

Well, for the most part I hid it from everyone at first. A girl in a study group one night brought up that she had dyslexia that somebody else should read the questions. Another person asked what that meant and we started talking. I ended up talking about my problem too. Since then it hasn't really bothered me. I guess I just needed to see that people are curious more than anything.

Elizabeth sees the potential of helping others by disclosing, but she is not ready to make that choice. She limits disclosure to situations where she has absolutely no choice, even to the degree of creating negative attributions from others who do not otherwise understand her behaviors and refusals to help with tasks. She explains:

I have to disclose them [disabilities] when I go to the doctor. I have to tell them what is wrong with me. I have had to, there have been really, really ill people in our family and with my friends that I really needed to help with, and I felt a desire to help with, and I would have to explain to them why I couldn't because wanting to help so much and wanting to do anything I could for them I would have to say I can't, I physically can't do this particular thing. And that is very painful for me to have to do because I am a person who would love to help other people that are disabled and have problems.[...] Like I said, I am a very private person. I have gone to functions and different things, and I have been asked to serve on committees and to help do things in the church and things that you really feel bad about saying no to, you feel like, so you go ahead and you try to do them anyway, and you get into a situation to where it makes life really difficult for you. It really can make life difficult for you if you can't, if you put yourself in situations for saying no, it makes you really feel bad about yourself and makes others feel bad about you.

Openness seems to work well for Kevin. His response is to simply not conceal his differences. He explains:

I like for it to be in the open, and I know there is no real way I can hide it that much. I sometimes catch myself tucking my hands in my coat or something, but I guess that is habit.[...] Basically I thought to myself there is no way you can hide it. If you conceal it and you act like its bothering you, then people see that you are bothered and will try to treat you different so just act the way you are.

This seems to serve him well, since he seems especially well-adjusted and comfortable with his identity. He and Erin have high self-esteem, and they share a common matter-of-fact attitude about their disabilities. In both cases, their disabilities are physical and difficult (if not impossible) to hide. The forced openness that they experienced seems to have had a positive effect. This suggests that a great deal of the oppression is created in the act of shame and concealment. Exposure and disclosure seem to be empowering, but creating an environment where individuals with concealable disabilities can recognize this would be difficult to create.

Stigma and shame

Disability and stigma carry very similar meanings in our society. Both reflect outcomes of identifying or being identified as different, defective, or dangerous. Sandahl (1999) writes:

What unites people with disabilities is not skin color or religion, but the shared experience of being categorized as disabled because of physical and mental conditions that are discursively marked "defective." Across this diverse minority, people with disabilities are linked by a common history and often personal experience of discrimination, social stigmatization, educational segregation, medicalization, paternalistic laws and attitudes, and limiting stereotypes. (p.13)

In this way, we see a similarity between individuals with disabilities and members of any other oppressed group. Identified socially with an assumption of inferiority promotes further oppression and dehumanization of these individuals. A hierarchy of privilege and caste begins to emerge as a result of the institutionalized forms of stigma and oppression in our society, which allows groups to be classified as defective. The "defect" isn't as simple to identify as making a medical or psychological diagnosis. Identifying as disabled proves to be a more complex issue than learning about an impairment. Caroline explains:

It's not so bad, the things I'm not ashamed of, but what I'm ashamed of isn't really my disability anyway. I know it sounds funny, but the problems I have that aren't considered a disability are far worse than learning disability or depression. Well, they make me depressed. My irritable bowels are my real disability, but I get special treatment because of my learning disability. Around here they treat a learning disability like it's kind of common. Everybody just about says they have a learning disability of some kind.

It is interesting to note that many of the participants viewed their "disability" as conditions and contexts outside the realm of their diagnosed impairment. In fact, a diagnosis only created permission for these individuals to describe difficulties and oppression based on other factors on the diagnosed impairment. Stigma seemed to be the greater concern, since the situations they described to explain disability often had more to do with social perceptions and beliefs than handicapping conditions. Invisible disabilities that cause extreme physical impairments create fewer stigmatizing social effects than visible disabilities that cause no impairment (Goldberg, 1974). Situations often centered around shame, being treated as stupid or dangerous, being stared at, not being trusted with tasks or responsibilities, being relegated to menial jobs and the physical tasks that gives them difficulty, becoming dependent on services and support that limit opportunities for advancement, being "put on the spot," being expected to be able to speak for all other individuals with similar conditions, and being treated like a child. Disability's legal discourse has equated functional and productive, suggesting that the value or worth of an individual hinges on surmountable or profound disability definitions (Goering, 2002). It is the type of production and limitation expressed that influences appraisal. Certainly, these individuals do have limitations that may be different from the limitations of the majority, but those limitations are usually addressed as a simple matter of fact, a non-issue. It is the psychological and social abuses that create a feeling of isolation, separation, and stigmatization. It is these experiences and their impact on the emotional, social, environmental, and physical

aspects of individuals' lives that influences aspects of identity, such as self-concept and self-esteem (Barnwell & Kavanagh, 1997). Of course, stigma has little power unless the object of that stigma employs it in his or her identity formation. Especially self-concept has a role in the reception of stigmatization. Perceived competence in valued skills has strong influence on a person's degree of self-confidence (Torry, Mueser, McHugo, & Drake, 2000).

It seems that a cycle begins to emerge when we look at the experiences of individuals with disabilities. An identity is formed, which results in behaviors. These behaviors are observed and interpreted by others, leading to an assessment of sorts. From that assessment comes a label, a label which either evokes stigma or support from others. This, in turn fosters identity development and continues the cycle. There is no clear beginning or end.

In the case of Caroline, we see an identity formed which makes her feel unsure and nervous. This creates behaviors, such as avoidance and physical responses, such as Irritable Bowel Syndrome. These behaviors are observed, formally by doctors who offer diagnostic labels, and informally by colleagues who respond with more stigmatizing labels. These labels then evoke either stigma or support from others, which reestablishes her identity. In the case where she is given support and encouragement, she excels.

Knowing inability to reciprocate has a harmful effect, society persists in creating this type of situation. In spite of the facts, society has the contradicting belief that benefactors have provided a meaningful, laudable service only when they receive nothing in return (Baron & Miller, 2000; S. H. Schwartz, 1975). Even our federal taxes reward this type of altruistic giving. The more humane choice would involve accepting a token service or good, leaving the benefactor's ego intact and guaranteeing an interdependent relationship, rather than a hierarchical relationship. Individuals with disabilities often find themselves in situations where they may not be trained in productive skill that makes this type of exchange possible. Even when they do have viable skills, coworkers and supervisors may reinforce a hierarchical relationship by treating them as if working there is a gift. The expected response is shame, which very well may be the response given. When the manner in which someone chooses to present himself or herself is undermined, that invasion of privacy may illicit shame (Velleman, 2001).

Caroline's reaction to shame has been immobilized by potential and felt shame. She surrendered friendship to deal with shame. She explains:

There is nothing more shameful than a grown up shitting herself. I had to drive back to Blacksburg in my mess and had to roll down all the car windows it was so bad. I wouldn't even talk to my friend anymore, and I wouldn't go over there for the longest time. When I finally did—her son's a little smart aleck—he was sitting there smirking at me, and I knew she told him.

The loss of friendship was not her only loss. She also left a job. Her reaction seems to be retreat in all cases. Because of embarrassment with this friend, Caroline states, "I won't go there again. She's the only one near my age from Sunday School. But, I still don't want to do anything with her now." The alternatives may not sound like possibilities to Caroline, since her self-esteem is weak and her emotions tend to rule her behaviors. Stoicism, defensiveness, or direct

confrontation would perhaps elicit as much dread for Caroline as the initial incident. She describes the humiliation she felt when she overheard others laughing and joking:

God knows what I'd go through, if my students found out about my bathroom problem. The teachers' bathroom is right next to the office and the teacher lounge. I already was too embarrassed because of noises. I heard another teacher in the lounge say "Good God!" when I made a noise in the bathroom. I wanted to die. I don't even know which one said it, but I could hear them giggling through the wall. And, the quieter I try to be, the worse it gets. I went home that day, told the principal they needed to get a substitute in that I was really sick. I quit a while later, after my parents agreed to help. It was hard to give a regular income and to be dependent on parents again, but it will help in the long run.

Her anxiety works against her, intensifying her problems. It is not surprising that she does not request accommodations. She asks, "Can you imagine carrying a note to your teachers that said you can control your stomach, you might run to the bathroom at any time, and you can't stop to ask or you'll have an accident?" Always fearing becoming a spectacle or object of ridicule, she resigns herself to the task of self-accommodation. Calvin talks about what life would be like if others could recognize an HIV+ status by sight. He exclaims, "God, they'd put us all in a leper colony or something. It's bad enough now. And, anybody that just happened to look like it but wasn't would be in as bad a situation." He is comforted in the fact that HIV is not visible. It perhaps benefits him that he had no social anxieties prior to his diagnosis, which came later than most. He had opportunity to develop a high self-esteem and to be treated with respect from others who were blind to his differences.

