Telling a Different Story: Marginality and Empowerment in the Lives of Adults with Cerebral Palsy

BY

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THESIS
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This thesis is dedicated to each of the participants in this study who shared their life stories.

It is also dedicated to my mother and father who gave me the tools to carve my own path, and the support to follow it.

Finally, it is dedicated to my husband, Ryan, whom I somehow discovered along the way.
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SUMMARY

This disability studies based dissertation is a qualitative, phenomenological exploration into the social and psychological experiences of adults with cerebral palsy (CP). While substantial research exists on the physical and social development of children with CP, information on the physical experiences of adults with CP is scant, and empirical studies regarding their social and psychological experiences are virtually nonexistent. However, research on public attitudes towards people with disabilities has indicated that individuals with CP remain one of the most stigmatized impairment groups, most likely because their disorder can be manifested in such a variety of ways (Yuker, 1988; Thomas, 2000). This project sought to explore how stigma impacted the personal identity and social and psychological well-being of individuals with CP. This has significant implications for their ability to live healthy and productive lives in their communities.

Twelve individuals with CP, ages 26 through 49, took part in the research. Participants were recruited from hospitals and disability advocacy organizations as well as from online discussion boards and social networking sites. The research activities included two individual interviews, a diary study, and a virtual focus group. The first interview focused primarily upon participants’ social experiences and their interactions with others during their everyday lives in the community. The second focused primarily upon their identities and psychological well-being. The two interviews were conducted several months apart, and in between participants were asked to maintain a diary where they discussed their regular social activities and/or where they could describe their thoughts and feelings related to having CP.
Most participants did describe instances of being treated differently or of feeling stigmatized in the course of their everyday lives, and several had experienced depression. Many suggested that they struggled for control, not only over their bodies, but to define and maintain their own identities in a culture that prizes health and consistently devalues disability. Yet most had developed strong relationships with a few key individuals: family members, longtime friends, or other people with disabilities. Although several cited the support of family members as critical to their healthy development and self-esteem, these same family members frequently exerted pressure – direct or indirect – on participants to be as “normal” as possible.

However, several had found a niche in the disability community where they were able to find others with similar experiences and unconditional acceptance of their disabilities. Consistent with previous findings (Gill, 1997; 2001), integration into the disability community frequently led to a reformulation of values and a stronger sense of self. While participants who were involved in the disability community more readily described experiences of devaluation in the mainstream community, this affiliation also helped to fortify them in the face of such devaluation. In contrast, those who were not affiliated with the disability community frequently felt a greater need to strictly control how they presented themselves to others as a means of avoiding stigmatization and rejection.

These findings have significant implications for researchers and clinicians who are concerned with the overall well-being of adults with CP. As more individuals with CP are becoming integrated into mainstream society, it is important to consider not only their physical health, but also upon the factors that can elevate their psychosocial health. In addition to working to
improve individual functioning, there should be an increased focus upon removing social barriers, facilitating interpersonal relationships, and building disability identity and community. Attending more closely to these factors will ensure that as people with CP age, they can lead meaningful and productive lives.
I. INTRODUCTION

A. Chapter Summary

In this chapter I outline my rationale for studying the lived social and psychological experiences of adults with cerebral palsy (CP). In discussing the motivations for pursuing this project, I first briefly describe how my personal experience with CP spurred an interest in pursuing this topic. Next, I describe my theoretical orientation before stating my specific research questions and providing a justification for my research methods. I then give an overview of the subsequent chapters in this dissertation.

B. Personal Background

As an adult woman with CP, I have grown quite accustomed to not seeing my own experience reflected or respected in the wider society. Although I have had an impairment my entire life that profoundly affects my embodiment, my everyday encounters with others, and my sense of self, I was raised to be as “normal” as possible and did not begin to identify positively as “disabled” until I reached college. I began college just as the Internet was taking off, and my persistent frustrations with attempting to fit into the mainstream while being one of only two visibly disabled students at school led me to reach out to other people with disabilities online. Discovering a whole new world of “people like me” helped to transform my career ambitions from teaching special education to becoming involved in the disability rights movement. When I discovered disability studies one day while surfing through disability related news articles, I knew that I had, at long last, found my niche. My experience at the University of Illinois at Chicago has completely transformed my life and has helped me to rethink the way I understand my own disability and the experience of
disability in general. Once I entered disability studies, my reading and thinking about
disability was no longer done in isolation, and my connections to people in the disability
community were no longer over a computer screen but rather face-to-face. I quickly found
true friends and mentors, people who genuinely understood and accepted who I was.
Realizing how difficult it was to walk around a large campus in the third largest city in
America, I elected to buy a mobility scooter. Whereas I had previously considered using a
scooter to be a sort of “giving in” to my impairment, I discovered that it was, in reality,
extraordinarily liberating; I found I could now easily keep up with my friends and had
significantly more energy. In short, I no longer viewed my disability as a burden in any way,
but rather as an integral, and very positive, part of who I was.

However, as I made my way through the Master’s program and eventually into the
Ph.D. program, I began to question some of the primary tenets of disability studies and
discovered that they did not always mesh with my own experience. For example, despite the
comfort I had among my friends and the disability community in general, I still felt
misunderstood (literally and figuratively) by non-disabled individuals whom I encountered
during the course of my everyday life. Patronizing looks at the coffee shop and
condescending treatment at the grocery store (“Honey, put your change away; close your
wallet, now”) left me feeling as though my competence as an adult woman was continually
being questioned. I always felt that when I was out in public, I had to be “on,” to never
fumble or make mistakes, and even then I would still be infantilized. And despite all I had
learned about disability being a “social” versus an “individual” problem, those types of
situations still made me feel bad; they often still do. Yet I have often struggled to find my
own experience reflected in the disability studies literature. As a psychology major in
college, I have long been interested in personal experience and the relationship between person and environment. However, as I will discuss extensively in the literature review, upon entering the disability studies field, I quickly became aware of the tenuous relationship that it maintains with psychology. This is primarily because psychology has traditionally perpetuated a very individualized, medicalized approach toward individuals with disabilities, treating them as maladjusted and as social deviants. The field of rehabilitation psychology was developed on the premise that people with disabilities need professional help in adapting to their situation and “fitting into” the mainstream society. Overall, psychologists have given scant attention to how the physical and social environment might be adapted to accommodate people with disabilities. Because disability studies was founded upon the premise that disability is primarily a social phenomenon, it has been understandably reluctant to engage with psychology. This is slowly changing as disability studies has grown and evolved in ways that better acknowledge the role of personal experience. Individuals with various types of impairments have published personal narratives that have been instrumental in helping us to better understand how individuals experience disability on a social and psychological level. However, there are relatively few empirical studies concerning these experiences from a disability studies perspective. Both disability studies and psychology should work to bridge the divide between disciplines, and it is hoped and anticipated that this dissertation will contribute toward that goal.

As I forayed further into the field, I also became aware that, in terms of the literature that is available on the experience of disability, certain impairment groups are underrepresented in comparison to others. Historically, much of the foundational literature in disability studies has been based in the experiences of individuals with acquired physical
impairments, without thoroughly reflecting those of individuals with developmental and intellectual impairments. As the discipline has grown, scholars have made significant strides in better capturing the experiences of individuals with intellectual disabilities and some developmental disabilities. However, particular impairment groups within this category have remained significantly understudied and underrepresented in the academic literature. My own impairment, cerebral palsy, is one example. Despite the prevalence of literature concerning children with CP, I have been disturbed by the lack of research available regarding the experiences of adults with CP who do not have intellectual impairments. Even information related to the medical needs and characteristics of adults with CP is hard to come by, and empirical research regarding the social and psychological experiences of this population is virtually nonexistent. It is likely that, in terms of their social and psychological experiences, adults with CP do share much in common with people with other types of physical impairments. However, it is also likely that they face unique issues, due to certain physical characteristics often associated with CP (e.g., speech difficulties, drooling, spasticity, etc). My research study consists of an initial effort to explore some of these issues from a disability studies perspective.

C. Disability: Political and Personal

As a student of disability studies, my research is grounded in the assumption that disability is primarily a social construction. That is, rather than adopting the mainstream view of disability as a characteristic of an individual, I operate upon a socio-political perspective that disability is imposed upon an individual by a society that is reluctant to accommodate bodily difference. As Reeve (2008) puts it: “Disability is often seen as a structural or material barrier which prevents someone with an impairment from taking part in society; it is
experienced *on top of* impairment, not *because of* impairment” (p. 1). Scholars and activists have worked diligently to combat the “tragedy model of disability” or the notion that disability is an individual burden that should be alleviated through whatever means possible. Instead, they often point out that there is nothing intrinsically bad about having an impairment; what is problematic, however, are the ways that society systemically oppresses and excludes individuals with impairments from multiple dimensions of daily life. However, in doing so, scholars have also neglected the very real psychological effects of navigating a disabling society. Fortunately, in the past few years, a number of researchers *have* begun to explore this vital topic. For instance, Carol Thomas (2004) has proposed an extended social relational definition of disablism, where she argues that disability is “a form of social oppression involving the social imposition of restrictions on activity of people with impairments and the socially engendered undermining of their psycho-emotional well-being” (p. 73).

Building off of Thomas’s work, Reeve (2008) has more thoroughly attended to the lived experiences of psycho-emotional disablism, which represents not only the barriers that limit “what people can do,” but also those that limit “who people can be” (p. 2). Both scholars discuss how the structural obstacles that disabled individuals encounter constitute only part of the oppression that they face. Equally, if not more, problematic are the pervasive negative attitudes and stereotypes that significantly restrict disabled people’s opportunities for social integration and equal participation alongside their non-disabled peers. These restrictions can profoundly influence the ways that disabled individuals come to view themselves and their capabilities; in other words, they may begin to internalize the societal
oppression that they encounter, and/or to “give up” in the face of such seemingly insurmountable obstacles.

Although Thomas and Reeve have both made vital contributions to the “psychology of disability” and indeed to the field of disability studies as a whole, their focus is largely restricted to the detrimental effects of living in a disabbling society. A more complete “psychology of disability,” however, must also include a focus upon how people with disabilities successfully navigate the barriers that they encounter in order to continuously grow and to find meaning in their lives. In her discussion of the disability experience, Gill (2001) notes that

…people with disabilities are organizing to set the record straight about who they are collectively. They are broadcasting their identities by developing and implementing far-reaching disability awareness education, excavating and celebrating disability history, engaging in media activism, and writing articles, books, plays, and television scripts about the disability experience. Most affirmatively, they are declaring positive disability identity through disability pride and cultural activities, including projects focusing on the peer mentoring of young disabled people. (p. 364)

D. Research Questions

To this end, the primary aim of this research project is to explore the lived experiences of adults with CP, particularly focusing upon their experiences of marginality, empowerment, and meaning making. I approach this project through the lens of social psychology, a “science that studies the influences of our situations, with special attention to how we view and affect one another” (Meyers, 2005, p. 4). Many scholars in disability studies are reluctant to engage with psychology, arguing that it “appears to be obsessed with difference” and “cattle-prodding back into submission that which deviates from the norm” (Goodley & Lawthom, 2006, p. 5). While it is true that disability has traditionally been relegated to the domains of abnormal and rehabilitation psychology, Goodley and Lawthom
point out that psychology is actually a “collection of many different communities, each with their like-minded members, constituting a myriad of psychological paradigms” (p. 5). In approaching my research through social psychology, I try to stay true to a disability studies perspective, which focuses upon how particular individuals are cast as “the other” through various interactions and situations. Questions of attitudes, stereotyping, and prejudice all fall under the umbrella of social psychology, as do issues of group identity and community. Specifically, my research questions are: (a) “How do adults with cerebral palsy experience their disabilities on a social and psychological level?” and (b) “How, and to what extent, are they able to effectively integrate these experiences in order to formulate lives that they characterize, through their narratives, as rich and meaningful?”

E. **Research Methods**

This dissertation is *not* an autobiographical or auto ethnographic study, nor is it an attempt to better understand and make sense of my own experience. I have described my personal journey thus far only as a means of delineating the rationale for this study; from herein, I will not be making reference to myself or to my own experience, except briefly in the course of discussing my methodology and in the relatively rare instance that it briefly comes up in conversations with interview participants. I recognize that, collectively, adults with CP have an incredibly diverse array of personal traits, backgrounds, and experiences. My objective is to better comprehend and to characterize some of these experiences, and to determine to what extent they share any common threads with one another.

In this study, I have utilized qualitative methods as such methods are best suited to an exploratory investigation with very broad research questions. Additionally, qualitative methods are frequently most effective for capturing participants’ own voice and genuine
experience, which is, of course, the primary goal of this research study. Specifically, I conducted two interviews with each participant and asked each participant to keep a diary of her/his experiences. I also facilitated an online discussion board where participants could “meet” and interact with one another.

Importantly, in no way do I mean to suggest, either here or later on in this manuscript, that there is a singular, unifying “experience of CP,” or that most individuals’ experiences resemble my own. As mentioned above, even before I set out to collect my data, I believed there to be an enormous array of experiences of CP and feelings about having CP. A glimpse into the lives of each of my participants confirmed that belief. However, the primary objective of this study is to capture those experiences and to determine whether there are, in fact, some similarities and why that may be so. At the same time, I am equally interested in exploring the differences among those experiences and speculating about why that may be the case. I elected to utilize phenomenological description as this study is a preliminary investigation in the experiences of adults with CP from a disability studies perspective. I utilize traditional disability and disability studies literature to provide background and then later to situate my findings. In future grounded theory investigations, I hope to individually explore each of these findings in greater depth. For purposes of this phenomenological study, however, my aim is primarily to describe participants’ experiences as thoroughly as possible, and then to offer some preliminary possible understandings of these experiences.

F. Outline of Chapters

Chapters two through four consist of an extensive literature review. Chapter two outlines the literature regarding disability and psychology, dating back to 1960 when Beatrice Wright published her seminal work *Disability: A Psychological Approach*. A
discussion of Erving Goffman’s (1963) classic *Stigma: Notes on the Management of Spoiled Identity* and Fred Davis’ (1961) descriptions of interactions between disabled and non-disabled individuals is complemented by a brief overview of the past and present rehabilitation psychology literature. This literature has traditionally conceptualized disability in terms of coping and adapting to loss, but has more recently adopted somewhat more enlightened approaches, taking into account environmental factors that contribute to disability and also personal and social factors contributing to individuals’ resilience.