Social anxiety is expressed through behaviors and attitudes that become habitual. For this reason preventing these effects of stigma may be difficult, since many of them grow from personality-shaping, childhood experiences. Habits have had a long time to develop. Self-esteem for Caroline seems to have been long nurtured. Even after some diagnoses of problems, she did not receive the counseling and support needed to develop good attitudes regarding herself. For example, Caroline describes herself, demonstrating her negative body image:

I was getting big, and my breasts got huge, which was embarrassing. A short chubby girl with huge breasts. They had to be reduced for my back a few years ago. They were giving me back trouble because they were too big for my size. They were too big for anyone's size, like a cow. It was one of the best things, since I always felt like people were looking at them. I used to burn up trying to wear a lot of baggy sweaters and coats and stuff to hide them. I looked like a short little blob all the time trying to hide them. I'm always self-conscious. I know it's crazy but I always feel like everybody is watching me. I love to go out and eat or shop, but when I get there I can't hardly enjoy it because of the people around. I wonder what they are thinking, if I'm doing something or have something on me or if I'll have to run to the bathroom or spill something. All I can think about is going home when I get there.

Adam also writes:

I avoid any activities that reveal my skin problems. I don't swim or go around with my shirt off. I have little red dots all over my body that under a magnifier look like little splotches of blood. I am not sure what this is, but I have had it my whole life. It is really weird and kind of gross.

Adolescence served to solidify already damaged self-images. Caroline labels herself with a variety of insults –cow, huge, chubby, short little blob, crazy. Hiding inside baggy clothes and trying to avoid the inspection of others, she tortured herself and couldn't enjoy social activities. She has also shared discussions that point to abuse. As research has shown, learning disabilities increase the likelihood that a child will be rejected, neglected, or mistreated (Wiener & Schneider, 2002). Suggesting that like Caroline and Ryan, many individuals with learning disabilities may have experienced abuse, which further has shaped their self-images and understanding of the world. Adam adds details of his avoidance of exposure, hiding himself in the same manner, fearing becoming a spectacle. Not seeing Adam in person, I am not sure, but I doubt that the splotches he describes would even be noticeable. I notice that he describes their appearance under a magnifying glass. However, his fear of stigmatization makes his differences more apparent and debilitating for him, limiting his activities and possibilities. The same is perhaps true of Caroline's stomach noises. She probably is much more aware of them than anyone around her. Her anxiety amplifies them to deafening proportions for her. Individuals around her probably are unaware. Caroline describes her perceptions:

I can't sit through worship for my stomach. And my stomach makes awful noises. I'm loud when I go to the bathroom. It's awful to wonder if people can hear me, because I have to go whenever I go anywhere or visit or anything. I'll turn on the water spigot to try to cover up the noise, but it doesn't help. There's nothing worse than a bathroom without a fan, because it's too quiet and makes the sounds echo. I come out ashamed and afraid to look anybody in the face. I get a nervous giggle when I'm embarrassed too. People must think I'm a freak. They hear water running and I start farting and cackling in the bathroom, then I come out looking like I'm ready to cry and looking at my feet. And, the more nervous I get, the more I have to go. I quit going to church because I'd have to get up and go to the bathroom three or four times, and I spend more time in the bathroom than in the pew. And, I started wondering if they could hear me. Nobody else ever leaves in the middle of the service, not even kids. Then, I come back and everyone is asking if I'm okay, and I just want to die.

She imagines the congregation listening to her, appraising her, judging her in some way for the sounds she believes they hear. Logically, even if they heard her stomach make a noise, the result would not likely be ostracism, hate, or disgust as she imagines. At most, it may elicit self-consciousness and fear of echoing the noises. Coping mechanisms, such as nervous giggles, usually stem from the anxiety over the situation itself and habit, both of which may diminish with time and positive experiences. Fear itself may prevent resolution. Also, this type of feared stigmatization may further decrease the number of students seeking services. This may be especially true when service providers have served to reinforce negative beliefs about potential stigma. Adam describes seeking services:

Incidentally, I was very sad and depressed during the two years that I was back home after finishing at the university the first time. I had everything that I needed, and my

family was there to help, but I was in a severe state of depression. I had to seek out free or reduced rates for access to psychotherapy and psychiatric services. It is great that these types of services exist, but it sometimes felt demeaning to go there. The stress of trying to deal with front desk workers who looked down on me often outweighed any benefit that may have been derived from the services that they tried to play gatekeeper for.

In an attempt to control access to services, front desk workers, the first contacts, have created an environment that Adam cannot tolerate. The potential benefit of services create shame and stigmatization that produce anxiety, depression, and lowered self-esteem. Hopefully, college experiences like these at community providers are rare. Perhaps, there is a fear that they will be. There are situations where students with disabilities must face others who confirm their fears. And, for individuals like the desk workers, justification for prejudice and scapegoating. Robin talks about shame after being placed in special education classes:

When I was in school, because I was sick, they made me have homeroom with the special ed students, and everyone at school used to tease me and call me names. Nobody wants to be grouped with people that have problems that they don't. I'm not like them, and I know there are people who would say they are not like me and wouldn't want to be grouped with me, but it's bad enough having my own problems without be teased for other people's problems too. I was cruel and hateful to the kids in that class, and I know I shouldn't have been, but I was just a kid too and I was afraid of being thought of like them. [...] I know all of that is wrong. I shouldn't feel that way. I just do; so, I won't lie about it. It's like a straight guy isn't going to hang out with gays, even if he says he isn't prejudiced, because he doesn't want everyone to think he's gay too. And, if he does hang out with them, no matter what, people will believe that birds of a feather flock together. I grew up being told that we are known by the company we keep, and it is absolutely true. I wouldn't come to a club for disabled people or a support group, because I don't think of myself that way. Disabled people need to fit in with normal people, not other disabled people.

It is hard to keep the company of stigmatized others, when an individual is paralyzed with the fear of being stigmatized like them. Robin notes, "I don't want people to think I have something wrong with me. It's embarrassing to tell people you have a learning disability. It sounds like you are retarded or something." Disability serves as the antithesis of society's valued characteristics, which it rewards with privilege; it is all that is not beautiful, wholesome, worthwhile, capable, intelligent, and good. "The cultural function of the disabled figure is to act as a synecdoche for all forms that nature deems non-normative" (Thomson, 2002, p.4). As a metaphor, illness elicits more than a casual association. In the words of Schor (1999):

[I]llness constitutes a special category of metaphor; to speak of cancer as just another word for what the dictionary defines as "a source of evil and anguish" is to massively deny the reality of mutilating surgery, chemotherapy, hair loss, pain, and hospice care, but also, and more importantly, to freight an already onerous diagnosis with the crippling stigma of an unspeakable disease. (p.76)

As weighty of a topic cannot be easily voiced. Individuals without the same differences cannot pretend to understand the extent of pain signified by the words that represent their experience.

Responses, such as denial or cognitive conservatism, may serve to protect an observer's social paradigm. Blindness to the degree of pain a difference inflicts may avoid challenge and the expectation to react. It is not the inner conflicts and hidden problems that society reacts to; it is the surface level differences that become stigmatized. Calvin reminds us of the stigma he faces:

I'm not exactly the guy everyone wants their son to hang out with. That has nothing to do with disability. I know I'm feminine, and that's who I am. Always have been and always will be.

Calvin shares his experiences where the stigma of being gay and expressing himself in a manner others consider effeminate has been tangled into the stigma and stereotypes associated with having an HIV-positive diagnosis. He goes on to explaining how others have reacted to his diagnosis:

I live with friends, two girls, in an apartment next to the college. I walk here in about five minutes. They both know. Mary [pseudonym] freaked a little at first, washing everything I touch and cleaning the bathroom constantly, but she's okay now. It's not even a topic now. I don't think it's been brought up for a month. You should see her dad when he found out she live with a Black man. I don't know if he's a racist, but he got all nervous and stuttered and all. He found out I was gay. Don't know if that helped or not. At dinner he kept making jokes about "Three's Company." It got tired quick. I think Mary told him about me, but she says not. But he went and bought all these antibacterial hand rubs and shower cleaner and all when he bought some groceries for her. He kept telling her she knew it was flu season and all to wash hands a lot, not to drink after anybody. He's talking about me. I [was] glad to see him leave.

Of course, Calvin's dual identity of both gay and disabled places him outside the bounds of multiple compulsory embodiments. Sandahl (Sandahl, 2003) explains:

As academic corollaries of minority civil rights movements, queer theory and disability studies both have origins in and ongoing commitments to activism. Their primary constituencies, sexual minorities and people with disabilities, share a history of injustice: both have been pathologized by medicine; demonized by religion; discriminated against in housing, employment, and education; stereotyped in representation; victimized by hate groups; and isolated socially, often in their families of origin. Both constituencies are diverse in terms of race, class, gender, sexuality, religion, political affiliation, and other respects and therefore share many members (e.g., those who are disabled and gay), as well as allies. Both have self-consciously created their own enclaves and vibrant subcultural practices. (p.26)

Whether inside or outside the subcultures produced by either identity, an individual with multiple oppressed identities stands in a precarious position as far as work, education, and social membership is concerned. While rights are afforded these groups, individuals regularly suffer the results of resentment, fear, and ignorant expressions of hostility, as in the case of forced sterilization or the murder of Matthew Sheppard. The jokes and obvious phobia Calvin witnessed in his roommate's father and his actions represented more than an oddity for Calvin. His statement, "I [was] glad to see him leave," was certainly an understatement. Such presentations

of fear, whether homophobic or nosophobic, stigmatize the objects of that behavior. That results in a response from the object of those behaviors. Calvin explains, “I never really date anymore. It scares people, but I’m honest. [...]I may end up being alone, but I still have friends. [...]I don’t want to just be alone.” Like with the roommate’s father with Calvin, covert exclusion and innuendo may serve to isolate. Kevin notes, “I didn’t like being left out when I went somewhere. It was easier sometimes to just stay home.” Calvin continues, “It’s not like going for a drink or catching some TV is putting them in any danger. But, a lot of people around here try not to include me in anything.” It is easier to choose isolation than to risk ostracism. Judith Butler (1993) writes “the subject is constituted through the force of exclusion and abjection, one which produces a constitutive outside to the subject, an abjected outside” (p. 3). It is in what individuals are not that they become known –absence begets identity. Oftentimes, spectator actions, such as exclusion, are directly attributable to clear motives. In Elizabeth’s case, it grows from dispositional attributions her friends attach to her behaviors. She explains:

A lot of that [exhibited jealousy and resentment] comes from my friends who like to go out and have coffee or go to parties or dances and so forth, and they think the reason I say no is because I just don’t want to be with them or that I am some kind of a snob or I don’t want to associate with them, when its exactly the opposite. There are just things I can and can't do that I just don’t want to discuss with them. It makes me feel like I am not a whole person when I have to tell someone about I can't do this or I can't do that because this or that is wrong with me. I don’t like to have to explain that.

This type of situation probably has its toll on many individuals who conceal their disabilities. Rather than explaining behaviors, which may seem unusual or unfriendly, they may allow others to assume that those behaviors are the result of character flaws. Even Kevin, who seems to have a high self-esteem and strong self-efficacy worries about how others are responding to him. He explains:

[T]he normal things that happened to most kids it kind of affected me more because I thought maybe that might be because of my disability, maybe they don’t like me because of my disability so I just thought more along those lines.[...]Sometimes when I am slowing somebody down with walking or something it makes me feel bad like they could be getting somewhere quick, but they are walking with me. They are trying to like, they will go out for a game of football, some of my friends, and I come along and they kind of feel like, kind of away because I can't really play so I am always like the scorekeeper or ref or something like that. So that kind of daunts [?] on me, but I just kind of feel like in the way with some things like that, some of the real physical stuff, I just feel in the way. [...] I mean there may be sometimes when like I will ask to get something and it kind of wears on them and they are like, they just I don’t know feel like they have done so much. I don’t know. Like my brother sometimes he would get agitated or I would have a friend or something, and I would ask for help with some things and I just felt like I ask a lot, and I feel bad.

Stigma is a strong force when it comes to social perceptions. It has forced the concealment of disability among our leaders. It is common knowledge that Franklin Delano Roosevelt had more medical problems than the government allowed us to know. The same was true of John F. Kennedy. A post-mortem diagnosis demonstrates a strong likelihood that Thomas Jefferson had

Asperger's Syndrome (Ledgin, 2000). Even in the wake of great successes, many have chosen to conceal their differences. Normalcy, or the illusion of that imaginary condition, becomes the object of desire for the whole of society. Being "normal" is not enough; individuals strive to be better than normal –individualistic normalcy, a paradoxical state too many pretend to occupy.

Stigma does not seem to dissipate with just education and legal sanctions. Unfortunately, the approaches that have been taken so far in those areas have a tendency to reinforce labeling and to single out individuals with differences, making them the subjects of further appraisal. Society needs to develop enough to allow for a paradigm shift, a paradigm shift that allows for dismissal of illusions of normalcy, retirement of discourse and labels that perpetuate stereotypes and prejudices, and a decision to create equitable resources and services for all members of society based on individual need rather than medical or psychological profiles.

Summary

These interviews suggest disability originates as a social construct that is defined by a minority discourse, not so much by medical or legal discourse, and is centered on stigma, ideas of "normalcy," behavioral "appropriateness," and appearances. The participants describe themselves in terms of personal definitions, which seem to grow from their experiences. Their attributions toward others seem to have grown from behaviors and physical appearances that signal difference, more so than actual abilities, diagnoses, or limitations. When individuals described who represented others with disabilities, they presented images of obvious differences –markers such as prosthetics, disfigurement, absence of limbs or senses, and nonstandard behaviors. It is not the arbitrary markers generated to determine access to services.

Medical or legal discourse might label someone "disabled" who demonstrates great athletic prowess as a basketball player from a wheelchair, but not label a peer who can walk but cannot climb a flight of stairs without getting out of breath. It may label a person who cannot lift twenty pounds as having a disability, but what about the person who cannot lift thirty, forty, fifty, or a hundred pounds? Ultimately, we start to realize that it is environment and attitudes that create official definitions of disability. If there are ramps, elevators, and ample access to spaces, mobility is not impaired for a person in a wheelchair. In a room full of people using sign language, it is the person who only speaks English who is impaired. Our society builds itself to accommodate a certain group of people, and it creates hegemony to maintain those preferences, even when individuals with differences are provided "special" accommodations –meaning more inclusive environments and treatment than is the norm.

Media has crafted a number of images of the American stereotypes of hillbillies, southerners, rednecks, gays or lesbians, yuppies, teenagers, druggies, and others. It has also crafted images of disability. Jerry Lewis selects charismatic children, who portray helpless victims with only one hope. *South Park* presents us with Timmy, who seems to be a conglomeration of many disability stereotypes. Cartoons have always presented characters with exaggerated problems –poor sight, speech impediments, low cognitive ability. Otherwise "normal" individuals with disabilities are conspicuously absent from much of television and movies, unless they are playing victim, martyr, inspiration, or villain. Rarely do we see impairment or difference as something incidental. Discussion and presentation of the character's differences seems obligatory, even if it is in the form of a disability joke.

It is hard to see beyond the images that our society presents. Certainly, some stereotypes do exist in some individuals, but that does not define the group. There were some themes that emerged in the interviews, and I want to be cautious not to present those themes as additional stereotypes and social baggage. These are glimpses at possibilities that might tell how some individuals might embody their differences and experience life.

Among the themes that emerged looking at experiences, most illuminated negative aspects of disability. Themes were grouped under the following categories: *education*; *invasions of privacy*; *personal relationships*; *religion and spirituality*; *therapy, treatments, and accommodations*; and *work experiences*.

Many themes emerged regarding *education*. Academic experiences seemed to have a strong influence on the participants. Negative experiences seemed most salient, often evoking a powerful emotional response. Even though education served as a place for some participants to escape the oppression of home, it also seemed to present a number of new obstacles. Negative encounters with faculty was common. In many cases, participants reported that individual faculty members had shown resentment or suspicion regarding the accommodation agreements made with the university. Two-thirds of the participants had opted not to seek accommodations, fearing those types of reactions from their instructors.

Invasions of privacy produced numerous themes as well. A common experience involved facing gatekeepers in situations off campus, individuals who restricted or managed accessibility to services. Public humiliation made access to these services uncomfortable. Tactics employed by these gatekeepers involved disclosure of private information and the creation of obstacles like high-traffic waiting areas or questioning. “Outing” also emerged as a theme. This term often is used in regard to sexual orientation, but that was not the only form of outing reported by participants. Most have had private information shared or gossiped about, removing individual choice to disclose or conceal. Staring, though not as overt as outing, emerged as another common theme. Not only did participants echo concerns about being stared at, they reported discomfort when they caught themselves staring at others.

The primary theme emerging from the category of *personal relationships* involved isolation. Isolation and ostracism has affected every participant. Whether this has occurred in adult relationships or in childhood, the emotional outcome has been profound. Even family and friends have excluded the participants in a variety of ways. Also, impairments have made some social activities difficult or impossible for them.

Religion and spirituality produced no consistent themes. A few individual responses discussed issues such as discourse or manipulation, but few common experiences were reported. A couple of the clients reported spiritual outlets, but the only common thread was a lack of commentary they were willing to share.

Therapy, treatment, and accommodations proved to be a category rich in themes. Side effects of psychotropic drugs and difficulty finding the right one was reported consistently. Individuals may fail to recognize the difficulty involved in acclimation to medications others may experience. Also, side effects, such as weight gain or loss, may create self-esteem and social

issues that are also concealed. Participants mostly advocated treatments and accommodations that did not involve exposure or obstacles to procurement.

Work experiences for the most part were described as meaningful and liberating. Work tended to be a place where individuals had opportunity to prove capability. Outside the structure of education and training, participants reported excelling in work situations. For a couple, concealment of pain and difficulties made the work experience unpleasant at times, but work overall seemed to be a positive outlet, affording income which allowed for even more autonomy.

The area of labels and discourse produced several themes. The categories of *attribution toward individuals with disabilities* and *social expectations and treatment* both housed a series of themes among the participants.

The category *attributions toward individuals with disabilities* illuminated many of the dynamics that may be involved regarding labels and discourse regarding disability. One theme that emerged was the fact that participants tended to regard themselves as unique among individuals with disabilities. They each regarded themselves as unlike others with disabilities, especially in regard to stereotypes. Most accepted a variety of stereotypes about disabilities, but all assumed that—even though those stereotypes have some truth—they are individually different, the outliers from the norm. They all reported discomfort associating with others with disabilities.

Social expectations and treatment often resulted in fear of stigmatization. Even acts of kindness, such as holding doors, made participants feel like attention was being drawn to their inabilities. Participants reported lowered expectations regarding their abilities, which served as markers and had a strong effect on self-esteem. Explicit ideas of “normalcy” shaped their self-definitions of themselves as deviants or failures. The irony of well-meant support and aid creating additional oppression reiterated itself in most of the participants' experiences.