Chapter three consists of a review of the disability studies based literature that does exist regarding disability, psychology, and personal experience, including a more in-depth discussion of why disability studies and psychology have maintained such a tenuous relationship. It reviews literature by well known psychologists in disability studies, including Donna Reeve, Carol Gill, Carol Thomas and others.

Chapter four reviews the very limited literature that does exist regarding the experiences of individuals with CP. After briefly summarizing the literature on the social and psychological experiences of children with CP, it discusses what little is known about those of adults with CP. In addition to empirical evidence, it includes anecdotal information gleaned from personal narratives, documentaries, and even poetry that provides insight into the lives of this group.

Chapter five details the methods I utilized to collect my data, including an explanation of why I chose to do a phenomenological qualitative study and why I chose the types of data collection techniques that I did. It discusses how I recruited and selected my participants, how I devised my interview guide, and the actual process of gathering
information. In this chapter, I also outline my analysis procedures and describe the ethical questions that arose during the course of the study.

In chapter six, consistent with phenomenological data analysis, I present descriptions of each participant’s experience with CP. These are “individual structural descriptions,” or reworded and reorganized versions of participants’ own descriptions (as gathered through their diary entries and responses to interview questions).

Chapter seven presents a summation or collective description of participants’ experiences. This chapter discusses the major themes and findings that emerged during the data collection process. Additionally, it compares and contrast participants’ experiences and hypothesizes about why particular similarities and differences might exist.

Similarly, chapter eight consists of a synthesis and critical examination of the underlying themes that emerged during the investigation, culminating in a unified statement concerning the social and psychological experience of individuals with CP. Here, instead of simply describing what individuals’ experience, an attempt is made to interpret why they experience it. Existing literature is utilized to help develop and explain findings from the present study. This chapter also discusses the study’s limitations, implications, and possible directions for future research.

G. **Chapter Conclusion**

In this initial chapter, I have attempted to “set the scene” for the reader by introducing both the research problem and how and why I intended to interrogate it. In the process, I have discussed both my personal and theoretical orientation towards disability in general and CP in particular. Throughout the writing of this document, and indeed throughout the entire research process, I have struggled with questions of orientation and intended audience. Is this
primarily intended to help fill the void of research on adults with cerebral palsy? Is it intended to examine the relationship between psychology and disability, and to bridge the gap between psychology and disability studies? Is it intended as a blending together of disability studies and phenomenology? Each of these objectives is worthy of an entire lifetime, and I cannot possibly expect to fully realize each of these intentions during the course of a doctoral thesis. However, for me, and I suspect for many students in my field, the dissertation journey has not been about answering the questions but rather about starting to understand what to ask.
II. TRADITIONAL APPROACHES TO EXAMINING DISABILITY, SOCIAL INTERACTION, AND PSYCHOLOGY

A. Chapter Summary

Throughout the past half-century, the social and psychological experience of disability has been conceptualized in a variety of different ways. This chapter outlines the early literature on disability and psychology, including the work of Beatrice Wright (1960), Erving Goffman (1963), and Fred Davis (1961). It also explores understandings of the disability experience as they have been detailed in past and present rehabilitation psychology literature, and discusses how more modern theories of social stigma and the self could be applied to disability.

B. Beatrice Wright: Pioneer

In 1960, Beatrice Wright, a rehabilitation psychologist far ahead of her time, introduced her book *Physical Disability: A Psychological Approach* with these words:

We are sure that there are far fewer psychological experiences peculiar to persons with disabilities than an offhand guess might indicate. Even in the case of sensory loss, as in blindness and deafness, the psychological significance of the deprivation has to do in large measure with such matters as the threat of social isolation, the struggle for independence, acceptance of a personal limitation, and so on—experiences in which many, if not all, human beings are conversant. (p. 3)

Wright and her colleagues were among the first to distinguish between “disability” and “handicap,” identifying the first as a “condition of impairment, physical or mental, having an objective aspect that can usually be described by a physician,” and the latter as a “the cumulative result of the obstacles that disability interposes between the individual and his maximum functional level” (p. 9). She later noted that “a handicap must be evaluated
in terms of the demands of the situation in which an individual finds himself,” suggesting that it is largely determined by external rather than internal influences. Importantly, this is the foundational premise of the social model of disability, which was developed by disability activists over two decades later.

Utilizing extensive empirical evidence, Wright also pointed to an “oversimplified connection” between disability and feelings of inferiority, despite a widespread belief among psychologists, rehabilitation professionals, and even the general public that the two were inextricably linked. She further suggested that the onset of disability is frequently accompanied by a shift in values that “appear[s] significant in the process of accepting one’s disability and oneself” (p. 107). Specifically, she argued that individuals with disabilities frequently place less emphasis upon their physical appearance than do their able-bodied counterparts. Instead, they come to value other characteristics such as their personality or their academic abilities. Additionally, they work to “contain the effects” of disability and focus upon the aspects of themselves that are still “normal,” working particularly hard to highlight these characteristics in their interactions with others. Finally, in some cases, individuals with disabilities actually learn to view their disability as an asset value; in other words, the disability has allowed them to accomplish something that they would not have otherwise done, or to have a particular characteristic that they would not otherwise have if not for the disability.

Wright went on to argue that these value changes have direct and significant implications for people with disabilities’ self-concept (p. 152). For instance, when individuals adopt other values that do not relate significantly to their disabilities, their disabilities typically will not play such large roles in determining their overall self-
concept as when the disability-related values assume precedence. Likewise, when individuals are able to “contain the effects” of their disabilities, the disabilities will likely have less influence upon their overall self-concept. Finally, to the extent that individuals are able to transform their disabilities into assets in certain situations, they are actually more likely to have heightened self-concepts.

Further, Wright described how individuals’ self-concepts have important ramifications for their everyday interactions with others and their interpersonal relationships. She wrote:

When [individuals] viewed their disability with shame and derision, they could only expect that others felt likewise; this is what they saw in the questioning, the staring, the help of others. When they were able to accept their disability more fully, it became sensible that others could view them as self-respecting, worthwhile, and even admirable. (p.167)

Although Wright acknowledged that expectations and self-regard do not control all social reality, she did suggest that they can significantly influence an individual’s perception of the situation and his or her subsequent behavior. Because others’ attitudes in a social situation are often difficult to pin down, individuals often behave according their own beliefs and expectations about how others are going to respond to them. This often results in a self-fulfilling prophecy. For example, if a disabled individual has frequently been rejected in the past, he or she may expect not to be accepted or liked by an interaction partner. He or she may then refrain from interacting with that person at all or give off cues of aloofness during the interaction. The potential partner therefore keeps his or her distance as well, and the individual’s expectations are confirmed. Wright suggests that the strength of these expectations is affected by a variety of factors, including frequency of past confirmation (has the individual been frequently rejected in the past?), and the
number of alternative expectations (what/how many alternative scenarios can the individual contemplate?). It is further influenced by supporting context (can similar hypotheses be supported?), motivational consequences (does the expectation of rejection satisfy an individual’s need in some way?), and shared verification (is the individual surrounded by others – i.e., family members – who believe that disability automatically results in rejection?). In summary, Wright argued that:

The self-concept is crucial in determining those expectations. The self-concept is psychologically of such great importance that it can hardly be overlooked, though to be sure other factors, such as environmental conditions and the actual attitudes of others must not be overlooked. (p. 169)

C. **Erving Goffman and Stigma**

Despite Wright’s contention that the psychological experiences of people with disabilities did not differ drastically from those of non-disabled individuals, eminent sociologist Erving Goffman (1963) believed differently. In his groundbreaking work, *Stigma: Notes on the Management of a Spoiled Identity*, Goffman argued that humans categorize one another as a means of making sense of the world around them (p. 2). When an individual possesses a relatively unique or unusual attribute, he or she is frequently marked as different and as having a shortcoming. To this end, Goffman defined “stigma” as an attribute that is deeply discrediting (p. 3). He argued that we often see individuals with stigmas only in terms of the discrediting attribute, that we sometimes view them as “not quite human,” and that, in accordance with the gestalt principle, we “impute many imperfections based upon the original one” (p. 5). Although Goffman referenced several marginalized groups in his writing, he most frequently highlighted the experiences of people with disabilities.
In contrast to Wright, Goffman argued that stigmatized individuals tend to internalize the negative attitudes towards them that “normals” (his term for non-stigmatized) individuals possess. He suggested that because stigmatized individuals frequently experience shame and self-hatred, they often work to avoid contact with “normals.” When they do have to interact, they make an effort to seem as typical as possible, all the while worrying what others are thinking (p.14). However, Goffman also argued that stigmatized individuals have a responsibility to integrate into the larger society as much as possible, and that they should attempt to put non-stigmatized individuals at ease and to protect them from a fear of difference (p. 104). To do so, contended Goffman, stigmatized individuals must educate the “normals,” satisfy their curiosity, and even request assistance from them as a means of “breaking the ice” (p. 110).

Goffman further discussed how both the degree of visibility and the perceived obtrusiveness of the stigma affect how it is perceived by others. For example, a disfigured hand or missing finger might not be highly visible to others, nor would it likely be considered to be particularly obtrusive in social encounters. However, a large facial scar would be immediately apparent and because we rely so heavily upon another’s facial cues and characteristics to provide information about that individual, such a scar might be very discrediting for an individual. As I will later argue in more detail, cerebral palsy could be considered one of the most stigmatizing impairments because it often affects multiple regions of the corporeal self. On the contrary, other impairments such as paraplegia, amputation, and even hearing and visual impairments are confined to a single region of the body. To this end, Goffman argued that an individual’s personal identity
significantly affects his social identity, and that the further an individual deviates from the norm, the more we question that personal identity (p. 59).

Goffman suggested that in order to combat these problems, stigmatized individuals frequently work to conceal their differences from others as much as possible. Writing that “the greatest rewards are in being considered normal,” he argued that individuals will often try to “pass” when it is feasible to do so in order to avoid stigmatization (p. 74). However, “passing” is a learning process in and of itself and often has its own set of problems, including the fear of being “brought out,” or “discredited,” as well as the difficulty with “biographical discontinuity” (e.g., leading a double life) (p. 78). Sometimes, Goffman indicated, individuals are confronted by an “unanticipated need to disclose their stigma,” such as when they are “betrayed by their bodies” or by other individuals with insider knowledge about their conditions” (p.83-84).

Goffman went on to explain that despite the pressure upon disabled and other stigmatized individuals to “pass,” they should not go as far as defining themselves as normal (p.115). Although he argues that “a [stigmatized] individual’s ‘real’ group is his fellow sufferers,” he also contends that “to identify with fellow sufferers leads to alienation, separation, and non-inclusivity” (p.113). He concluded his discussion of stigma by stressing that stigma management is a general feature of society, that everyone has experience with stigma to some degree or the other, and that it serves a general purpose of moving society forward.

D. **Fred Davis and Deviance**

Psychologist Fred Davis’ (1961) empirical work appeared to substantiate Goffman’s assertion that people with disabilities occupied an inferior social position as
compared to their non-disabled counterparts. Davis was interested in everyday social interactions between visibly disabled and non-disabled individuals. In particular, he was concerned with “situations which fall within a range of involvement which can also be thought of as the zone of first impressions” (p.164). After interviewing individuals with physical impairments, including blindness, orthopedic conditions, and facial disfigurements, Davis found evidence of strained interactions between individuals with and without disabilities.

Davis referred to an individual’s impairment as posing a “threat to sociable interaction” in several distinct ways. First, at least initially, the impairment may become the focal point of the interaction, simply because of its distinctive character. In trying to pretend as though he is not focused primarily upon the impairment, the non-disabled interaction partner may consciously avoid making any reference to it. This effort significantly contributes to his or her discomfort and thus increases the overall strain of the interaction (p.166).

Strongly related to this, for the non-disabled interaction partner, an individual’s impairment may mask the other characteristics of an individual. If the partner is even aware of any other characteristics besides the impairment, then he or she must work to reconcile the fact that a person with a disability can also be intelligent, attractive, hard working, etc, or even that he or she can be in a store buying his groceries or at a restaurant eating dinner like an ordinary Joe (p.166).

Thirdly, Davis stressed that the presence of the impairment may preclude, or at least impede, joint activity between interaction partners (p.166). For example, in many instances the non-disabled individual is left to wonder to what extent the individual with
a disability can participate in given activities, but is reluctant to simply ask the disabled person for fear of offending him. The disabled individual, on the other hand, is left to wonder whether he is really wanted or whether his interaction partner is “merely being polite” (167).

Davis further suggested that successful interactions between members of the two groups proceed through several stages, including “fictionalized acceptance,” “breaking through,” and “institutionalization of the normalized relationship.” During “fictionalized acceptance,” “the disability…is at the forefront of consciousness of both parties, and both must take steps to normalize the meeting,” a process that Davis called “deviance disavowal”. Here, the participants try to conduct themselves as if “nothing were amiss, as if there were no hidden agenda” (p. 168). Although he suggested that both parties contributed to smoothing over the interaction, Davis implied, as did Goffman, that the disabled individual was primarily responsible for putting his non-disabled interaction partner at ease and to make him less nervous about the possibility of saying something hurtful or inappropriate. Furthermore, Davis suggested that, in many cases, the relationship may never progress beyond this “fictionalized acceptance.” “As with the poor relation at the wedding party,” he wrote, “so the reception given the handicapped person in many social situations: sufficient that he is here, he should not expect to dance with the bride” (p.168). Although Davis acknowledged that this type of interaction is “transparent” and “confining” for the individual with a disability, he also argued that “it is frequently the only basis upon which the contact can develop into something more sociable.” In other words, only by carrying the initial burden of putting a partner at ease
can a disabled individual expect to eventually have a genuine, comfortable interaction (p. 168).