Outcomes of disabilities were varied and extensive. Still, participants reported numerous themes in all of the categories. Categories included: *anxiety and depression*, *awareness of condition*, *contexts for concealment and disclosure*, and *stigma and shame*.

All participants discussed *anxiety and depression*. In some cases, mood seemed to be situational and immediate. Others described a chronic, clinical condition. Situational concerns included questions of ability and acceptance, social fears, loneliness, and ostracism. Anxiety and depression served to limit participants' abilities by undermining ability to focus and motivation. Participants reported hopelessness and a desire for resignation.

Awareness of condition as a category illuminated a few themes. The salient issue among all participants wasn't understanding a diagnosis, but recognizing a difference from others. Of course, those with physical differences recognized and received diagnoses more readily than those with psychological differences. Individuals with psychological differences often questioned themselves, wondering if difficulties they encountered resulted from a personal flaw in disposition or intelligence. The result often appeared initially as shame and lowered self-esteem. Some developed an acceptance, but many report continued self-doubt.

The category of *contexts for concealment and disclosure* simply echoed many of the themes emerging in other categories. Participants had a tendency to conceal differences because

of fear or shame. They felt like disclosure might result in stigmatization, anger, distress, or trauma. Situations where beliefs have been voiced, such as the belief that accommodations afford advantage not equity, promote the likelihood that disabilities will remain hidden. Ultimately, the issue here seems to be trust, and all of the participants have in some situation found an inability to trust others to respond to disclosure in a supportive and caring manner.

Stigma and shame as a category encompasses the majority of problems associated with disability for the participants. All of the participants report feeling they are perceived as different, defective, or dangerous. Implicit in this is the assumption that they are inferior to “normal” individuals. They report feeling ashamed, and as a result not feeling like they belong. This results in feelings of self-doubt, low self-esteem, and often retreat from challenges.

Themes emerging from this study carve out an often grim image of the experiences of the participants. Social hindrances have impeded their chances for success at college, but all of these can be countered with awareness among faculty and staff. Information and understanding of the dynamics involved in provision of educational and social development to diverse population may allow old stereotypes and assumption to be challenged. Perhaps, the barriers to equity and disclosure of differences without stigma can be dismantled over time, as colleges and universities promote inclusion and acceptance.

CHAPTER 5: SUMMARY AND IMPLICATIONS

Overview of the problem

Concealed disabilities exist throughout our society. In fact, it extends far beyond the scope I initially imagined. As Thomson (2002) writes:

I would argue that disability is perhaps the essential characteristic of being human. The body is dynamic, constantly interactive with history and environment. We evolve into disability. Our bodies need care; we all need assistance to live. (p.21)

Disability, when self-defined, encompasses nearly every sector of society and almost every member. As Herndon (Herndon, 2002) writes:

Examining the terrain of disability from the perspective that problems inhere, not within particular individuals, but rather within social contexts, social expectations, and built environments allows us to map disability as a socially-constructed phenomenon rather than a physical trait. (p.122)

Ultimately, that condition or experience stigmatized by society and labeled as disability does not necessarily coincide with impairments and handicaps that have been medically diagnosed or legally defined. These impairments and handicaps often serve as merely superficial elements of a much more complex syndrome, involving both issues of efficacy and economics. Society oppresses and restricts functioning of individuals using disability/ability discourse, lowered expectations, stigmatized labels, invasive procedures and “red tape” to hinder access to accommodations, economic hegemony, and prejudiced beliefs. Limiting the potential of others in this manner creates an inequity in our society and imposes dependency on many individuals who otherwise could enjoy being valued by society.

While social change is a necessary step in the procurement of equity for these individuals, the specifics of what they experience and how it affects their choices about disclosure and concealment needs to be explored. We all have qualities and conditions that we choose to conceal in certain contexts, whether those differences are medical, psychological, physiological, learned, congenital, acquired, chosen, or inherited. The line between a difference and a disability is arbitrary and ambiguous. The subjectivity of these labels does not necessarily need to be problematic. Why do we need to identify certain differences as disabilities? The primary motive tends to the control of access to resources, such as medical treatment. A capitalistic economy, of course, defines these labels according to ability to function within a work environment, rather than social functioning, self-esteem, psychological health, or salience with personal attributes. Yet attempts to get an accurate census of individuals with disabilities has resulted in questionable results, since many individuals with disabilities only disclose their differences in specific contexts, when the reward outweighs the cost (Burkhauser et al., 2002).

The real concern perhaps should be the degree to which an individual can function and what influences functioning. The three key influences to functioning seem to be an individual's biology, psychology, and social context, which results in a variety of issues, including behavior, beliefs, identity, stigma, and labeling.

Purpose

This research has tried to expand our understanding of the dynamics involved among individuals with disabilities and the circumstances surrounding when they choose to disclose or conceal those disabilities. As Simi Linton (1998) has written, disability research serves as a “prism through which one can gain a broader understanding of society and human experience” (p.118). The concern of this research focuses primarily on the social and psychological implications of disability presentation and enactment, not legal ramifications of these choices about public policy and procurement of services and support. While services and support are addressed as motivation for disclosure or concealment, this study looks more at the interpersonal and intrapersonal dynamics involved in affect and behavior related to disability labels. Sandahl (1999) explains:

As the promulgation of the Vocational Rehabilitation Act and the Americans with Disabilities Act illustrates, changing metaphorical constructs can have powerful effects on material conditions. Understanding people with disabilities as a minority community (instead of a hodgepodge collection of individual medical victims) has forced changes in access, architecture, and attitudes. (p.13)

In this same manner, by exploring the stories and experiences of these individuals, I hope to humanize them. By stripping away the stigmatized stereotypes created out of ignorance and blindness to diversity, I hope to allow them to illuminate meaningful details of their experiences and identities.

Participants

The participants consisted of student volunteers from a major research university in a rural area who were invited via advertisements, E-Mails, and referrals. I received a total of twenty-seven volunteers. From those, I selected sixteen for screenings, because my initial contact suggested they may have met the criteria for participation. All screened individuals:

- Self-identified as an individual with a disability.
- Had full-time status as an enrolled student at Virginia Tech’s Blacksburg campus.
- Reported concealment of disabilities in at least one context or situation, including at school work, with family or friends, in the community.

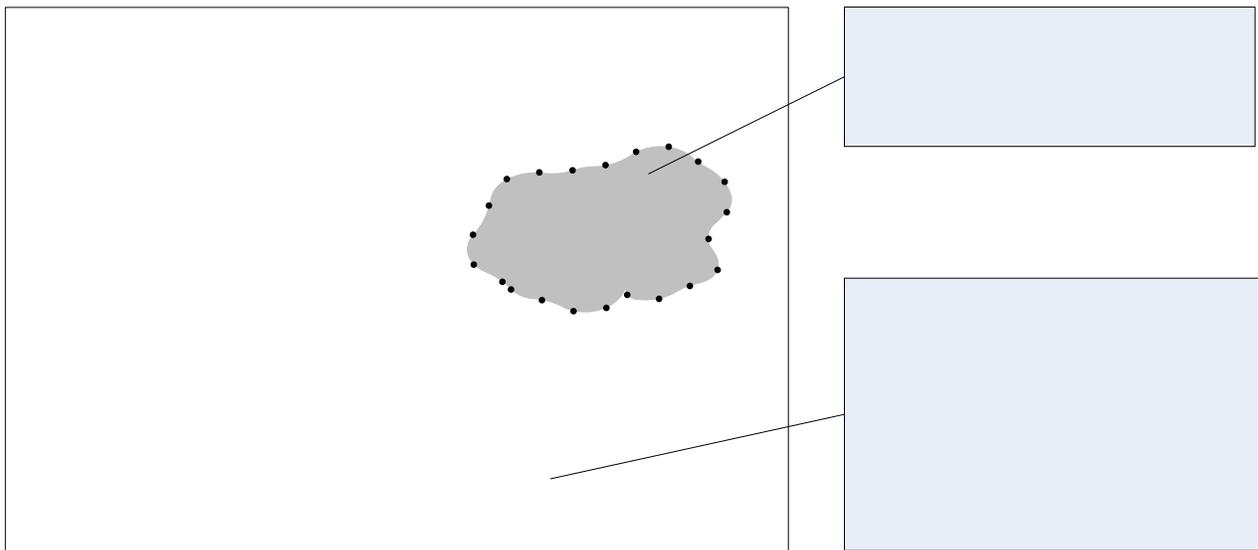
I selected for optimal diversity of participants in regard to age, sex, race, sexual orientation, and disability type. I had hoped for more diversity in relation to ethnicity, but most volunteers were White. Of course, the level of diversity at the university and among students identifying as disabled may make this a reasonable slice of participants. Eighty-three percent of students receiving services at Virginia Tech identified as White, while White participants in this study made up only forty-five percent. The population was limited to students who volunteered.

Conclusions

We must develop a better means of creating equity across society, especially in relation to differences that have an impact on ability to function without the courtesy of accommodation for those differences. Labels and stereotypes have served to promote the hegemony that allows oppression and stigmatization of individuals whose differences are observed. It is not surprising that many people choose to hide the labels and differences from others, hoping to avoid the outcomes of transgressing the social “norms.”