The second stage of the interaction, according to Davis, involves the non-disabled individual relating to the disabled individual as though he were also non-disabled, “a goal Davis presumed is desirable to most disabled persons” (Gill, 2001, p.356). During this stage, which Davis referred to as “breaking through,” the disabled individual begins to disclose information about himself as a means of emphasizing his normality and shared interests and perspectives with his interaction partner, thereby encouraging him or her to identify with him on an equal level. “In broadening the area of minor verbal involvements, this also functions to drain away some of the stifling burden of unspoken awareness that, as we have seen, so taxes ease of interaction” (p. 168). Importantly, Davis also pointed out that this process can have significant implications for the disabled individual’s positive identity and psychological well-being. “As the handicapped person expands the interactional nexus,” wrote Davis, “he simultaneously disavows the deviancy latent in his status” (p. 169).

Davis further indicated that “deviance disavowal” can assume multiple forms. For instance, during the course of a conversation, a person with a disability may act particularly attentive to the non-disabled individual’s interests. Alternatively, he may simply highlight his participation in “normal” activities. In other cases, he might emphasize his own talents, or may utilize humor (especially regarding his own impairment) to break the tension. Davis points out that the ways that deviance disavowal is accomplished is largely dependent on contextual factors as well as personal characteristics of the interaction partners.
Finally, the third stage of the interaction involves “institutionalizing” the relationship, such that the normalization that has just taken place can be sustained, even in other unfamiliar situations and with other unfamiliar individuals and where the disabled individual’s behavior may deviate even further from the norm (p. 171). For example, during the process of institutionalization, the non-disabled individual might have to learn how to provide physical help to the disabled person or how to successfully involve the disabled person in larger group activities. Davis also suggested that the relationship can also be institutionalized through the non-disabled individual “joining the handicapped person in a marginal, half-alienated, half-tolerant outsider’s orientation to the Philistine world of normals” (p.171). Davis never went on to explore the potential psychological ramifications of this course of action for the individual with a disability. However, as did Goffman (1963), Davis also highlighted in his concluding remarks how the experience of feeling socially marginalized is a relatively common one. Writing that “the interactional problems of the visibly handicapped are not so dissimilar from those that all of us confront, if only now and then and to a lesser degree” (p.172), Davis did allude to a need to more thoroughly study the psychological ramifications of these interactions from a disabled individual’s personal perspective.

E. **Traditional and Modern Rehabilitation Psychology Perspectives**

Most of the present day literature relating to disability and psychology has been in the area of rehabilitation psychology. However, in his critique of rehabilitation psychology, Joseph Stubbins (1989) wrote that:

Rehabilitation psychologists (as well as other kinds of rehabilitationists) have, in effect, constructed a world consisting of a disabled person whose environment is either a constant or is only marginally relevant to the particular individual’s problems. The disabled person does not resemble many in real life. He or she is a
static entity with a functional deficit that could be dealt with more competently, a
person who needs advice and training in the business of finding a sympathetic
employer, and counseling in how to break out of social isolation. (p. 209)

Stubbins goes on to describe how the traditional goal of most social science
disciplines dealing with the “problem of disability” has been to “measure, manipulate,
and change” (209). Since its inception, rehabilitation psychology has been primarily
concerned with helping disabled individuals adjust and adapt to their situation. The
rehabilitation psychology literature has been largely devoted to theorizing and working to
validate the various “stages of adjustment” that a person with a disability must go
through. Consequently, this literature has been almost exclusively devoted to individuals
with acquired impairments, and rarely acknowledges the experiences of individuals with
congenital impairments or with impairments acquired in childhood. However, after years
of seeking concrete evidence for a linear progression of stages, rehabilitation
psychologists now acknowledge significant variation in individuals’ experience of
disability (Gill, 2001).

Although research does indicate that many individuals with acquired impairments
do often experience similar patterns of adjustment, there is insufficient evidence to
conclude that all individuals experience all stages, or that the stages always occur in a
particular order (Antonak & Liveneh, 1995). Moreover, an individual may fluctuate
between stages rather than experiencing them linearly. Additionally, age, education level,
socioeconomic status, emotional support, and individual and familial attitudes towards
disability in general all appear to play important roles in the adjustment process. Again,
the research addressing adjustment to disability naturally addresses individuals with
acquired impairments. While extensive research exists on familial adjustment to
childhood disability, little research is available regarding the ways that children adapt to and reconceptualize their own disability experience as they grow.

Paralleling discussions of adjustment, another significant theme in the rehabilitation literature is the concept of “normalization,” which first appeared in the late 1960s, and has been frequently applied to the educational and therapeutic treatment of individuals with developmental disabilities (Wolfensberger & Tullman, 1982). In discussing the application of their theory to rehabilitation psychology, Wolfensberger and Tullman wrote that “Normalization implies the use of culturally valued means to enable, establish, and/or maintain valued roles for people” (p. 131). It is premised upon the theory that if an otherwise socially devalued individual were to acquire and maintain socially appropriate valued roles, then he would be more likely to be positively perceived and treated by others. This, in turn, would positively affect his own behavior and potential for achievement and integration. “People who are cast into a socially devalued role,” continued Wolfensberger and Tullman, “need to experience not only life conditions that are relatively typical, common, and prevalent for non-devalued citizens, but optimally even those conditions that are highly valued by the culture” (p. 140).

Wolfensberger and Tullman further described how social role enhancement is achieved through both image enhancement and competence enhancement, and indicated that “often people with physical, mental, or emotional impairments also have functional impairment(s) that render them less competent than non-impaired persons” (p. 140). Like Goffman, Wolfensberger “stressed the appearance of conformity and the need for people to hide their deviancy” (Preventer, 2001, p. 277).
Thus, for several decades, rehabilitation psychology as a discipline appears to have been significantly more concerned with empirically demonstrating its theories of adjustment and with successfully “normalizing” people with disabilities than with how disabled individuals actually experienced their own lives. However, with the advent of the Independent Living and Disability Rights Movements, increasing numbers of individuals with disabilities began to assert their civil rights and to demand equal opportunities for societal participation. As models of rehabilitation have gradually evolved beyond the functionalist paradigm to acknowledge the role of the external environment in the disability experience, rehabilitation psychology as a field has also acknowledged that disability is about far more than just adjustment and normalization. The most comprehensive health model of disability to date, the International Classification of Functioning (ICF), which has been widely adopted by rehabilitation professionals, including rehabilitation psychologists, cites social barriers as a significant aspect of the disability experience. The ICF is centered upon two broad components: body functions and structure, and activities and participation. According to the Centers for Disease Control:

Functioning and disability are viewed as a complex interaction between the health condition of the individual and the contextual factors of the environment. The picture produced by this combination of factors and dimensions is of the person in his or her world. (Centers for Disease Control, 2008)

However, Lutz and Bowers (2007) point out that:

As in previous rehabilitation models, the defining construct is the health condition (i.e., the disease or disorder) and its resulting effect on individual function. Disabling barriers of society are considered as context; however, functionalist assumptions prevail in the ICF by continuing to direct our attention (as researchers and practitioners) to the health condition and its effect on a person’s ability to function in social roles. (p. 16)
Thus, despite an increased emphasis upon contextual factors, rehabilitation psychology remains tethered to traditional understandings of disabilities. Rather than focusing upon altering the physical and social environment to accommodate individuals with disabilities, it is primarily concerned with altering the individual to more effectively cope with the demands of his or her environment. Many rehabilitation psychologists readily acknowledge that people with disabilities will experience stigma and discrimination due to their abnormality. In their discussion of the personal impact of disability, Phemister and Crewe (2007) note that:

...generally our society values good health, a particular physique, and the concept of body beautiful. This is a social standard that, for many individuals with disabilities, simply cannot be met--a discrepancy that cannot be reduced...human differences are the basis of stigma and those individuals who have differences may feel permanently stigmatized in situations where their differences are pronounced...unless social attitudes change, [this] could mean that an individual is continually striving against the grain. (148-149)

The authors emphasize that younger individuals are particularly at risk of internalizing others’ negative perceptions of them because they are still in the process of forming their identities, while older individuals have already established their identities. Like Goffman and Davis, in assuming that disabled individuals will always subscribe to mainstream values and strive to attain societal ideals, they paint a relatively bleak picture of disabled people’s psychological makeup. Moreover, they suggest that it is ultimately incumbent upon disabled individuals (perhaps with the help of therapeutic intervention) to effectively negotiate these situations in order to maintain a sense of wholeness and balance in the face of seemingly inevitable social discrimination.

F. Applying Recent Research on Stigma and Self-esteem to Disability
However, other research has suggested, along the lines of Beatrice Wright, that people with disabilities are frequently more immune to societal attitudes, and that they often put less emphasis upon their impairments and instead come to value other aspects of themselves (Gill, 2001). This idea has been supported by more general findings on stigma and self-esteem demonstrating that an individual’s self-esteem depends largely upon the beliefs and meanings that an individual possesses, particularly beliefs about what makes her worthwhile. In other words, self-esteem is not necessarily based upon the approval of others, but rather is a reflection of the abilities and characteristics that an individual deems important and whether she possesses them (Crocker & Quinn, 2000). For example, an individual with CP who cannot attain our high cultural standards of athleticism might instead come to place greater value upon her intellect or even her emotional connections with others, taking these as “evidence” that she is a worthwhile individual. While some rehab psychologists might consider this to be an aspect of “coping” with a disability or settling for less, to emphasize one’s abilities does not seem to be unique to individuals with disabilities at all, but rather a more general feature of the human condition.

Similar research has indicated that situational factors play a significant role in determining the extent to which a stigmatizing attribute affects self-esteem (Crocker & Quinn, 2000). Although we tend to view self-esteem as a stable personality characteristic, Crocker and Quinn argue that typically it is actually highly dependent upon the situation at hand. As discussed above, an individual’s particular set of values and beliefs exerts a significant role in this process, but these values can assume a variety of different meanings from situation to situation. For example, while an individual with CP might not
value athleticism on a day-to-day basis that may change if she suddenly is in a situation where everyone is playing basketball and she is left out of the game. Moreover, the authors point out that very subtle features of the situation can affect the way an individual perceives it and its corresponding effect on her self-esteem. They also note that the situation may have different implications for some stigmatized individuals but not for others, writing that:

To understand the effects of having a devalued identity on the self, we must understand both the collective representations that stigmatized individuals bring to situations, and the features of the situation (often very subtle features) that make those collective representations relevant or irrelevant in that situation. (159)

Attributions can also play a vital role in determining how devaluation affects self-esteem and overall self-concept. In a series of experiments, Crocker and colleagues (1991) found that women and African-Americans who blamed experiences of being treated differently upon gender and racial discrimination had higher self-esteem than those who blamed those experiences on personal shortcomings. Moreover, if participants were given reason to suspect that their interaction partner had sexist or racist tendencies, they were even more likely to attribute the devaluation to discrimination. If, on the other hand, they believed that their interaction partner was unaware of their gender or race, then they attributed devaluation to personal shortcomings, which, in turn, appeared to negatively influence self-esteem. Other researchers have demonstrated that simply being aware of the existence of stereotypes about their group can lower one’s self-esteem or lead her to doubt her abilities (Steele & Aronson, 1995). For example, researchers found that African-Americans performed worse on a test if they were primed beforehand to believe that the test was diagnostic of intellectual ability than if they did not receive any information about why the test was being given.
Finally, the perceived controllability of a stigmatizing attribute also affects its degree of influence on self-esteem (Croker & Quinn, 2000). Research with overweight women, for instance, indicates that when women are primed to believe that they can control their weight, they are more likely to attribute social rejection to their weight, and to see themselves as deserving of such rejection. On the other hand, when women are primed to believe that their weight is due to genetic factors and their biological makeup, then they are more likely to attribute social rejection to prejudice. These studies have significant implications for individuals with disabilities. To the extent that disabled people view their bodily differences as deviances and the barriers that they encounter as functional limitations, they may be more likely to internalize the mistreatment they face and to attribute it to their personal shortcomings.

**Chapter Conclusion**

This chapter has demonstrated that while much of society readily acknowledges the existence of racism and sexism, when it comes to disability, we are still entrenched in ideologies that effectively “blame the victim.” In other words, despite scholars’ and activists’ attempts to show otherwise, society still views disability as an individual issue rather than a social one. Even many people with disabilities themselves attribute difficulties negotiating their environment to their impairment rather than to external physical and social obstacles. Psychology, as a field, acknowledges the relevance of situational factors and constructed meaning when researching human behavior. Nonetheless, the experiences of individuals with disabilities are often still relegated to the domain of rehabilitation psychology, which remains firmly entrenched in the traditional functional and individualistic paradigm of disability.
III. DISABILITY STUDIES BASED APPROACHES TO EXAMINING DISABILITY, SOCIAL INTERACTION, AND PSYCHOLOGY

A. Chapter Summary

The previous chapter examined traditional understandings of the social and psychological experience of disability. This chapter explores newer perspectives on the disability experience, especially those based upon the social and related models of disability. A discussion of disability as a form of social oppression is followed by a review of the disability identity literature. Next, a call for more phenomenologically based investigations is complemented by illustrations from qualitative studies that have been conducted regarding the social and psychological experience of disability. Finally, this chapter also addresses and explains the historically tenuous relationship between psychology and disability studies, illustrating how recent research has worked to bridge the divide and how the present study is intended to contribute to this effort.

B. Social Model of Disability and Disability as Social Oppression

Despite the ICF’s comprehensiveness and its effort to acknowledge the role that the social environment plays in creating and sustaining disability, it still “locates disability in the person; its central focus is on the disease process and in the patient’s resulting functional limitations” (Lutz & Bowers, 2007, p. 14). Disability studies scholars and activists thus refer to this as the “individual model” or the “medical model” of disability. In contrast, such scholars and activists typically subscribe to the “social model” perspective of disability that has its roots in the disability rights and independent living movements of the 1960’s and 70’s, as well as the early days of
disability studies academic discourse. The social model fundamentally locates disability in the external environment, and proponents claim that:

Disability is not a condition of the individual. The experiences of disabled people are of social restrictions in the world around them, not being a person with a ‘disabling condition.’ This is not to deny that individuals experience ‘disability’; rather it is to assert that the individual’s experience of disability is created in interactions with a social world. (Swain, Finkelstein, French, & Oliver, 1993, p.2).

The social model distinguishes between “impairment” and “disability,” defining impairment as “lacking all or part of a limb, or having a defective limb, organ or mechanism of the body.” “Disability,” on the other hand is understood as “the disadvantage or restriction caused by a contemporary social organization that takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (UPIAS, 1976, p.3). Thus, according to the social model, individual impairments do not cause disability; instead “disability is manufactured by attitudinal and environmental barriers rather than functional limitations” (Finklestein, 1991, p.39). For many proponents of the social model, impairment is simply another aspect of human diversity, like sex or skin color. Disability, like gender or race, is a culturally constructed category based upon particular social norms and standards. For example, an individual with CP who uses a wheelchair would be disabled not by the CP itself, but by a society that systematically oppresses individuals with CP because they do not meet culturally sanctioned standards of appearance and/or ability.

As disability studies scholar James Charlton indicates, oppression occurs when: “Individuals are systematically subjected to political, economic, cultural or social degradation because they belong to a social group. Oppression of people results from structures of domination and subordination, and, correspondingly, ideologies of
superiority and inferiority” (Charlton, 1988, p.8). As it is often manifested in terms of poverty and powerlessness, some have argued that up to 85 percent of the world’s population suffers from oppression, and sociologist Iris Marion Young (1990) contends that, for minority groups: “Oppression is the central category of political discourse” (p.39).

Young identifies and distinguishes between five distinct types of oppression: (a) marginalization of individuals that society deems as not useful; (b) exploitation of individuals such that the energies and labor of the lower classes are continually expended to maintain the power, status, and wealth of the dominant class; c) powerlessness of the working class, which is forced into subordination and generally unable to exercise any significant autonomy, expertise, or creativity; (d) cultural imperialism by the dominant class, such that its experience is rendered as the norm while the experiences of other groups either become invisible or are deemed less important or deviant; and (e) violence against individuals simply because they belong to a certain social group.

As a group, people with disabilities are subject to each of these types of oppression (Barnes & Mercer, 2003; Charlton, 1998). Throughout most of history, disabled individuals have been made to live on the margins of society, systematically excluded from the mainstream of everyday life. Often segregated into institutions or forced to rely upon welfare benefits and services, they have been denied basic privileges, choices, and citizenship rights that many non-disabled individuals take for granted. Even when they are physically integrated into the mainstream, disabled individuals frequently continue to experience various forms of social exclusion.
For example, as a group, people with disabilities are undereducated and underemployed. As children, they are often placed in segregated schools or classrooms where they are subject to lowered expectations and receive an inferior education in comparison to their non-disabled peers (Barnes & Mercer, 2003). As adults, individuals with disabilities often have difficulties securing good employment opportunities, both because of their poor education and training, and also because of pervasive attitudinal barriers and misinformation about what disability is really like. These negative attitudes become reinforced and culturally sanctioned through dominant media imagery that typically portrays people with disabilities as childlike, pitiable, angry, self-loathing, and/or in need of care. Rare are the images of disabled individuals as content, well-adjusted, and successfully integrated into their communities, and the media hardly ever address, or even acknowledge, the broader social arrangements that contribute to their devaluation (Marks, 1999).

Further, despite federal legislation such as the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, both of which were designed to promote equal access for people with disabilities in a wide variety of arenas, many of the regulations associated with these laws have been subject to significant opposition and have not been consistently enforced. Thus, individuals with disabilities frequently remain oppressed through architectural, environmental, and attitudinal barriers that limit both their social and economic participation.

Clearly, then, for many individuals, social oppression is indeed a significant component of the disability experience. However, common experiences of oppression have also facilitated the unification, shared identities, and building of community among
many disabled individuals. The next section will discuss the factors that contribute to the development and expression of disability identity.

C. **Identity**

Identity, like disability, is fundamentally a social phenomenon. Although we often perceive identities as being natural and fixed (i.e., being a women, being an African-American, being disabled), they are, in reality, highly fluid and malleable, and have “differing meanings and relevance to different people at different times and in different circumstances” (Rhodes et al., 2008). While social identities are frequently ascribed to particular individuals as a means of oppressing them, individuals can also strive to reject these identities and to create their own narratives about themselves.

Alternatively, individuals can reclaim and reformulate these social identities as positive, integral aspects of themselves and their lived experience. In the instance of disability, Rhodes et al. (2008) suggest that:

Whether or not people accept or resist the label ‘disabled’ as a master status or simply as an aspect of their identity when it is imposed upon them by others or choose to adopt it for themselves will be influenced by how it is interpreted and the conceptual framework(s) within which such interpretation is made, the context, and crucially, the relationships of power between people. (p. 387)

Maintaining strong individual and group disability identities can be a vital means of collectively resisting systemic injustice and promoting liberation. “Progressive social change,” argues Paula Moya (2000), “is predicated on an acknowledgement of, and a familiarity with, past and present structures of inequality—structures that are often highly correlated with categories of identity” (p. 8). Group identification is furthermore a means of minority group members actually affirming the value of their differences and of human diversity in general.
However, developing a positive minority identity can be significantly more challenging for people with disabilities than for members of other marginalized groups. This is not only because disability is still so stigmatized in our society, but also because (with the exception of a few impairment groups) disability status is not transmitted through families the way that racial and ethnic status is. As is frequently the case for gay men and lesbians, disabled children typically grow up in families where they are the only “person of difference.” Therefore, they are inculcated into the standards and values of the non-disabled majority at the same time as they realize that they cannot possibly attain these standards (Gill, 1997).

Several other scholars have articulated the benefits of formulating and sustaining a disability identity, both on an individual level and on a collective level as well. In her article on developing a framework for political disability identity, Putnam (2005) notes that a significant individual benefit of formulating a disability identity is an increase in a sense of self-worth. This typically stems from the realization that although people with disabilities are typically devalued by society, there is nothing intrinsically “bad” or “wrong” about them as individuals. Rather, whatever stigmatization and discrimination that they may encounter on a personal level actually results from this larger pattern of the societal devaluation of people with disabilities. Similarly, another frequent benefit to developing a disability identity is an increase in pride in one’s individuality and a concomitant acknowledgment that impairment is simply another aspect of human diversity.

On a collective level, strong disability identity is essential for promoting social and political change. Once individuals with disabilities realize that they are of equal
worth as non-disabled individuals and that the problems that they encounter are frequently the product of oppressive social forces, they can then begin to advocate with one another for policy alternatives that will be more accepting and accommodating of difference. To promote a strong collective disability identity is not to suggest that everyone experiences their impairments and/or their disabilities in precisely the same manner. Instead, it is to recognize the role of social forces in disabling people and to make a commitment to combating them.

Other scholars, however, have argued that minority identities can actually be disempowering because they highlight individual difference rather than erasing it or facilitating its natural inclusion into the larger society (Davis, 2002). These scholars maintain that in articulating a strong and positive disability identity, disabled individuals are thus increasing the likelihood of their marginalization. Further, they contend that maintaining disability as a separate category of identity actually means acknowledging that impairment plays a fundamental role in disabled people’s experiences. Thus, they argue, those who are in favor of maintaining the category actually want it both ways. According to Shakespeare (2006):

A pure barriers approach does not specify a group of subjects who could adopt a political identity as disabled. But, equally, the basis of disabled identity could not be located in impairment. The social model was based on the irrelevance of impairment to the definition of disability. Therefore the basis of identity had to be found in shared resistance to oppression...Without a basis in impairment, disability identity becomes voluntaristic and difficult to define or police. (76-77)

Moreover, given the extraordinary diversity of disabled people’s experiences, critics of disability identity question what exactly constitutes the exemplary, authentic, and definitive “disability experience,” and to what extent can one person’s experience effectively represent the experiences of all people with disabilities? Although these
arguments have been made with respect to virtually all categories of minority membership, they are especially pertinent when examining the stability and the importance of disability identity. This is because disability is such a broad category, and also because it remains such a stigmatized one as well. Even more importantly, disability is a category that anybody has the potential to join, at any moment. The boundary between disabled and non-disabled is highly fragile and permeable, continuously reminding us of our vulnerability as humans.

Some individuals do not choose to identify as disabled, even when others generally identify them in this way. In his article “Well, I know this is going to sound very strange to you, but I don’t see myself as disabled,” Nick Watson (2002) points out that many individuals consider their disabilities to be just a single characteristic of their being, and often not a very important one at that. These individuals describe a sort of separation of self and body, particularly in those instances where impairment plays a relatively minor role in bodily experience, but also just when individuals, for whatever reason, choose to attend more closely to various other aspects of their lived experience. Watson points out that disabled individuals do sometimes come to identify with one another based upon shared experiences of oppression, but more often than not, these individuals either do not view themselves as “different” from “normal” individuals or else they reject the notion of “normal” altogether.

In a similar vein, in a critique of recent theory pertaining to identity politics in disability studies, Anna Hollow (2004) questions the extent to which identity politics “demand the authentication of one’s identity” (p. 280). In other words, while critical realists argue that personal experience serves as a validation of identity, Mollow wonders
how it may actually invalidate it, to the extent that someone with an impairment (particularly a hidden one) does not have the “right” or the “most legitimate” experience. Finally, Olney and Brockelmen (2003) argue that, for many individuals, choices about whether or not to identify as disabled can change according to one’s specific experiences and unique situations at hand. Rather than making a concerted choice to either always identify as disabled or to never identify as disabled, they found that university students repeatedly negotiated their identities in ways that were not particularly linear or sequential. Instead, these negotiations were strategic and reflected careful decision making. The researchers suggest that the presentation of self by individuals with disabilities can be understood according to social identity theory, which posits interdependence between one’s relationship to the in-group, one’s relationship to the out-group, and the ensuing power relationships. For example, Olney and Brockelman found that while in some situations an impairment was concealed as a means of circumventing oppression, at other times it was indeed flaunted for precisely the same reasons.

D. Towards a Psychology of Disability

Despite an emphasis upon and renewed debates about disability identity, there remains a relative absence of disability studies based theory directly related to disabled individuals’ lived psychological experiences. There exists a plethora of personal narrative accounts by disabled individuals that describe some of these lived experiences in acute detail. However, a substantial corresponding academic literature that posits how and why these experiences occur has yet to emerge. Psychologist and disability studies scholar Donna Reeve (2006) writes: “There appears to have been an avoidance of engaging with anything psychological within disability studies lest the individual tragedy model be re-
invoked through suggesting that disabled people need some form of psychological help” (p.94).

Even so, Reeve and others within the field have begun to argue that such a drastic swing of the pendulum (i.e., shifting from the individual pathology perspective to the idea that disability is exclusively a social construction) effectively ignores the lived psychological experience of disability. As disability studies scholar Russell Shuttleworth (2000) argues, “From an existential-phenomenological point of view, access-obstruction is experienced as a continuum of intention and felt-sense that are often not recognized in academic discussions of the social model” (p.263). Researchers Paterson and Hughes (1999) concur, writing:

> Just as the interactionist perspectives can be criticized for their micro-analysis of disability at the expense of any macro-analysis, the converse can be said of disability studies’ approach to understanding disability. It suggests that research should be concerned with spotlighting the ways in which society disables individuals rather than the effects on individuals. Here, the everyday reality of lived experience is neglected in favor of a purely structural analysis of disability. (p.601)

The authors point out that many people with disabilities are perpetually reminded of their own bodily differences because they are forced to navigate a world that does not accommodate their needs. “Disabled people,” they suggest, “may be hyper-sensitive about discrimination and prejudice, but this is precisely because of their lived experience of a world which does not carry their carnal information.”

Reeve (2008) particularly highlights the importance of attending to the role of personal experience outside of the public domain. This is particularly relevant for women, whose primary roles frequently still occur within the private sphere of home and family. Similarly, feminist theorists in disability studies have argued that viewing
disability exclusively or even primarily in terms of macro-societal structures has a marginalizing effect upon women because it discounts their day-to-day realities, including the experiences of managing households and caring for children (Crow, 1996). However, both disabled women and men are profoundly affected by unwelcoming social environments as well as by the misinformed, prejudiced attitudes of others.

Thus, Reeve and others have stressed the need for a psychology of disability that is underpinned by a social model approach rather than the individual pathology approach that has traditionally prevailed in rehabilitation psychology and related disciplines. Specifically, as early pioneer of the Disability Studies field Vic Finklestein argues, a psychology of disability should be based upon how “we make sense of our world according to the way we experience it” (Finklestein, 1990, p.1). Reeve describes cyclical patterns of strained social interactions, feelings of isolation, and internalized oppression as being key dimensions to any psychology of disability, and suggests that these psycho-emotional barriers may, for some individuals, be significantly more disabling than any physical, architectural, or structural ones. Thomas (1997) refers to dimensions as the “intangible dimensions of social exclusion,” writing that:

In the daily lives of disabled people, the accumulated consequences of numerous encounters with disablism mean that it is difficult, sometimes impossible, to prize apart the impact and effects of this or that dimension or feature, of disability…’Lived experience’ is thus rich and multi-dimensional, where already complex features of impairment effects and disability meld together with other facets of our social identities. (p.48)

Thomas indicates that experiences of rejection, from family, friends and co-workers, appear to be particularly pervasive among people with disabilities, especially women with disabilities. Thus, she contends that the personal consequences of disablism still need to be “theorized and challenged,” and Shakespeare, Gillespie-Sells and Davies
(1996) note that “Dealing with anger, self-loathing and daily experiences of rejection and humiliation are among the hardest aspects of being a disabled person” (pp. 42-43).