The results of this research confirm many of the assumptions made by Goffman (1959; Goffman, 1963) and E. E. Jones, et al. (1984). Being marked or labeled coincided with stigmatization for many of the participants, and fear of labeling interfered with functioning. It has reinforced the ideas of privilege and its dynamics in relation to differences, The privileged characteristics created within our society include being White, male, “able,” Christian, heterosexual, and “attractive.” (See Figure 14). The list is indefinite, including an impossible combination of what society hails as ideals. As McIntosh (1998) illustrates, society perpetuates its assumptions of the norm through subtle and not so subtle cues in advertising, entertainment, products, and services. It is unlikely, if not impossible, that anyone meets all or even a majority of the criteria for privilege. Everyone lives at some distance outside the realm of this ideal, the outside encompassing a much larger collection of attributes –everyone not White, not male, not “abled,” not Christian, not heterosexual, and not “attractive.” It is this collection of outside, unprivileged characteristics that one is most likely to conceal to avoid stigma, to feign homogeneity with the “in-group,” and gain privileges that these characteristics earn.

Figure 14. The subset of privileged characteristics.



What is true of the set of characteristics that are privileged? They are arbitrary. Privileged characteristics change with the context and era when they are expressed. The waif-like models of

the recent turn of the century would not be nearly as appealing to the masses at the turn of the previous century. Within a homogenous group, sharing features from either outside or inside the set of privileges that the traditional, patriarchal, White discourse creates, the shared characteristics will still become the privileged characteristics within that particular group.

This is clearly seen within subcultures and ethnic groups, who learn to value their group identity more than they fear the results of prejudicial discourse. Within hereditary communities, this is not surprising, Familial identities are central to self-concept; so, traditions, religion, ethnicity, and other acculturated characteristics may not be hidden. It is, however, interesting to note that non-hereditary communities may create valued group identities as well. Homosexuality, acquired differences, and social assimilation, all of which generally have no familial connection, may become central to a positive self-concept, regardless of discourse. This may come at the cost of privilege and acceptance, because of transgressing the social standard. Individuals with disabilities within “normal” society may have good reason to conceal their disabilities in the face of possible stigmatization; however, when within a homogenous community may value their difference and attribute their identity to that difference. For example, a strong Deaf culture has emerged in American society, which departs from the medical and impairment discourses regarding disability. Within the Deaf community, deafness and hearing impairment become as salient as ethnicity or gender in positive identity formation. The same is true of individuals with achondroplasia, who may also identify as members of a particular community, rather than victims of impairment.

Academic institutions only accommodate a fraction of individuals who need services in order to have an equitable chance for success. The current paradigm frames disability in a manner that creates stigma and doubt regarding need. The dual notions of competition and equity cannot function simultaneously, leaving students, faculty, and staff with a paradoxical duty to include and exclude. Whether we envision this as inclusive exclusion or exclusive inclusion, students and potential students are placed in the awkward situation of identifying with a stigmatized group to gain equitable access to the privileges afforded those without stigma.

Privacy legislation may help protect individuals with concealed disabilities from publicity, but it will not eradicate the disability discourse that depicts individuals with certain differences in terms of deficit, impairment, and failure, not to mention legal and religious discourse, which further constructs an image of individuals in terms of immorality, culpability, incompetence, and worth. Political correctness does little to help. It merely moves the rhetoric into more covert and offensive contexts.

It is interesting to note that many of the participants viewed their “disability” as conditions and contexts outside the realm of their diagnosed impairment. In fact, diagnosis only created permission for these individuals to describe difficulties and oppression based on other factors in addition to the diagnosis by validating the actuality of limitations. Stigma seemed to be a greater concern, since situations they described to explain disability often had more to do with social perceptions and beliefs than handicapping conditions. Situations often centered around shame, being treated as stupid or dangerous, being stared at, not being trusted with tasks or responsibilities, being relegated to menial jobs and the physical tasks that give them difficulty, becoming dependent on services and support that limit opportunities for advancement, being “put on the spot,” being expected to be able to speak for all other individuals with similar

conditions, and being treated like a child. Certainly, these individuals do have limitations that may differ from the limitations of the majority, but these limitations are usually addressed as a simple matter of fact, a non-issue. It is the psychological and social abuses that create feelings of isolation, separation, and stigmatization.

When we think of these individuals in terms of marginalization, we must come to realize that laws and political reforms will not help them become accepted as functional participants in society to the degree necessary. At most, they reinforce tolerance and accommodation, but it will not result in unconditional acceptance. What is needed is a “universalizing view” of disability that will replace the view that relegates individuals with disabilities to an unprivileged, minority position (Sedgwick, 1990). Melting pot philosophies have created an assumption that assimilation will foster acceptance, but assimilation is about conformity. It involves changing individuals with differences to meet the pre-existing social values and, in essence, preserving the marginalization and stigma for those who do not conform. Of course, changing social values and developing a much wider array of valued characteristics is a much more difficult task.

Implications for further research

This research raises numerous questions:

- How much of the attrition in higher education can be attributed to students not securing accommodations because they choose instead to conceal their disabilities?
- How many students with disabilities successfully hide their disabilities while in college? How many of these students successfully complete a program? Do these students have significantly different evaluations?
- How do invasions of privacy regarding disabilities and other stigmatized roles affect the selection and utilization of services on college campuses? If policies and changes to insure privacy continue to be implemented, will more students seek out accommodations and other services?
- How successfully do colleges accommodate individual needs? Do college provided accommodations serve to provide options that will be available to students when they use college training in a post-college career?
- When do treatment side-effects outweigh potential benefits? What guidelines, if any exist, should be used as template for provision of treatment?
- What is the relationship between anxiety and depression and disability labeling? How does awareness of a condition affect the experience of that condition? How does diagnosis or labeling affect the experience of disability?
- When do the benefits of disclosure outweigh the damages? When does the benefits of concealment outweigh the benefits of disclosure? What changes would diminish damages and increase benefits of disclosure?

- Where does shame about a condition originate? What causes one individual with a difference to become self-conscious and ashamed while another person with the same difference becomes self-assured and confident?
- How has our images of disability changed over the last few decades? How will we picture disability in the future? What elements of society can help us predict future discourse and attitudes regarding disability?

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APPENDICES

Appendix A –Informed Consent of Participant

Title of Project: The Dynamics of Concealed Disabilities at Virginia Tech

Investigators: James Michael King [731-4923]

Faculty advisor: Susan B. Asselin, Ph.D. [231-8206]

Committee members: Jane Abraham, PhD; Susan Angle, PhD; Megan Boler, PhD; Karen DePauw, PhD; Virginia Reilly, PhD

I. Purpose

This study will be conducted by Virginia Tech in order to describe how individuals with concealed disabilities who attend Virginia Tech describe their experiences in relation to the disability. Since the identities of individuals with concealed disabilities go far beyond a physical or psychological impairment, disability will be addressed as a construct and mode of identification, not simply a diagnosis or description of impairment. The construction of identity and the way an individual perceives experiences grows out of a life narrative, not just isolated segments of a person's life. Therefore, the research will explore the life narratives generated by individuals with concealed disabilities.

II. Procedures

This study focus on students who identify as disabled and conceal that fact in at least one context. If you choose to participate in this study, I will ask you to answer open-ended questions about what role you think your concealed disability may have played in your recent and past experiences and collect data you provide in response and request that you create a rough timeline of significant life events. The interviews will be held at a time and place convenient for you. You may stop the interview at any time or refuse to answer any question. You are also welcome to request any information be kept "off the record." You are encouraged to seek clarification of any question you do not understand and may address any issues that you wish. With your permission, interviews will be audio taped and later be transcribed to insure an accurate representation of your thoughts. An interview will consist of a meeting in a private area where our conversation can be recorded. I will encourage and prompt stories of your experiences regarding disability. After the interview, our conversation will be transcribed. I will contact you if I need clarification or exploration in an area we discussed. If you prefer exclusion of parts of our conversation, you may contact me afterwards to make the appropriate adjustments. You will be offered a copy of this form for your records.

III. Benefits and Risks

There will be no risks other than what you would ordinarily experience in your everyday life. You will control the extent of your participation by choosing what you say to the researcher. You may also withdraw from the study at any time. Therefore, any potential risks will be minimized. Personal benefits may come to you from thinking about your history and getting to voice your opinions and concerns, but the larger benefits will be for others who read your words. Perhaps, this may help improve the quality of opportunities and accommodations provided to people diagnosed with disabilities.

V. Extent of Anonymity

Complete anonymity may be difficult to protect for people with distinct or unique circumstances. Your identity may be recognizable from your responses. If you desire anonymity, every effort will be made to comply. Pseudonyms will be given; interview tapes will be erased or destroyed after transcription. At a university of this size, it is unlikely that anyone would be able to identify you, unless you share particularly unusual events to which he or she may have been privy. Yet, it is still possible that anonymity will be compromised. All foreseeable precautions will be closely adhered to in order to prevent this.

VI. Compensation

There will be no material compensation to any volunteer by anyone supporting this research. This is strictly voluntary.

VII. Freedom to Withdraw

You may refuse to answer any questions and limit your participation in any manner you desire. You may fully withdraw from this research at any time by informing the interviewer [731-4923] or the faculty advisor [231-8206]. Upon withdrawal, all records of your prior participation (recordings, transcripts, and notes) will be destroyed.

VIII. Approval of Research

This research project was approved as required, by the Institutional Review Board for Research involving Human Subjects at Virginia Polytechnic and State University by the Department of Teaching and Learning on September 25, 2003.