Further, as Finklestein and French (1993) posit, a psychology of disability, “provides fresh insights into the way disabled people, and others, make sense of, cope with, manage, and overcome disabling social and psychological barriers” (p. 32). Thomas has thus re-conceptualized the social model approach to disability to include these psychological dimensions, defining disability as: “A form of social oppression involving the social imposition of restrictions of activity and the socially engendered undermining of their psychoemotional well being” (p.60). Examples include being stared at or patronized, that, Reeve argues, can make disabled people feel worthless and limits their participation in mainstream society. Accordingly, Reeve defines psychoemotional disablism as: “Internalized oppression and the experience of prejudiced reactions from other people” (2008, p. 3)

According to the participants in Reeve’s study, non-disabled individuals frequently expressed fear and/or avoidance in their interactions, and demonstrated acute anxiety and confusion about how to behave. In order to get their needs met, and to make themselves more “acceptable” to others, people with disabilities either had to educate their non-disabled interaction partners or else they had to apologize for asking for help and then to act as though they were extremely grateful. Reeve refers to this “work” performed during interactions as emotional labor, and argues that psychoemotional disablism is increased when emotional labor is at odds with how a disabled individual actually feels. Reeve re-iterates that, for individuals with impairments, negotiating this type of disablism can frequently prove to more exhausting than structural disablism.
In a discussion of how public attitudes affect disabled women’s sense of self, Keith (1996) refers to dealing with others’ reactions and preconceptions as “doing disability.” “Strangers,” writes Keith, “do not let us forget that their perceptions of us are dominated by how we are different” (p.75). She further suggests that while Erving Goffman failed to understand the structural roots of encounters between disabled and non-disabled individuals, he was correct about the importance of understanding these encounters as they have significant implications for how people with disabilities see themselves. Reeve (2004) concurs, arguing that although Goffman failed to capture the complex and true nature of disability oppression, it is frequently these sorts of encounters that negatively impact disabled people’s participation in mainstream society.

As indicated earlier in this chapter, cultural oppression of people with disabilities is a very real and very damaging phenomenon. In particular, notes Thomas (2004), pervasive cultural inscriptions of people with disabilities as “the other” can contribute to how disabled individuals are treated in the course of their everyday lives, and, in turn, can significantly undermine their psycho-emotional well-being (p. 45). Not only do these inscriptions serve to perpetuate non-disabled individuals’ stereotypes about what disability experience is actually like, but they also serve to undermine disabled people’s own self-worth. “The psycho-emotional dimensions of disablism,” writes Thomas, “are closely bound up with socio-cultural processes that generate negative attitudes about impairment and disability, and sustain prejudicial meanings, ideas, discourses, images and stereotypes” (p. 46). Keith (1996) concurs with this assessment, suggesting that the public’s attitudes towards people with disabilities, and, by extension, encounters between people with and without disabilities, are frequently based upon false assumptions about
“how awful our quality of life must be” (p. 77). “People think of me,” she says, “as someone they are glad they are not,” and points out that: “It is acceptable to talk to people with disabilities in ways it would never be acceptable to talk to non-disabled people.” Disabled people are often relegated to second-class citizens regardless of what other characteristics they may possess (p. 72).

Besides investigating how individuals with disabilities negotiate social barriers and interactions with others, it is also crucial to examine how manifestations of impairment affect their overall social and psychological well-being. For example, how does pain, fatigue, or other physical symptoms associated with CP limit opportunities for participation? Another critique that has emerged regarding the social model of disability in its original form is that it fails to adequately address the often very real and problematic role that impairment plays in the daily lives of many people with disabilities (Shakespeare, 2006; Wendell, 1999). Many scholars have thus called for new models within disability studies that place greater emphasis upon the role of impairment in the overall lived experience of disability (but without assuming, as does the ICF, that “the problem of disability” is fundamentally based on impairment). As Crow (1996) writes:

We need to focus on disability and impairment: on the external and internal constituents they bring to our experiences… One cannot be fully understood without attention to the other, because while they exist independently of each other, there are also circumstances where they interact. And whilst there are common strands to the way they operate, their impact and the explanations of their cause and effect will vary according to each individual’s situation and from time to time. (p. 218)

She also argues that:

Many of us remain frustrated and disheartened by pain, fatigue, depression, and chronic illness… many of us fear our futures with progressive or additional impairments; we mourn past activities that are no longer possible to us; we are afraid that we may die early or that suicide may seem our only option; we
desperately seek some kind of medical intervention; we feel ambivalent about the possibilities of our children having impairments; and we are motivated to work for the prevention of impairment…(p. 209-210)

Therefore, a comprehensive psychology of disability should address not only how social barriers influence individuals’ overall well-being, but how impairment effects do as well.

Just as the discipline of psychology has much to contribute to disability studies, so too can disability studies help to expand the lens of psychology. Psychologists and disability studies scholars Goodley and Lawthom (2006) argue that “to situate psychology as a bounded discipline engaged with enforcing normalcy does a disservice to the dynamic nature of knowledge disciplines” and that “psychology assumes a stability of the self that is far from reality” (p.5). Specifically, that psychological knowledge is so heavily derived from controlled laboratory experiments as opposed to “real world” situations naturally posits a dichotomy between psychology and disability studies, a field that is so strongly rooted in the notion of social construction. Goodley and Lawthom contend that much of current psychological research and practice still promotes exclusion by continuing to emphasize the importance of normalcy and conformity rather than celebrating difference and examining the social barriers that limit equal opportunities for participation.

Further, in their article “Can Disability Studies and Psychology Join Hands,” Olkin and Pledger (2003) note that: “Disability has been ghettoized into rehabilitation psychology and virtually ignored in mainstream inquiries” (p. 300). Thus, both research and clinical psychologists frequently see disability as restricted to the purview of rehabilitation rather than as a social issue and/or as an aspect of human diversity. Olkin
and Pledger argue that psychologists need to more effectively address the contextual factors involved in creating and sustaining disability and the interplay between disability and other personal factors (gender, race, age, etc). Finally, they suggest that psychologists need to be more educated about and to attend more carefully to the real concerns that disabled people frequently express, including discrimination, abuse, intimacy issues, and questions of disability identity.

However, the researchers also point out that a psychology of disability should avoid focusing excessively upon the disablism that individuals encounter at the expense of examining how they successfully negotiate this disablism to create meaningful lives. As previously discussed, letting go of mainstream values, developing a disability identity, and integrating themselves into the disability community and counterculture often facilitates strong self-esteem and overall well-being (Gill, 2001; 1997). An understanding of disability as a form of systematic and pervasive oppression rather than as an individual problem can serve as a buffer against psychoemotional disablism, as can having a strong social support network.

As Gill (2001) writes:

Despite the negative trends in the literature, many disabled persons have enjoyed salutary connections with nondisabled family members, friends, intimate partners, health professionals, and employers. In their narratives, disabled individuals describe key allies in their lives who seem devoid of disability prejudice but who know and despise it when they see it. They make the effort to learn who their disabled associates are in their full glory and full ordinariness. In disability cultural parlance, these non-disabled friends and relatives are the ones who “get it” (p. 368).

On the other end of the spectrum are those individuals who do not identify as being disabled and who thus may not experience, or be aware of experiencing, psychoemotional disablism. Recall Watson’s (2002) finding that for some individuals,
disability is just a single example of many traits that they possess, and has a relatively minimal role in their everyday experience. Several participants in Watson’s study were adamant that they were not in denial about their disabilities, but that they did not see themselves as “different” in any significant way; for these participants, disability was just a “fact of life.”

Similarly, in a large mixed-method study of people with disabilities, the majority of respondents indicated that they had an excellent or good quality of life (Albrecht & Devlieger, 1999). They generally attributed their quality of life to family support, spirituality, a well-defined set of personal values, and a strong sense of inner strength. Other important factors seemed to include having a sense of control, being able to perform expected social roles, feeling needed and wanted by others, and feeling a sense of purpose in life. Thus, Albrecht and Devlieger concluded that a life of high quality was largely driven by sense of balance between the body, mind, and spirit, and with social and contextual factors (p. 985). These results bolster Gerhart et al.’s (1994), who asked a sample of quadriplegic individuals to assess their own quality of life. Ninety-two percent of the respondents reported that they were happy to be alive and rated their own quality of life as being at or above average.

E. **Chapter Conclusion**

This chapter began by articulating how people with disabilities constitute an oppressed minority group. It further revealed some of the questions and debates concerning disability as an identity category before re-iterating and supporting previous calls for an expanded emphasis within disability studies upon the lived social and psychological experience of disabled individuals, particularly experiences of
“psychoemotional disablism.” The next chapter will explore the empirical literature and narrative accounts concerning the experiences of individuals with cerebral palsy and will conclude by reiterating the justification for the present study.
IV. RESEARCH REGARDING THE SOCIAL AND PSYCHOLOGICAL EXPERIENCES OF ADULTS WITH CEREBRAL PALSY

A. Chapter Summary

This chapter summarizes the limited literature on the social and psychological experiences of adults with cerebral palsy (CP). It begins with a brief description of the impairment itself, followed by a discussion of the empirical literature that has emerged from medicine and rehabilitation pertaining to the lived experiences of individuals with CP. This discussion is complemented by examples from personal narratives that highlight the complex ways that the impairment manifests itself in individuals’ everyday experience and interactions with others. The chapter concludes by indicating the gaps in the present empirical and anecdotal literature, and then re-iterating the importance of a more in-depth and nuanced exploration of this topic.

B. Characteristics of and Attitudes Towards CP

CP is a developmental disorder characterized by impaired motor function traceable to atypical brain physiology. Presenting itself at or before birth, CP is one of the most common impairments, with approximately 2 cases for every 1000 live births. CP is most often diagnosed during infancy and is frequently accompanied by orthopedic disorders, although disturbances in perception, cognition, and/or communication are relatively common as well (Batshaw & Perret, 1992).

CP may be characterized by non-average muscle tone, posture, reflexes, and/or coordination, and is typically manifested in terms of spasticity, spasms, other involuntary movements, unsteady balance, and/or decreased muscle mass. There is no cure for CP and its diverse symptomology can make diagnosis and treatment quite difficult. Typical interventions
include physical, occupational, and speech therapy as well as orthotic devices and mobility and communication aides. Certain surgical procedures and/or pharmaceuticals can also sometimes be effective in alleviating symptoms of CP.

Historians believe that CP has always existed, although it was not first identified until 1860 (Batshaw & Peret, 1992). We now know there are several causes of the disorder, including asphyxia, birth trauma, premature birth, and maternal infections during pregnancy and or before birth. Nonetheless, individuals with CP have historically been subject to many cultural myths and false perceptions, including the notions that they were the products of incest or partial smotherings, and that they were possessed by evil spirits. Even today, slow and difficult movements, muscle tension (particularly in or near the face), slurred speech, and trouble controlling saliva are all frequently misinterpreted as evidence of cognitive impairment, although only about 30 percent of persons with CP actually have this symptom.

Research on public attitudes and perceptions suggest that the social acceptability of an impairment is dictated primarily by its influence on physical appearance (particularly facial appearance), productivity, and cognitive ability (Yuker, 1988). Since cerebral palsy can affect all of these (or at least appear to do so), it is generally considered to be among the lowest on the hierarchy of social acceptability, only above intellectual disability, mental illness, and multiple disabilities. This hierarchy has remained relatively stable since the 1970s, and seems to be consistent even among demographically heterogeneous samples, including participants who have impairments themselves (Thomas, 2000).
In short, because CP encompasses several types of impairments while also being associated with others, and because it can manifest in various ways, many of which are distinctly “different” compared to the normative body, CP constitutes a unique form of embodiment. Correspondingly, non-disabled individuals, particularly social interaction partners unfamiliar with CP, may experience confusion when communicating with an individual with CP. They therefore may display various responses that reflect this confusion and subsequent insecurity, including, but not limited to, disregard, condescension, overattentiveness, and overprotection (Politano, 2007). Although these are relatively common reactions to people with disabilities in general, they may be especially pronounced when interacting with a person with cerebral palsy precisely because there is so much impairment-related variation among this particular group.

C. **Quantitative Research on the Experiences of Adults with CP**

As previously mentioned, there is very little empirical research into the experiences of adults with CP in general; the majority of literature that does exist pertains primarily to children with CP. Despite the relative plethora of studies related to the medical, therapeutic, educational and even social experiences of children with CP, adults with CP have been largely ignored by the research community. Further, there are only a few studies and/or theoretical articles that examine these experiences from a disability studies perspective.

The research that does exist regarding the lived social and psychological experiences of people with CP, however, suggests that negative perceptions of their bodies, perceptions of difference from others, and restricted autonomy can combine to sometimes make it difficult to manage daily life. Some researchers have examined the
overall well-being of adults with CP, although many have focused their investigations specifically on health-related domains. For example, to measure subjective well-being, Furukawa, Nshiyama, Nii, and Ushida (2001) administered the Philadelphia Geriatric Center Morale Scale to 81 individuals with CP, ranging in age from 26 to 51 years. The researchers found that many participants reported decreased stamina and increased pain at a much earlier age, relative to when non-disabled adults begin to show these signs of aging. This, in turn, significantly reduced their participation in social life, and, in turn, their overall well-being. The researchers concluded that not only do individuals with CP require improved medical treatment and therapeutic support, but also that their immediate living and their larger social environments should be constructed in ways that better attend to their needs and physical limitations.

A more recent review article on the health and well-being of adults with CP indicated that these individuals have medical problems at “higher than expected rates,” including significant pain, fatigue, muscle dysfunction, bowel and bladder disorders, sexual dysfunction, and deterioration of functional ambulation (Liptak, 2008). These concerns, as well as functional limitations and/or impaired communication, often resulted in restricted activity and participation levels for people with CP, including opportunities for employment and for finding and maintaining fulfilling relationships. At the same time, however, the reviewer cautions that while functional status measures “are reliable indicators of physical functioning”, they “do not correlate consistently with psychosocial well-being” and that social support networks and individual adaptability appear to be better indicators (p. 139). The results of the review yielded nine life domains important for the health and well being of adults with cerebral palsy: learning and applying
knowledge, general tasks and demands, communication, mobility, self care, domestic life, interpersonal interactions and relationships, major life areas (education, work, and economic life), and community, social, and civic life.

In a notable exception to this trend of focusing primarily upon health-related well-being, researchers in Munich, Germany gathered a random sample of 35 adults with CP, aged 25-40, to complete the Bern Questionnaire on Subjective Well-Being, an instrument that specifically measures psychological well-being “independently from health status, functional level, and participation level” (Hergenroder & Blank, 2008, p. 390). They found that subjective well-being and life satisfaction in individuals with CP did not differ significantly from that of a non-disabled reference group. In fact, respondents with CP scored higher on the subscale “joy of life” than did their non-disabled peers. Several disabled respondents did report lower levels of community inclusion as compared to their peers; however this did not seem to significantly impact their overall life satisfaction. Importantly, this questionnaire was administered to individuals with a broad range of types and manifestations of CP, including those with intellectual disabilities and those with very significant physical impairments, and the completion rate for these populations was substantially lower than for those who had less severe impairments. Therefore, the researchers caution that the results have somewhat limited applicability.

Several researchers have also explored life satisfaction and self-efficacy among individuals with CP. For example, a recent Danish study (Michelson, Udall, Hansen & Madsen, 2006) found that degree of social integration, evidenced by living in the community, being married, having children, and participating in the labor market, all functioned as predictors of life satisfaction in these individuals. Furthermore, they
determined that, in general, degree of life satisfaction among individuals with CP appeared comparable to that of their able-bodied peers.

Additionally, in a study of twenty-two adult subjects with CP, Andren and Grimby (2004) determined that general life satisfaction remained relatively high even as levels of functional independence decreased, suggesting that participants may gradually alter their self-concepts and effectively adjust their priorities as a means of successfully adapting to their diminished physical capacity. On the other hand, Becker and Schiller (1995) determined that degree of self-efficacy was significantly related to functional status, and that mechanical interventions improved perceptions of self-efficacy in individuals with cerebral palsy while the need for personal assistance significantly decreased those perceptions.

Moreover, Jahnsen, Villen, Stanghelle, and Holm (2001) found that participants with CP experienced a diminished “sense of coherence” relative to non-disabled controls. Through upwards of 400 questionnaire responses, researchers concluded that subjects experienced life as less manageable, meaningful, and comprehensible than did the non-disabled control group. Further, the most important predictors of this “sense of coherence” were level of education, marital status, life satisfaction, and level of fatigue.

Investigators have focused more attention on the social experiences of adolescents and young adults with CP, as they are frequently still in the educational system and/or are being followed within large pediatric clinics. A recent meta-analysis on the quality of life among adolescents with CP indicated that these adolescents demonstrated a reduced quality of life as compared to their non-disabled peers (Livingston, Rosenbaum, Russell & Palisano, 2007). Well-being was reported as significantly lower, although overall only
physical well-being (and not psychosocial well-being) was correlated with functional health status.

Another review study on the social and sexual relationships of adolescents and young adults with CP (Wiegerink, Roebroeck, Donkervoort, & Cohen-Kettenis, 2006) found that, in general, individuals with CP were more isolated and less socially active than their non-disabled peers. This isolation increased significantly once individuals left school. Additionally, both adolescents and young adults began dating at a later age, and also had less sexual knowledge and experience than their peers. The reviewed articles indicated a number of reasons for these trends, including decreased self-efficacy and lowered self-esteem among individuals with CP in this age group. Impaired physical functioning also played a role, as did several environmental factors, including family over-protectiveness, fewer peer relationships, others’ negative attitudes, and lack of accessibility (particularly accessible transportation).

D. Qualitative Research on the Experiences of Adults with CP

The aforementioned results were gathered via quantitatively based methodologies, such as close-ended questionnaires, and therefore may not have entirely captured the experiences of adolescents and adults with CP. Additionally, while many of the researchers mention the role of social and environmental factors, they almost all adopt an individual, deficit-based approach to the overall experience of having CP rather than examining the experience from a more holistic perspective.

A notable exception to this is a qualitative investigation with twenty-two community living adults. Via open-ended interviews, Sandstrom (2007) found that the self-image of participants with cerebral palsy, as compared with their non-disabled peers,
was challenged by the differential treatment they encountered. Participants commented on how, as children, they felt simultaneously overprotected and undervalued by parents, teachers, and medical professionals. Several believed that having been confined to segregated settings as children contributed to their awkwardness and discomfort once they had to navigate the world as adults. Specifically, others’ misinformed attitudes and sometimes blatant discrimination resulted in diminished self-confidence and indignity. Additionally, some participants also experienced a sense of restricted autonomy and/or of feeling caught “in-between” the disabled world and the non-disabled world. In general, participants believed that a strong support network and a sense of stubbornness were key to circumventing these obstacles.

In another qualitative study with ten young adults with CP, King, Gathers, Polger, Mackinnon, and Havens (2000) found two types of emergent themes: those related to employment, education, and independent living, and those related to relationships, attitudes, and perceptions of support (p. 739). Most participants defined success in terms of being happy and of having the ability to get or do what they wanted in life. Participants also indicated that being believed in by others was an important component of success, as was believing in themselves. However, others’ lowered expectations frequently functioned as a barrier to success, although these expectations sometimes resulted in an even greater sense of determination.

Although King et al.’s study was limited to young adults with CP, some of the results may be applicable to older adults with CP as well. In their discussion of the data, the authors noted that life success and happiness are closely related to resilience, personal competence, and acceptance of self and life. Further, they suggested that the three factors
that participants identified as key determinants of life success -- being believed in, believing in oneself, and being accepted by others -- are also key to resilience, adaptation, and overall happiness. Notably, findings from this study indicated that young adults with CP are very similar to their non-disabled peers in terms of their overall needs and desires.

King et al.’s qualitative study is a refreshing departure from some of the more clinical investigations regarding individuals’ with CP psychological experiences; however, it fails to address many of the broader social and environmental factors that might affect young adults’ perceptions. It also focuses upon a specific construct – success -- and utilizes participants from a narrow age range; it is unclear whether findings from the study can be applied more broadly. Likewise, although Sandstrom did address psychosocial issues in her study, much of the article was focused upon bodily experiences. As mentioned several times previously, empirical, disability studies based investigations regarding the more general social and psychological experiences of individuals with CP are rare; however, there has been some effort to address specific aspects of these experiences, both theoretically and empirically. Additionally, a few key personal narratives and creative endeavors by disability studies scholars have also provided insight into area.

For example, Shuttleworth (2000) conducted a phenomenological study exploring the search for intimacy among men with CP. Via a series of life history interviews with 14 men and complementary interviews with their relatives, friends, service providers, and partners, Shuttleworth gained insight into how the men effectively negotiated and established sexual intimacy with others. Several prominent themes emerged, including socio-sexual isolation during childhood and adolescence, parental over-protectiveness,
lack of role models for people with disabilities, cultural ideals of attractiveness, body image, embodied responses, and friendship. Additionally, participants mentioned that expectations of normative mobility and communication often presented obstacles in establishing and maintaining relationships, as did expectations of masculinity, such as hugging, kissing, or otherwise touching a partner. Shuttleworth also found that these expectations, often coupled with a sense that others failed to see them as sexual beings, sometimes led these men to feel immobilized during romantic (or potentially romantic) encounters, or to disengage from their sexual selves altogether. Other participants, however, had not experienced these concerns, or were able to successfully overcome them, and were ultimately able to develop meaningful and lasting relationships. To do so, they often utilized practical strategies of interpersonal connection, cultivated wide networks of support, expanded the masculine repertoire to include emotional intimacy, and diffused the importance of their disabilities through seeing themselves as more than their disabilities and encouraging potential partners to do the same.

However, formulating meaningful and intimate relationships, as Shuttleworth witnessed, is very difficult to do when initial encounters between disabled and non-disabled individuals are plagued by superficial understandings and interpretations. In a creative study demonstrating how these encounters can be problematic, researchers worked with a young man with CP, Elton, mounting a camera on the back of his wheelchair that recorded his interactions with strangers at a local pub (Lenney & Sercombe, 2002). Afterwards, the researchers approached the interaction partners and asked them about the encounters. For the most part, individuals either reported not wanting to be seen as staring at Elton, or not wanting to interact with Elton because they
did not want to appear rude by drawing attention to his distinct embodiment. Additionally, many participants reported experiencing curiosity about Elton’s impairment, but not wanting to offend him by asking direct questions. Several also avoided interactions because they viewed him as dependent and pitiable.

For Elton’s part, prior to the interactions he reported that he enjoyed looking at beautiful women and that he felt special when women spoke to him. He saw himself as being “no different to other people” and as a “good looking young man” who felt confident and outgoing. The researchers reported that after much deliberation and fear of hurting him, they finally read Elton the manuscript they had prepared based upon the encounters. “He was hurt,” they reported, “but we talked about his reactions and what this meant to him, and he was able to work the issue through. ‘Why should I expect every woman who approaches me to find me attractive?’” he concludes (Lenney & Sercombe, 2002, p.15). This investigation, and particularly this quote, is revealing in that it suggests that, despite the general public’s negative attitudes toward and misconceptions about people with CP, individuals themselves likely do not internalize these misconceptions but instead manage to find meaning and happiness in their lives. On the other hand, individuals may just not be aware of how they are affected or might wish to appear unaffected.

However, in an investigation into the meaning of health and disability for women with CP, Tighe (2001) found that participants worked hard to fit their bodies into cultural standards of normalcy and beauty, but frequently felt unable to measure up to those standards in the long run. Moreover, they viewed their wheelchairs as being symbols of stigma, and believed that non-disabled individuals often failed to see past the wheelchair
to the person utilizing it. Women in the study also noted the prevalence of physical, attitudinal, and larger cultural barriers that prevented them from fully integrating themselves into their communities, and from fully and positively integrating their disabilities into their overall self-concepts. In addition to negative attitudes and physical inaccessibility, the societal obsession with productivity and keeping up the pace often left women feeling extraordinarily fatigued, especially in cases when they intentionally tried to “prove” their abilities and independence to others. Likewise, the women in this study felt that it was important “not to let the disability get the best of them” and to avoid becoming the object of other people’s pity. In a similar vein, they did not want to be viewed as vulnerable and as easy to take advantage of, although a couple of women did, in fact, say that they viewed themselves that way. To counteract these assumptions, they consciously worked at exercising control and appearing strong and self-sufficient in front of others. In particular, a couple of women noted that they feared being taken advantage of sexually. However, besides expressing fears of being sexually violated, most participants did not see, or at least did not talk about (even when asked) their sexuality as integral to who they were. Only one participant in the study was married, and several had not had meaningful intimate, sexual relationships at any point in their lives. Thus, although in many other respects these women worked hard to achieve heteronormative able-bodied norms, they often, to refer back to Shuttleworth’s (2000) terminology, effectively “disengaged” from their sexual selves.

In an article intended to demonstrate the limitations of the social model of disability, scholar Bill Hughes who has CP and a significant speech impairment, presents a bit of his own narrative (Paterson & Hughes, 1999). Although speaking from a more
scholarly perspective and largely omitting his own personal reactions to the events, Hughes relates two anecdotes meant to illustrate the importance of an expanded emphasis upon phenomenology in disability studies. In the first, he describes being in an elevator at his university with a stranger who turned to ask him a question. Aware that his speech impairment would prevent him from responding adequately and appropriately within the few seconds until one of them had to exit, he elected just to smile and not to communicate with her. In such a mundane encounter that many of us experience every day, Hughes was forced to quickly consider his restricted set of options, and because of his impairment, choose the one that would be the most innocuous (i.e., to “ignore” the stranger or hold up the elevator during his laborious attempt to respond to her). In the second encounter, Hughes describes how he answered a delivery person’s knock at the door only to have her question: “Oh, is your mum not in?” Hughes comments upon the encounter, describing it as “an example of how my dys-appearance brings me home to my homelessness in the order of everyday life.” Reflecting upon the incident, he writes: “She obviously thought that I was not a responsible adult, and therefore not eligible to participate in the partnership required to complete her task.” He later adds: “Instantaneous, infantilizing judgments are commonplace reactions in my experience, and are clearly (unthinking) reactions to my body, its movement and speech” (Paterson & Hughes, 1999, p.606). These examples are strong illustrations of the types of encounters that people with disabilities, and particularly individuals with CP, must contend with and negotiate on a regular basis.

E. Narratives Accounts of CP
Probably the most famous autobiographical account of an individual’s experience with CP is Christy Brown’s (1954) *My Left Foot*, which details the author’s struggle to learn to read, write, type, and even to paint with the use of a single toe. In his autobiography, Brown vividly describes the stares, ridicule, and condescending attitudes he endured as both a child and adult. For example, in articulating his disappointment as a teenager over an unrequited love, Brown writes: “I knew then, as I came to know many times later, how bitter and crushing a simple look of pity can be to someone like myself who needs something other than sympathy – the strength that only genuine human affection can give to the weakest heart (p.74).”

Likewise, in her memoir *Geri* (1984), actress and comedian Geri Jewell depicts her turbulent adolescence and early adulthood with CP. The victim of stigma, misunderstanding, and vastly lowered expectations from almost everyone she encountered, Jewell eventually gained notoriety as a comedian and then as a secondary character on the television show *The Facts of Life*. Still, she writes of attending a star-studded party where she witnessed herself performing on TV: “Time seemed to stand still for me, there in the spotlight. My disability was in full view now, without camouflage. I had put it all on the line, my heart beating madly the entire time, hoping to ‘pass’ (p.211).

More modern but no less poignant accounts are Eli Clare’s *Exile and Pride* (1999) and *The Marrow’s Telling* (2007). Throughout his musings, Clare vividly and acutely describes his embodied experiences with his impairment as well as how those experiences have affected his relationships with others and his overall identity. In one particularly poignant reflection on his childhood, he muses:

Gawking, gaping, staring: I can’t say when it first happened. When a first pair of eyes caught me, held me in their vice grip, tore skin from muscle, muscle from
bone. Those eyes always shouted, “Freak, retard, cripple,” demanded an answer from tremoring hands, a tomboy’s unsteady gait I never grew out of. (2007, p. 81).

In another passage, Clare acknowledges the psychosocial challenges that his disability presents even in adulthood, admitting that he still sometimes must:

Pull self-hatred out of the bag…I need to stare down the self who wants to be normal, the kid who thought she could and should pass as non-disabled, the crip still embarrassed by the way her body moves. I can feel the slivers of shame, silence, and isolation still embedded deep in my body. I hate these fragments. (1999, p.93)

Finally, in a poem entitled “How to Talk to a New Lover about Cerebral Palsy,” he writes:

Tell her: Complete strangers/have patted my head, kissed/my cheek, called me courageous/...They taunted me retard, monkey, defect. The words sank into my body./ The rocks and fists left bruises...Try not to be ashamed as you flinch and tremble/under her warm hands. Think of the stories you haven’t/told yet. Tension locks behind your shoulder blades. (2007, p.95)

This passage is particularly compelling as it acutely describes how Clare’s distinct embodiment affects his sense of self, and, by extension, his relationships with others.