IX. Subject's Responsibility

By signing this document, you are affirming the following statement to be true:

I voluntarily agree to participate in this study being conducted by Virginia Tech. I will participate in at least one or two interviews of less than two hours with the researcher. The time and place will be mutually agreed upon. With my permission and prior knowledge, the questions and my answers will be audio taped.

X. Subject's Permission

By signing this document, you are also affirming the following statement to be true:

I have read and understand the Informed Consent and conditions of this project. I have had all my questions answered regarding this document. I hereby acknowledge the above and give my voluntary consent for participation in this project. If I participate, I may withdraw at any time without penalty.

Volunteering Participant

Date

Appendix B –Synopsis of research project for IRB

Statement of the Problem

Students of higher education with concealed disabilities seem to exist on the border dividing the experiences of abled and disabled. These students have an option to disclose, as well as a fear of discovery. The outcomes of inhabiting both sides of this border may be profound as any other type of division and marginalization between two divorced entities. The manner in which individuals experience and survive (or are destroyed) should teach much about both sides of the border and the borderlands, the area in between.

On one side of the border, we find individuals who do not perceive themselves to be disabled in any manner. Even though they may have superficial or long-term impairments, they do not consider these to be disabling. They do not consider themselves part of any group or category of people with disabilities. They generally consider themselves as “abled,” with no thought of that being a temporary condition. They have imagined ability as a blank slate on which disabilities may be written to mar the surface and, perhaps, may be erased. They assume “ability” is the *natural* condition. Being abled, however, from a biological point of view remains the minority condition. Ideas of ability and perfection are the additions to the blank slate in the metaphor above. If society has a norm, it would more likely be that of impairment, difference, or disability to some degree.

On the other side of the border from the “abled” are people who perceive themselves as having a disability and identify, perhaps reluctantly, with a disability community. The physical or psychological existence of an actual impairment does not justify nor negate one’s perception and belief regarding having a disability or being disabled. The use of disability, as a generic term without qualification, will refer to a self-concept, not necessarily a diagnosis or physical condition. Of course, a person’s self-concept may be associated with an actual difference, diagnosed impairment, or handicapping factor. Generally, disabilities are visible, but they may also be invisible. Invisible disabilities are those disabilities that do not need to be concealed to go unnoticed; they simply do not have easily identifiable signs readily detected by casual acquaintances. Of course, significant others are more likely to recognize the signs and changes due to an invisible condition or a socially constructed condition. Identifying oneself as having a disability may include behaviors such as disclosure, use of support or services when needed, activism, awareness, interaction with others because of shared disability status, membership in a community (such as a Deaf community), and recognition of others with similar conditions. Denial of disability may result in isolation and deprivation.

Some people do not fit on either side of the border between “ability” and disability. They perceive themselves as having a disability, but they choose to conceal the disability and attempt to pass as part of the “abled” community in at least one social context. They may travel back and forth between communities, only partially participating and belonging. As imposters in both contexts, they may have difficulty utilizing the privileges of either. Concealed disability is a much more complex issue than simply impairment or perceptions of impairment. The real issue here is a stigma felt (or feared) by an individual that perceives herself or himself to have deficit

or disability of some sort. Rather than embracing difference, these individuals may feel shame, inferiority, and fear of alienation. An actual diagnosis is not important; the condition of becoming marginalized may be a result of self-esteem, mental health, physical health, or aesthetic appraisals of oneself. These people may forego support, services, and even treatment in an attempt to conceal their “disabling condition.” For these people, disability is perceived as a condition, rarely a culture, or identity.

To illustrate this, the Johari Window may be helpful (Luft, 1969). The Johari Window serves to illustrate the categories of a person’s identity in four quadrants –open, hidden, blind, and unknown. The open quadrant refers to those aspects of oneself known by oneself and others. The hidden quadrant refers to those aspects of oneself known by oneself but not by others. The blind quadrant refers to aspects of oneself not known to oneself but known by others. Finally, the unknown quadrant refers to aspects of oneself that nobody knows about, aspects yet to be discovered. I am most interested in the open and hidden quadrants pertaining to disability. These are quadrants to the left that involve the knowledge of the subject and personal volition. They grow or shrink according to the amount of feedback received. Notice that with feedback the “Blind” quadrant shrinks and the “open” quadrant grows. In the same manner, with disclosure, the “Open” quadrant grows and the “Hidden” quadrant shrinks.

The central concern here is concealment of conditions and the factors that encourage disclosure or concealment. Some of the following questions may be explored through the narratives of participants in this study:

- Why do some individuals identify themselves as having a disability while others try to conceal their conditions? What is unique to those that conceal their disabilities?
- In what contexts do people with disabilities conceal their perceived differences?
- With what types of life experiences does concealment/disclosure seem to be related? Which behavior does society seem to encourage and why?
- How do people with concealed disabilities express their identities? How is disability performed? How is concealed disability performed? The same way “ability” is performed?
- Do people with concealed disabilities embody disability in a particular way that is different from other people with disabilities? What discourse frames their communication?
- Is the outcome of disclosure/concealment big enough to outweigh the benefits of the alternative?
- What does the label of having a disability mean to participants? Where do negative/positive perceptions about disability status originate?

- Is the convergence of social expectations and disability significant? What do participants perceive the interrelationship between them to be?
- What features of society alienate and encourage concealment among people with disabilities? Legal? Educational? Attitudinal? Architectural?
- What can we learn from the life experiences of people with concealed disabilities in higher education? Are there dynamics teachers, students, administrators, researchers, and service providers should consider?

Limitations

Of course, I will not be able to study students with every type of disability or condition, living in every possible context, from every demographic group represented in higher education. The results of this research will not offer answers to every question. In fact, I anticipate the research generating even more questions that need to be explored. Perhaps, insight into the experiences, attitudes, and ideas these individuals present offer a starting place for other researchers and a little more awareness of some of the dynamics involved in having a concealed disability. Hopefully, this research can begin to piece together a framework from which will create some insights and entry points for understanding this population.

Other problematic concerns involve the participation of subjects. I must ask the questions:

- Who would choose to participate in this study?
- Would they reflect the attitudes of the total population?
- To what degree do the subjects shape their narratives to fit this context?
- Do they have an agenda that shapes their responses?

Still, the diversity of individuals with concealed disabilities makes this type of research even more imperative. Exploring more cases presents an opportunity to begin to map some of the possibilities and to begin to identify some reference points on the landscape of experiences.

[...]

Methodology

Through an analysis of life stories, I will examine the nature of social, academic, and professional interactions and the effect that concealed disability has on the lives of students. Because of their hidden differences, people operate between the worlds of the non-disabled and the disabled. The nature of their marginalization may help us to understand their experiences and needs. This may bring us closer to a unified theory of disability and gender, which may offer a greater respect and acknowledgement of all experiences. Eisner (1997) suggests:

To the extent that experience itself can be conceived of as the primary medium of education, stories are among the most useful means for sharing what one has experienced. Narrative –which means a telling– makes it possible for others to have access not only to our own lives when our stories are about them but also to the lives of others. (p.262)

Perhaps, this project can provide some access into the lives of students with concealed disabilities and illuminate what marginalization means to them. I intend to pattern this analysis after cultural studies, speaking to an audience of cultural critics. Since I am essentially exploring a dynamic condition, it cannot be isolated and scrutinized outside of a complex context. Therefore, I see part of this process involving the development of vocabulary that will mediate understanding, creating a metatextual dialog that explores the texts participants present as an interpretation of their experiences.

Working with this population will require particular prudence. A text has the potential to empower and acknowledge people or to leave them bound and further establish stereotypes. As Moser (2000) explains:

It is important to make visible and describe the lives of disabled people, but a naïve faith in the innocence of description and representation is party to reproducing the conditions for the marginalisation [sic] and the differences that we want to draw attention to. Descriptions of reality constitute, order and mobilise [sic] reality, discursively. To make change possible, we have to describe how differences are constituted and how they work. (p.210)

Taking into account my responsibility to my subjects and the population I explore, I need to become sensitive to the traps of areas of discourse that reinforce stigmatization, while presenting an accurate picture of the landscape my subjects expose and not negating norms they associate with group membership.

The scope and depth of the questions I hope to address make a qualitative/cultural study hybrid a suitable means for exploration and discussion. As Patton (1975, cited in Sofaer, 1999) explains, “The defect of quantification is that it does not always support, as well as qualitative work, the understanding of complex, dynamic, and multi-dimensional ‘wholes’” (p.1102). Joachim and Acorn (2000) add, “The relationship between visibility and invisibility and disclosure and non-disclosure is poorly understood” (p.247). Researchers may be able to depend on quantitative methods to explore some answers that lend themselves to dissection and simplification, but qualitative methods can allow a means for exploration of areas we do not understand in depth (Sofaer, 1999). We can explore what questions we need to ask. Still, there can be reluctance to new methodologies, especially a hybrid, as I suggest here. Reid (2001) notes:

As a field, special educators have been reluctant to move beyond quantitative conceptions of science that privilege generalization and quantification. As a result we have innocently disempowered the voices of people with disabilities who speak to us mostly through autobiography [. . .]. (p.104)

I plan to develop life stories in a series of profiles, which will help to illuminate the dynamics of these issues in relation to concealed disabilities. Oyserman and Swim (2001) report that the majority of research looking at stigmatized groups has focused on an outsider perspective, meaning from the point of view of the stigmatizer. They voice a need for more research focusing on an insider perspective, which, among other things, will help us “to understand how their life experiences and worldviews may differ from nonstigmatized people” (Oyserman & Swim, 2001, p.11).

The methodology for this research will consist of collecting and analyzing life story narratives. As Benjamin (Benjamin, 1988) suggests, intrapsychic and intersubjective approaches should be viewed as both complementary and necessary, especially in the context of motivation among individuals to either conceal or disclose their disabilities. I will collect data from interviews, observations, and texts, as well as published dialogues and contexts. I will provide journals to adults with concealed disabilities among students of higher education living in the Blacksburg area, inviting participants to express their own opinions about their lives as individuals with concealed disabilities and narrate their experiences in journal-type format. Journaling and sharing additional materials will be optional. In addition, I plan to observe and collect any available artifacts that may help in the exploration of individual experiences. Each life story will be presented in hopes to answer my questions about what experiences helped to create the participants’ attitudes about disabilities.

Participants

I tentatively plan to collect data from around six to twelve participants. I hope to recruit a diverse group of participants in regard to characteristics such as sex, gendered roles, age, college major, and ethnicity. Among the six to twelve participants, I hope to have near the same number of male and female participants. Of course, availability of participants will ultimately dictate the exact constitution of my participants. As Lincoln and Guba suggested, I will continue sampling “until a point of saturation or redundancy is reached” (Quoted in Merriam, 2001, p.64). I will use human service connections, primarily on campus, to get in contact with individuals who would possibly enjoy an invitation to participate, since individuals involved in these institutions may serve as “informal gatekeepers” through which I may gain access to participants (Seidman, 1998, pp.38-39). Dr. Susan Angle, at Virginia Tech’s Services for Students with Disabilities, has agreed to make information available to students with disabilities that use services in her office. From those students who chose to respond, I will conduct intake interviews to determine if they fit the definition of concealed disabilities I have posited and if they have experiences regarding this identity that I feel may contribute to the study. After I have conducted intake interviews with all of the volunteers during a prescribed time, I will select as diverse a group possible. Participation will be limited to people with concealed disabilities who currently are students at Virginia Tech’s Blacksburg campus. I will gain informed consent from each participant. (See attached Informed Consent Form).

There will be no risks other than what participants experience in everyday life. They will control the extent of their participation by choosing what to say to the researcher. They may also withdraw from the study at any time. Therefore, any potential risks will be minimalized.

Personal benefits may come from thinking about personal history and getting to voice opinions and concerns, but the larger benefits will be for others who read their words. Cotterill and Letherby (1993) write about qualitative research, “Due to the research experience, all participants are likely to have increased knowledge, both of the research topic and of the life of the other person they have spent such a long time with” (p.8). While Merriam (2001) warns against data collection becoming therapeutic, I am skeptical about any disclosure of personal information to an unbiased party offering unconditional positive regard not being cathartic, psycho-educational, and therapeutic. As Ozer (1990) reflected, “In the course of the last two years I have also found a voice to express my situation as a woman with a hidden disability. Writing about it transforms the pain from a prison into poetry” (p.632). I expect this will happen in the telling of life stories as well. It will provide opportunity for these individuals to practice openness in a safe environment, and it will allow them draw insight from acknowledging the experiences they choose to share. Polkinghorne (1988, cited in Reid, 2001) explains:

We achieve our personal identities and self-concept through the use of the narrative configuration, and it is an expression of a single unfolding and developing story. We are in the middle of our stories and cannot be sure how they will end; we are constantly having to revise the plot as new events are added to our lives. Self, then, is not a static thing or a substance, but a configuring of personal events into an historical unity which includes not only what one has been but also anticipations of what one will be. (p.103)

The element that researchers should avoid is not descriptive of a therapeutic relationship, but rather a medical model, where diagnoses and treatments are presented, either as advice or prescriptively. My goal is description –not prescription– and creating a common vocabulary for exploration, without judgment. This in mind, I will refrain from offering commentary or projecting assumptions onto the participants, making interactions during the interview-phase centered on summarizing, paraphrasing, and inquiring. Of course, I am not assuming that I can approach any subject as a blank, objective recorder. I cannot erase the fact of my values, biases, and even motives in the choice of this topic. I believe that social change is necessary and hope to create an impetus for social revision by illuminating the problems and issues that exist and exposing the dynamics of disability for scrutiny.

Data Collection

I anticipate two to three meetings, which will last between one and two hours each. Following a semi-structured interview format, as described by Merriam (2001), a set of twenty-five guiding questions will be used to encourage dialog during the interview, if needed:

- What are your earliest memories of having a difference –being sick, physically unique, or incapacitated? Do you remember any particular feelings associated with this?
- Having known anyone impaired with an illness, injury, or disorder? How did this affect you?
- What did you feel about this person? What did you feel about their impairment?

- What does disability look like? How does it behave? Is disability “performed” in a particular manner?
- Have you known anyone who pretended to have impairment? Have you known anyone who you believed was pretending? How did you recognize this person was pretending? What caused you to infer they did not have an impairment?
- What do you believe motivated them to pretend? How did this affect you? What did you feel about this person?
- Can a person have an impairment and not be disabled? Can a person be disabled and not have an impairment? What are the differences among impairments, handicaps, and disabilities? What terms would least offend you? What labels have others applied to you that you found offensive?
- Have you known people who tried to hide, conceal, or disguise disabilities or impairments? What might have been their motives? How did you feel about them?
- When did you discover you had a disability? Did you have this disability before you had some sort of diagnosis? If so, did this condition affect you before you knew about it?
- How has it affected to you at home? How has it affected you at work? How has it affected you at school? How has affected you among friends and family?
- How did it make you feel about yourself?
- Have you received any support, accommodations, or services? From what sources?
- What was the process of getting support, accommodations, or services like? Was the process clinical or personal? Did the providers seem to be benefactors, gatekeepers, guards, greeters, facilitators, or obstacles? How so?
- Do you feel confident that the support, accommodations, or services you receive will not be taken away?
- Are there individuals who exhibit jealousy or anger because you receive support, accommodations, or services? How were you made aware of these feelings?
- How would your experience have been different if your disability could be seen?
- How does your disability affect others?
- During what period of your life have you been happiest? Saddest? Most in control? Most out of control?

- When you choose to disclose or hide your disability, what informs that choice? Are there certain people with whom you share details about your disability? What qualities do these people have?
- Do you feel like you have to explain or apologize for having a disability? What makes you feel this way?
- Are there any people who seemed to expect apologies or explanations? What do you think makes them feel this way?
- Do you ever hesitate to do things you are capable of doing because of what you believe in others will think or expect? Have you ever been judged for doing things others do not expect you to do because of your disability?
- Have other people ever chastised, threatened, or derided you for activities you carry out, money you spend, or recreation you enjoy because of your disability?
- If your privacy has ever been compromised regarding your disability, how did this take place and who did this? Did a professional do this? What was his or her motivation?
- If you were to wake up tomorrow and that some miracle your disability would be gone, how would your life change? How would you change?
- If you were going to offer advice to someone with a disability, what would it be?

In the process, I will remain open to the possibility of including additional documents, voices, and observations to expand my understanding of the dynamics involved in the experiences of individuals with concealed disabilities. Additional texts salient in the study may include released disability documentation, university disability policies, demographics, and volunteered personal journals or notes.

All meetings will be individual and private. The first will involve the collection of demographic data, providing a journal, and offering suggestions for when and what to include. Journals will be optional tools for them to record thoughts and experiences when they occur. I will explain that the journal needs to be all their own words –to be careful to put quotes around anyone else’s words they may decide to include. They will be given the option of highlighting sections of their journals that they decide they prefer not to share or for me not to use. They may opt not to use the journal.

The second meeting will take place at an agreed upon time and location. At that time, we will discuss the process and, if necessary, I will focus the subject on especially helpful information they have shared. During this meeting, I will be able to encourage the participants.

An additional meeting will take place later, if needed. We may not complete some activities in only two meetings and need a follow-up meeting. I will look at the journal or any other shared documents with the participants, asking for explanations and details where I do not

understand their text. We will discuss the process and the experience of being involved in the process of being interviewed and journaling. I will also assure them that I will return their journals after I have scanned copies for myself to use. During the interims between meetings, I will send letters or E-mail encouraging participants to continue with the journaling process. I will also express appreciation for their help and reminders of the next meeting.

While I cannot predict what additional “texts” may become available, I will be receptive to any data that better extends and develops their narratives. The participants will be invited to share any artifacts they feel may further illuminate their situation. As Sofaer (1999) pointed out, “One of the great advantages of qualitative methods is that they enhance the capacity not only to describe events but to understand how and why the ‘same’ events are often interpreted in a different, sometimes even conflicting manner, by different stakeholders” (p.1106). Concealed disability, being a highly politicized topic, should present many potential concerns regarding how it has been defined, embodied, and represented in our society by different agents. Cotterill and Letherby (1993) explain:

Under the general rubric of the life history method, oral narratives can include an account of one person’s life as told by her to another, or indeed multiple biographies, generated using semi-structured interviews and focusing on one or more aspects of many people’s lives. The narrative technique allows respondents to ‘tell the story’ in whichever way they choose and, importantly, validates individual experience and provides a vehicle through which this experience can be expressed to a wider audience. [...] They [life histories] are invaluable because they do not fracture life experiences, but provide a means of evaluating the present, re-evaluating the past, and anticipating the future. (p.6)

This in mind, the lived experiences of the narrator may provide complex details of interrelationships and the narrator’s involvement in communities and groups. The expression of experiences will be dynamic; it will involve changing perspectives, attitudes, and understandings as participants explore events and experiences within the framework of the data collection. The interaction between the researcher and the participant will undoubtedly add to the context and understanding of what the participant shares. As a researcher, I will need to explore several questions throughout the collection process:

- How has the context of the interviews influenced the narratives?
- How much are the participants’ responses affected by my presence as the researcher?
- How much is not being disclosed or being edited?
- Have I led the participants to view or express their stories in particular ways? Are the questions leading?
- What degree of trust and rapport has been established between researcher and participant?