Other recent examples of memoirs and personal narratives written by individuals with CP include Brian Johnson’s (2010) The Life with Cerebral Palsy, Elizabeth Hocutt’s Living with Cerebral Palsy (2007), and Christine Komoroski-McCohnell’s (2009) Only You, Christine, Only You. While, like Clare’s works, these pieces often capture the experience of living with CP differently than do traditional research methodologies, they do provide some insight into the lived social and psychological experience of these individuals. For example, in a particularly compelling passage, Johnson (2010) reveals his frustration with his communication difficulties, his reliance on assistive technology
that does not always function properly, and other individuals who do not understand or respond to his frustration:

Sometimes it’s hard to make my voice be heard, but I know I have to keep trying if I want to benefit not only myself, but other people with disabilities… I think that it’s extremely important to keep fighting for what we want and need…I also know that we have feelings like everybody else and shouldn’t be tossed aside like dirt, but sometimes I feel like we are tossed aside. (pp. 90-91)

In reading these narratives, it appears that the resolve to keep fighting even in the face of seemingly insurmountable social obstacles frequently derives from the support and encouragement that individuals have received from their families. For example, as Hocutt (2007) writes:

God has blessed me with the two greatest parents in the world. They believe that I should go anyplace with them no matter what...They taught me to be independent and proud of who I was. When I failed, they were still proud of me. All through life, they have stood up for me. If they found a problem, they got it fixed right away. They didn’t let people stop them along the way. When I needed help they were there – and still are. (p. 32)

Lastly, in her memoir, Only You, Christine, Only you, Christine Komoroski-McCohnell (2009) beautifully narrates her lived experience, from the moment of her birth in 1974, when mother was advised to “put her in an institution and go on with your life,” up until 2005, at which point she married and had begun a career in disability studies. In the prologue to the book, Komoroski-McCohnell advises prospective readers that: “My story is not a Hallmark story. Like most people with disabilities, I am not some quasi-saint with no ‘mean gene’ but I am not a she-devil either” (p. ix). In many ways, her story is largely one of the “normal” trial and tribulations of everyday life (seeking independence from overprotective parents, venturing out to find a job and building a career, and meeting prospective partners, breaking up, and ultimately finding true love). However, we also witness how the undercurrent of disability oppression, which she refers
to throughout the book as a “staircase,” affects so much of what she does and feels. For example, early in the book, Komoroski-McCohnell describes how when she was visiting a college as a prospective undergraduate, the learning specialist asked her “are you sure you were accepted to Rider? This is a prestigious university; maybe a two-year college would be better.” Recollecting the incident, Komoroski-McCohnell writes:

What? This was the first time in my life I had experienced educational discrimination. I sobbed all the way home…I continued to sob all night, but I didn’t know why I was so sad. I did carry on with my life, but that learning experience I will always have with me. (p. 43)

Later on, in describing the ins and outs of her daily existence as a professional with CP, she says:

The good reviews say that I’m an excellent teacher, kind hearted and approachable. They also like that we interact with one another. I am thorough in my presentations. I get a natural high when I’m teaching. I feel that I’m at the top of the staircase. But the staircase never ends. And then the next day when I go to the mall and people ask me, “Is your mommy with you?” I regress a few steps. That kind of stuff leaves me emotionally empty…A part of me can’t believe that I have a wonderful career with all the damn shit I’ve gone through. I’m finally up there. And yet, when I leave the office or the classroom, the oppression of the staircase is omnipresent. (p. 122-123)

F. **Literature Synthesis and Chapter Conclusion**

This literature review presents many complex and often contradictory findings, suggesting that the experiences of adults with CP is multifaceted and worthy of further investigation. One theme that emerged in several studies is the importance of social support networks to the quality of life in adults with CP, and that this is often more influential than functional status or even community participation on a wider scale. Although some studies do demonstrate that increased functional status and the ability to fulfill typical roles (worker, spouse, parent, student, etc) do contribute to overall happiness, social support and meaningful relationships seem to trump these. Adolescents
and young adults with CP often seem to experience social isolation and lowered self-esteem, and often feel overprotected and undervalued. Segregation into special education and/or therapeutic environments often contributes to a sense of restricted autonomy and feelings of inferiority, particularly in contrast to their non-disabled peers.

Not surprisingly, the qualitative studies and narrative accounts tended to focus less on functional status and more upon social obstacles, and also to concentrate on how individuals with CP find meaning in their lives. In particular, they more acutely address the complexity of the CP experience. For example, even individuals who have successfully developed social support networks and have accepted alternative value structures can still sometimes feel pressure to conform to cultural standards and to internalize a failure to conform. These accounts, combined with the more theoretical discussion from the previous chapters, point to the need for a carefully crafted, empirically based and disability studies based investigation into the lived social and psychological experiences of adults with CP. The following chapter will detail the methodology that I utilized to conduct this investigation.
V. METHODOLOGICAL APPROACH AND CONSIDERATIONS

A. Chapter Summary

This chapter details the methods that I utilized to conduct my study. First, I provide a justification for adopting a qualitative approach to this research project, followed by an explanation of how and why the approach is phenomenological. Next, I outline the procedures I used to collect my data, including a discussion of how I selected participants, what information I tried to elicit from them, the rationale for wanting to gather this information, and how I actually went about doing so. After discussing the measures I took to protect participants’ rights as research subjects, I also describe the data analysis procedures. Finally, I address some of the issues and questions that have emerged during the research process resulting from my personal experience as an individual with cerebral palsy.

B. Justification for and Description of a Qualitative Approach

I chose to utilize qualitative methods in this investigation for three main reasons. First, as evidenced by the literature review, very little information currently exists concerning the lived social and psychological experiences of adults with CP from their perspectives. Qualitative methods are particularly well-suited for broad, exploratory investigations in which the researcher does not approach his or her area of study with a highly specific question or hypothesis in mind but rather wishes to gain an improved understanding of the phenomenon of interest (Patton, 2001; Mertens, 2004).

Second, this research project was based on the premise that the only way to gain a genuine understanding of lived experience is to elicit the “insider perspective.” Therefore, it was vitally important that participants were able to openly share their thoughts and feelings, unfettered by the constraints imposed by a more structured format, such as a survey, a
checklist, or even a more structured interview. As indicated in the literature review, there is potentially a very wide array of social and psychological experiences that people with CP can have, and even a single individual’s experience can vary significantly, as it is based upon multiple realities that are time and context dependent. Thus, a full and detailed understanding of an individual’s personal experience with CP is not likely to be readily captured via more quantitatively-based methodologies.

Third, qualitative strategies generally permit greater flexibility to adjust research questions and methodological approaches even after the research has begun. Because of the exploratory nature of the study and the fact that I did not have any specific hypothesis that I was “testing,” I was able to shift the focus of the research even after the study was well underway in order to more accurately and comprehensively reflect participants’ reported lived experiences.

1. **Justification for and Description of a Phenomenological Approach**

Within this qualitative approach, phenomenological research has been selected as the mode of inquiry because it is the “interpretive study of human experience” (Seamon, 2000, p.1). As a branch of philosophy, phenomenology attempts to study objectively those topics usually reserved for subjective inquiry, such as judgments, perceptions, and emotions. In other words, phenomenology seeks to systematically study the essential elements and properties of consciousness. Although various schools and styles of phenomenology exist, they are each fundamentally based in the writings of philosopher Edmund Husserl (1913). Husserl believed that, despite the ever-changing nature of human experience, there are particular structures of human consciousness that are identifiable through systematic reflection and that exist in a “pure” region, separate
from the flux of thought. On the other hand, thinkers such as Heidegger (1927) and Merleau-Ponty (1962) disputed this line of reasoning, contending that consciousness was not separate from the world and human existence, but rather that essential structures were wholly based in human experience, and that they in fact functioned as basic categories of human experience. In particular, Merleau-Ponty rejected Husserl’s view of body and mind as separate entities, arguing instead that the human body played an active, essential role in experience. As Seamon writes:

As a philosophical tradition, phenomenology has changed considerably since its founding by Husserl, moving from cerebral structures to lived experience…[Phenomenology can thus be defined] as the exploration and description of phenomena, where phenomena refers to things or experiences as beings experience them. Any object, event, situation, or experience that a person can see, hear, touch, smell, taste, feel, intuit, know, understand, or live through is a legitimate topic for phenomenological investigation. (p.3)

Thus, the principal purpose of phenomenological research is to examine and analyze the fundamental building blocks of everyday experience, often referred to in phenomenological philosophy and psychology as “essences,” or as the “essential natures” or “true beings” of things. Phenomenological inquiry, according to Seamon:

Clarifies human situations, events, meanings, and experiences as they spontaneously occur in the course of everyday life. The goal is a rigorous description of a human life as it is lived and reflected upon in all of its first-person concreteness, urgency, and ambiguity. (p. 4)

Further, In Researching Lived Experience, van Manen (1990) writes that:

Phenomenology is the study of the lifeworld – the world as we immediately experience it…phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences. Phenomenology asks, “What is this or that kind of experience like?” (p. 9)

Van Manen goes on to indicate that: “Anything that presents itself to consciousness is potentially of interest to phenomenology, whether the object is real or imagined,
empirically measurable, or felt” (p.9). However, he points out that phenomenological research is always retrospective rather than introspective because it is impossible for an individual to reflect upon an experience while living through the experience (Seamon, 2000, p. 1). Further, Van Manen writes that phenomenology is: “An attempt to uncover and describe the structures of lived experience…phenomenology attempts to explicate the meanings as we live them in our everyday existence, our lifeworld” (10).

Phenomenological research is, above all, a science that has systematic methods of data collection and analysis. It is explicit in its attempts to uncover and convey the structure and meanings of lived experience, and it is self-critical in that skilled phenomenologists continually reflect upon the methods being utilized and their overall effectiveness in contributing to a better understanding of phenomena. In addition to being systematic, phenomenological researchers are supposed to be open to phenomena as they present themselves. Researchers must also be creative in the ways they gather information and analyze it to uncover meaning structures. Finally, researchers must be clear and compelling in how they present information to their readers, while remaining true to the ways that individuals genuinely experience the phenomenon at hand (pp.18-20).

Van Manen stresses, however, that while phenomenology is a scientific method, it is not an empirical analytic science, in that it is not based upon facts and cannot lead to broad generalizations about experience. Phenomenology cannot show or prove that something is verifiably true as it is based upon the idea that each individual experiences his or her world subjectively and therefore at least somewhat differently than any other individual. Thus, phenomenological research must walk the fine line between
particularity and universality; in other words, although research findings are not
generalizable, they can lend insight about what experiences might be like for other
individuals in other contexts (p.23).

Following Heidegger and Merleau-Ponty, a core assumption of phenomenological
research is that individuals do not exist apart from their lifeworld, but rather are
“intimately caught up and immersed in it” (Seamon, p.6). In other words, contrary to
philosophers such as Descartes who believed in a mind-body dualism, phenomenology is
guided by the principle that humans necessarily act upon and direct their world, such that
they are “fundamentally related to the contexts in which they live;” thus “all being is to
be understood as being-in-the-world”. Referring to this concept as “intentionality,”
phenomenologists posit that human experience and consciousness is always directed
towards the external lifeworld, which Seamon defines as:

The tacit context, tenor, and pace of daily life to which normally people give no
reflective attention. The lifeworld includes both the routine and the unusual, the
mundane and the surprising. Whether an experience is ordinary or extraordinary,
however, the lifeworld in which the experience happens is normally out of sight.
Typically human beings do not make their experience in the lifeworld an object of
conscious awareness. Rather these experiences just happen, and people do not
consider how they happen, whether they could happen differently, or of what
larger experiential structures they might be a part…The person takes the everyday
world for granted and assumes it to be only what it is…people are immersed in a
world that normally unfolds automatically.

For instance, phenomenological researchers have examined and written about the
experience of children playing hide-and-seek, about the experience of people eating
unfamiliar foods, and about individuals using modern technology like cell phones and
mp3 players while out in their communities. However, other researchers have adopted a
phenomenological approach to study “how particular circumstances relating to the
environment or the person lead to particular lifeworld experiences,” even experiences
related to disability (Seamon, p.7). For example, Toombs (1992) has examined the physical experience of disability and Michalko (1987) has studied the experiences of parents who learn that their child is blind. Phenomenology is often utilized in nursing research to explore the experiences of patients and their families in the course of dealing with illness.

Another core assumption of a phenomenological approach is that: “The researcher seeks to be open to the phenomenon and to allow it to show itself in its fullness and complexity through her own direct involvement and understanding” (Seamon, 10). In other words, a researcher’s understanding derives from his or her own awareness of and interaction with the phenomenon of interest. “This style of study,” writes Seamon, “arises through firsthand, grounded contact with the phenomenon. Understanding derives directly from the researcher’s personal sensibility and awareness rather than from the usual second hand constructions of positivist science” (p.10). This is accomplished through phenomenological reduction, where “the phenomenologist works to circumvent the taken-for-grantedness of the natural attitude and bring to the lifeworld a directed, sympathetic attention” (p.10). As Van Manen explains, reduction requires the researcher to first be open to “a profound sense of wonder and amazement at the mysteriousness of the belief in the world” that “animates one’s questioning of the meaning of the experience of the world.” The researcher must also be able to see the phenomenon as clearly and concretely as possible by separating it from related theories or abstractions. Finally, the researcher must strive to see past the particularity of the experience as it is lived by a single individual towards the broader essence of the phenomenon; notably, this is not the same as formulating generalizations about experiences to other individuals under other
circumstances, but rather about gaining clarity about the overall phenomenon, as it is lived by that individual.