- How much do I project my own understandings and experiences onto the participants?

In the final text, I envision a series of narratives. I intend to construct the data I gather into portraits of these individuals, rich in detail and description. I do not intend to quantify the results in the portraits. I will reserve identification of themes for the analysis that follows. The portraits themselves will try to paint for reader a picture of each participant's life experiences as they center on disability. I will attempt to offer these first without interpretation and with as little subjectivity as possible. Of course, it is impossible to erase the fact that this information will be filtered through the observer, limiting the results to perspectives I am able to take as an individual. I will try to be honest in the presentation of myself and the biases and paradigms to which I subscribe, when I am aware of them. Still, like all other qualitative research, there is value in exploration. It allows us to learn not only about the participants, but it also teaches us about ourselves as observers. Of course, this will produce a temporal snapshot, a moment in a participant's evolving understanding of experience.

To help avoid misrepresentation of information, I will utilize participant feedback, feedback from colleagues, and ongoing reevaluation of my work.

Analysis

I will continually ask myself through the whole process, what have I "learned from doing the interviews, studying the transcripts, marking and labeling them, crafting profiles, and organizing categories of excerpts" (Seidman, 1998, p.110). I envision this being a recursive process of analysis and reflection, where I will continually move between data collection, transcription, journaling, observing, and exploring. My background in composition from my first Masters degree has allowed me to develop a standard process that works for me. Part of my writing process is keeping an ongoing personal journal in which I wrestle with ideas and possibilities. I anticipate the journal being helpful as I reconstruct my thoughts and concerns as I analyze the data. Being visually oriented, I generally use diagrams, charts, and sketches to record information. In the event that these graphics present information in a unique manner, I will incorporate them into the text.

Pope, Ziebland, and Mays (2000) suggest, I will use sequential, or interim, analysis, which will allow me to shape my questions and explore avenues of inquiry that present themselves throughout. In this manner, I will be given more opportunity to develop hypotheses and a grounded theory. Pope, et al. (2000) offers the definition:

The term grounded theory is used to describe the inductive process of identifying analytical categories as they emerge from data (developing hypotheses from the ground or research field upwards rather than defining them a priori). (p.111)

I hope to explore my findings with a blank slate, which will permit me to discover important themes without imposing a template. I cannot erase that I have expectations based on personal experiences, the experiences described by clients and students, and study.

Seidman (Seidman, 1998) presents the process of creating and analyzing that I intend to work with as I study the transcripts of the interviews and other artifacts. The first step will involve locating and marking selections of the texts that are interesting. Using the same close reading skills I use analyzing texts as an instructor and scholar of English, I will exercise my best judgment to distill the text to significant passages that contribute to the study. From these condensed passages, I plan to develop profiles of the participants with metatextual observations of context, behavior, and affect. I plan to aim for a lucid, accessible text designed through a recursive revision process that will omit idiosyncrasies of oral speech and repetitions that may distract from the overall flow and presentation (H. S. Becker, 1986).

Appendix C –IRB Approval**Institutional Review Board**

Dr. David M. Moore
IRB (Human Subjects) Chair
Assistant Vice Provost for Research Compliance
CVM Phase II - Duckpond Dr., Blacksburg, VA 24061-0442
Office: 540/231-4991; FAX: 540/231-6033
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October 1, 2003

MEMORANDUM

TO: Susan Asselin Teaching and Learning 313
James Michael King T&L 0313

FROM: David M. Moore 

SUBJECT: **Expedited Approval** – “The Dynamics of Concealed Disabilities”– IRB # 03-338

This memo is regarding the above-mentioned protocol. The proposed research is eligible for expedited review according to the specifications authorized by 45 CFR 46.110 and 21 CFR 56.110. As Chair of the Virginia Tech Institutional Review Board, I have granted approval to the study for a period of 12 months, effective September 25, 2003.

Approval of your research by the IRB provides the appropriate review as required by federal and state laws regarding human subject research. It is your responsibility to report to the IRB any adverse reactions that can be attributed to this study.

To continue the project past the 12 month approval period, a continuing review application must be submitted (30) days prior to the anniversary of the original approval date and a summary of the project to date must be provided. My office will send you a reminder of this (60) days prior to the anniversary date.

Cc: File

Department Reviewer: Jan Nespore T&L 0313

Appendix D – Interview Prompts

Self

- What causes you to feel that you have a disability? How do you refer to your disability?
- What terms do you prefer and which ones offend you?

History

- What are your earliest memories of having a difference –being sick, physically unique, or incapacitated? What particular feelings do you associate with this?
- When did you discover you had a disability? How long did you have this disability before it was diagnosed? How did this disability affect you before you knew about it?
- During what period of your life have you been happiest? Saddest? Most in control? Most out of control? What role did disability play in this?

Home and community

- How has your disability affected you at home and in your community?
- What special accommodations do you require at home? Tell me about these.
- Do you live with others? If so, how does your disability have an impact on them?

Work

- How has your disability affected you at work?
- What accommodations do you receive at work? How did you get these accommodations?
- Did you disclose your disability before being hired and have you disclosed it since? Please explain.

School

- How has disability affected you at school or in college?
- Where do you live – on or off campus? Do you have roommates? If so, tell me about them.
- What support, accommodations, or services have you received? If so, what was the process of getting support, accommodations, or services like? Do you feel confident that the support, accommodations, or services you receive will not be taken away? Explain.
- How many individuals exhibit jealousy or anger because you receive support, accommodations, or services? Who are they? How were you made aware of these feelings?
- How have faculty and staff been supportive and understanding in their treatment of you? How have they been otherwise? How have other students treated you?

Personal Relationships

- How has disability affected you among friends and family?
- How does your disability affect the development of close or intimate relationships?
- Who enables you to conceal your disability? What are their motives?
- Who encourages you to disclose your disability? What are their motives?
- How does your disability affect others?

Disclosure

- When you choose to disclose your disability, what determines that choice?
- With whom do you share details about your disability?
- What qualities do these individuals have?

Concealment

- When you choose to hide your disability, what determines that choice?
- If your privacy has ever been compromised regarding your disability, how did this take place and who did this? Did a professional do this? What was his or her motivation?
- How would your experience have been different if your disability could be seen?

Expectations from others

- When do you feel like you have to explain or apologize for having a disability? What makes you feel this way?
- Which individuals seem to expect apologies or explanations? What do you think makes them feel this way?
- When do you hesitate to do things you are capable of doing because of what you believe in others will think or expect? How have you been judged for doing things others do not expect you to do because of your disability?
- If you ever have taken on projects or challenges that may not be realistic just to prove others wrong about their expectations of you, would you describe some of those situations?
- When have other individuals ever chastised, threatened, or derided you for activities you carry out, money you spend, or recreation because of your disability?

Others with disabilities

- Who have you known impaired with an illness, injury, or disorder? How did this affect you? What did you feel about this person? What did you feel about his or her impairment?
- What does a disabled person look like? How does he or she behave? Do individuals with disabilities behave in a particular manner?

- Who have you known who tried to hide, conceal, or disguise disabilities? What might have been his or her motives? How did you feel about him or her?

Personal Attitudes

- If you were to wake up tomorrow and by some miracle your disability would be gone, how would your life change? How would you change?
- If you were going to offer advice to someone with a disability, what would it be?

VITA

James Michael King graduated from Pulaski County High School in 1983. He earned three degrees from Radford University. In 1987, he completed his Bachelor of Science degree in English Education. During his undergraduate education, he served as the editor of the university's literary magazine. In 1990, he graduated with a Master of Science degree in English Composition. He participated in the Graduate Teaching Assistantship (GTA) program as an English instructor and founded the RU Writer's Group, which he led for three years and served as advisor for after becoming a faculty member at Radford University. He served as a mentor in the same GTA program as a faculty member as well. In 2000, he earned his third degree, a second Master of Science degree, from Radford University in Counseling and Human Development. During and after his second masters, he worked with the Student Transition Program at Radford University as an instructor and mentor, interned in the Multicultural Affairs Office, and interned and later worked in the Services for Students with Disabilities Office at Virginia Tech. In that office, he coached students with ADD. He also worked in a variety of community counseling and social work situations, taught Governor's School summer classes, worked in an art department, served as advisor for the literary magazine at Radford University, worked as a member of the programming staff for a camp, taught adjunct for New River Community College in English and psychology, and participated in numerous community and college activities. In 2004, he completed requirements for his Ph.D. in Curriculum and Instruction. He is now under contract with Clayton County Public Schools in Jonesboro, Georgia.