Following reduction, a researcher must engage in deep reflection about the phenomenon. Van Manen (1990) writes that:

A true reflection on lived experience is a thoughtful, reflective grasping of what it is that renders this or that particular experience its special significance. Phenomenological research consists of reflectively bringing into nearness that which tends to be obscure, that which tends to evade the intelligibility of our natural attitude of everyday life. (32)

The essence of a phenomenon, writes van Manen, is never one-dimensional; rather it is multi-layered, and reflection involves peeling at the layers to understand the phenomenon at its fullest, to seek meaning. In phenomenological research, reflection is achieved through an in-depth, systematic process of uncovering themes, or what phenomenologists frequently refer to as the “structures of experience” (79). “[Themes] are not objects of generalizations; metaphorically speaking they are more like knots in our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes” (90). Themes can be unearthed from raw data in a variety of ways, including attending to the text as a whole and formulating a phrase or multiple phrases that capture its fundamental meaning, attending to the text as a whole and pulling out existing phrases that capture its meaning, or attending to each text line-by-line and asking what each reveals about the phenomenon of interest. In the process of picking out themes, notes van Manen, it is important to distinguish between essential themes and incidental themes; essential themes are those aspects or qualities of a phenomenon that make the phenomenon what it is, while incidental themes do not change the fundamental quality of the experience. Finally, writing may be considered the most important part of the
phenomenological research process, and is indeed the very object of the process. “Writing,” argues van Manen, “is our method…Writing is closely fused into the research activity and reflection itself…writing is the essence of research” (125-126). To write is to measure a researcher’s thoughtfulness, and his or her ability to see and to provide insight into individuals’ lifeworlds. Phenomenology differs from other qualitative approaches such as grounded theory, ethnography, and discourse analysis because, contrary to these other approaches, the goal of phenomenology is not to develop theory about how social processes work, but rather to better understand a single experience of a phenomenon (Starks & Brown-Trinidad, 2007). Whereas other common approaches tend to be concerned more with abstract interpretations and often focus upon group processes, phenomenology is focused on finding specific concrete meanings in the experiences of single individuals. Although grounded theory, ethnography, and discourse analysis frequently rely on similar data collection methods, phenomenological methods are often suitable when there is not much known about the phenomenon of interest, and thus the goal of the project is to describe what the phenomenon is like rather than to build more complex theory related to how it works and under what conditions it occurs. In other words, phenomenology asks “What?” whereas other methods focus upon “How?” or “Why?” In this way, however, phenomenology may be used as a stepping stone to other methods that do promote the development of more theoretical understandings.

2. Phenomenology, Disability Studies, and Embodiment

A phenomenological approach is especially well suited to this particular investigation because of its emphasis on embodiment. For example, scholars such as Merleau-Ponty (1945) emphasize that individuals fundamentally experience the world
through their bodies. Specifically, Merleau-Ponty argued that a phenomenology of the body is guided by fundamental categories—time, space/motility, sexuality, and speech—and that, taken together, these elements form the basis of an individuals’ lived experience and situate them in their social worlds. Describing these categories, Wilde writes that:

Embodied time includes an orientation to meaningful events that are in some way exhibited on the body, such as scars or major bodily changes. Awareness of space/motility requires attending to bodily movements within the context of everyday activity. Sexuality is viewed very broadly, encompassing meaningful involvement in the world as well as emotions related to sexuality. Speech, a key concept in Merleau-Ponty’s phenomenology, is always embodied (known through the body) and emerges from within social and historical context, linking thought with experiences of everyday life. These concepts (embodied existentials) are connected by what Merleau-Ponty calls an intentional arc, which connects the projects and activities of life over time and contributes towards meaning in one’s life. (Wilde, 2002, p. 17)

This is fundamentally a disability studies based dissertation and is thus primarily concerned with how individuals with CP experience their social world rather than with how they experience their impairment per se. Nonetheless, that individuals with CP often possess unique forms of embodiment and physically navigate through their worlds in different ways as compared to most non-disabled individuals makes phenomenology a suitable approach. Each of us, disabled or not, relates to the outside world through our bodies and, in turn, others relate to us through socially influenced perceptions of our bodies. As Hughes and Paterson (1997) suggest:

Phenomenology interrogates the ‘felt world’ in which the carnal, the emotional, the cognitive and the cultural are indistinguishable. ‘Lived experience’ is itself a concept that refers to the collapse of these analytically separable domains into a perceptual unity…the felt world combines feelings, thoughts, and bodily processes into a single vital structure. A phenomenological sociology of the body…proposes a paradigm in which the social is embodied and the body is social. (p.336)
Considering each of Merleau-Ponty’s existentials—time, space, speech, and sexuality—we can see how individuals with CP may experience one or more of these elements differently from the way that non-disabled individuals do and in ways that significantly influence their social and psychological experience of being in the world. For example, because individuals with CP often have difficulties with both fine motor and gross motor movements, it requires more time to complete everyday tasks. In a fast-paced society, people with disabilities, and particularly those with CP, often, either intentionally or inadvertently, end up on the margins simply because they are unable to keep up. Even when they are able to successfully integrate into the mainstream, simple differences in movement patterns can draw attention to their impairments and result in differential treatment. For example, when I am using my scooter and am in a line to purchase something, I very seldom attend directly to my CP and it generally appears that others do not either. However, during the transaction if I am fumbling with bills and change while simultaneously trying to gather my purchase, then my impairment becomes much more obvious, both to me and to those around me. It is at this moment that I (and my CP) become the subject of unwanted attention and patronizing comments (“Honey, put your change away; close your wallet, now”). Even if the other people in line do not seem impatient or even particularly aware of me, my mere presence has disrupted the “natural” flow of the checkout line. To this end, Hughes (1999) argues that:

Codes of movement and timing are based on a carnal order, which is informed primarily by non-impaired bodies. It is these ‘hegemonic’ bodies that constitute the norms of timing and movement in much the same way that architectural conceptions of space cater primarily for ‘ideal’-typical bodies. (p.605)

Space, suggests Hughes, is really the one existential that disability studies has taken up through the social model, as individuals with disabilities are perpetually
excluded from physical spaces due to architectural inaccessibility. In considering the ways that people with disabilities relate to and navigate through space, we must consider what types of spaces are open to them and what types are closed to all but the “ideal-typical body.” Individuals with disabilities, and particularly those with CP, utilize a variety of assistive devices like wheelchairs, scooters, walkers, and canes to navigate through their environments, yet most of those with whom they share that space think only in terms of the person walking fully upright and without assistance. Thus, disabled people frequently struggle to get through to their destination even when spaces are technically accessible because their movements do not conform to “embodied norms.” For example, when I am out on the streets of Chicago, I struggle to make people aware of my presence so that they can make the necessary space for my scooter. So while the environment may be free of curbs and stairs, it remains inaccessible unless other individuals alter their behavior to accommodate me. Furthermore, I experience space, and the distance between two points, very differently depending upon whether I am using my scooter or I am walking.

Of course, the lived experience of speech also has significant meaning and implications for individuals with CP, as many struggle to produce intelligible speech and/or utilize augmentative communication devices. As Hughes writes:

My body ‘dys-appears’, both functionally and aesthetically, when faced with (socially produced) embodied norms of communication. Embodied norms of communication are oppressive to individuals with speech impairment...the scripts for communication, timing and proprioception are therefore, predisposed to the exclusion of people with impairments. It is not the exclusion from social space which is at issue here, but ostracism from opportunities to participate in the everyday, mundane, sensate, minutiae of the lifeworld. (p.605)
In our culture, speech structures social interactions, and the clarity and effectiveness with which individuals speak signal their degree of social competence. In everyday society social competence is frequently judged based upon a “knee-jerk” reaction to a momentary encounter. Thus, a disabled individual who cannot converse according to particular social norms, whether it is because she communicates slowly, less intelligibly, through sign language or an interpreter, or through use of an augmentative communication device is frequently deemed less competent. This judgment on the part of the interaction partner can significantly affect the rest of the interaction and, more importantly, the disabled individual’s experience of the interaction. Further, as Hughes suggests, individuals who do not conform to the “conventions of conversation” (and are thus deemed less competent) are frequently marginalized within multiple aspects of everyday social life.

Sexuality is the last of Merleau-Ponty’s existentials, and has particular significance when looking at the experience of individuals with disabilities and particularly of individuals with CP. In his article, “The search for sexual intimacy in men with cerebral palsy,” Shuttleworth (2000) elaborates upon Paterson and Hughes’ (1999) discussion of the relevance of speech and motility, noting how they each contribute to sexuality among men with CP, both in terms of how men experience their own sexuality and in terms of how their sexual relationships with others are structured. For example, a few of the men spoke of being automatically rejected as potential sexual partners as soon as it became evident that their patterns of mobility and communication differed from the norm. This rejection was experienced not only in their minds but in also in their bodies as they struggled unsuccessfully to find intimacy and to have their masculinity validated by others. Feelings of immobilization prevented some men from seeking out relationships
when they genuinely wanted to do so; others employed strategies of disengagement and gave up trying to pursue sexual intimacy altogether. Others, however, were able to find successful strategies, such as seeking out romantic relationships with friends and personal assistants, prioritizing emotional intimacy over sexual intimacy, and learning how to take risks and handle rejection. Nonetheless, each of these activities involves the fundamental connection between mind and body that is central to a phenomenological perspective on personal experience.

C. **Determining Who and What to Ask**

Although several methods can be utilized in a phenomenological investigation, the long interview is the most common (Moustakas, 1994). As an informal and interactive process, the interview typically involves a series of broad, open-ended questions designed to elicit comprehensive descriptions about a particular experience. Phenomenologist and social scientist Clarke Moustakas (1994) suggests that researchers utilize the following types of questions “to facilitate obtaining rich, vital, substantive descriptions of the [participant’s] experience of the phenomenon” (p.116).

- What dimensions, incidents, and people intimately connected with the experience stand out for you?
- How did the experience affect you; what changes do you associate with the experience?
- How did the experience affect significant others in your life?
- What feelings were generated by the experience?
- What thoughts stood out for you?
- What bodily changes were you aware of at the time?
• Have you shared all that is significant with reference to the experience?

Accordingly, during the first interview in my study, I began by asking participants to “tell the story” of one or more encounters where they felt that they were treated differently and/or were devalued because of their CP. Specifically, I asked them to describe not only what took place during the encounters, but also how the encounters made them feel at the time, and how they responded both emotionally and behaviorally to the encounters. Additionally, I requested that participants discuss how, in the long term, they have made sense of these encounters, how the encounters have affected the way they see and feel about themselves as individuals, and how they have moved on from or gotten past the encounters. I also asked whether there were particular individuals in participants’ lives with whom they shared the encounters and, if so, how these individuals reacted and/or provided them with support. The interview guide will be described in greater detail below.

In order to develop a more comprehensive understanding of the social and psychological experiences of individuals with cerebral palsy, I utilized multiple data collection strategies. Specifically, I conducted two interviews with each participant (see appendices A and B for interview guides). The first interview was intended to get an overview of participants’ social interactions and experiences in the course of their everyday lives in their communities, focusing particularly upon their experiences of stigma and devaluation. Additionally, during the month following their initial interview, each participant maintained a diary where they recorded their social experiences, thoughts, and feelings that they felt were relevant to their overall lived experience of having CP. The objective of this activity was to have participants attend more closely to
their experiences, and to describe these experiences soon after they unfolded. My hope was that they could provide fuller and more concrete descriptions of what the actual experiences were as well as their thoughts and feelings related to the experiences.

The original intent of the second interview was to elicit fuller descriptions of the information participants had shared in their diaries, and to conduct member checking after preliminary analyses of the first interviews and the diaries. However, as the purpose of the project gradually evolved from a study of stigma to a more general exploration into participants’ social and psychological experiences, I chose to utilize the second interview as an opportunity to explore these experiences more thoroughly, and in particular to focus upon participants’ identities and ability to find meaning in their lives with CP. Finally, participants joined a virtual focus group where they engaged in active discussion about these topics (see appendix C for discussion group guide). The goal of this activity was to develop a richer and more nuanced understanding of participants’ experiences by encouraging them to exchange diverse perspectives with one another.

1. **Pilot Interviewing**

Prior to beginning data collection, I pilot tested my first interview guide with two individuals with CP. Pilot testing allows the researcher to “try out” the interview guide with a small group of participants (Mertens, 2004). Consistent with the typical protocol for pilot testing, I selected two individuals who met the criteria for inclusion in my sample, and who I believed would be able to provide me with detailed feedback regarding the quality of the interview guide and of the overall interview process.
Striving for as much diversity as possible, I selected a 25-year-old male who walked unaided and had significant speech impairment. I also selected a 49 year-old female who used a wheelchair full time and did not have significant speech impairment. Although I was not friends with either of these individuals, I was sufficiently acquainted with both of them to believe that they would be able to provide helpful feedback.

Both individuals gave very helpful feedback on both the interview process and the interview questions. Although neither recommended significant alterations in the content of the questions, both suggested some slight changes in their wording and ordering in order to clarify meanings for participants and to improve the overall flow of the interview guide. After pondering these suggestions and reviewing them with my dissertation advisor, I did ultimately incorporate them into the final interview.

2. **Sampling Strategy**

In order to participate in the study, individuals had to have cerebral palsy and be between the ages of twenty-five and fifty-five. This age range was selected as this is the “prime of one’s life;” in other words, all participants were of the typical age to be immersed in some capacity in a career and/or in raising a family, and also to be appropriately knowledgeable of and influenced by contemporary cultural norms and practices. Additionally, in order to be eligible for the study, participants had to have lived in the community (rather than in an institutional setting), have served as their own guardian, and have possessed the capacity to understand the questions asked of them and/or to respond competently and appropriately to these questions. Because there is such a broad range of cognitive ability associated with CP, and because cognitive ability presumably influences one’s typical social experiences, I felt the need to limit this
preliminary investigation to those individuals who would be most likely to be regularly immersed in the public arena and who could effectively comprehend, describe, and discuss their social interactions and their psychological experiences.

I initially planned to recruit 10 participants to take part in the research, and strived for maximum variability in terms of gender, age, race, ethnicity, and socioeconomic status in order to capture a highly diverse array of lived experiences. Additionally, I strived for as much diversity as possible in terms of degree and manifestation of impairment; for example, I was able to recruit ambulatory individuals as well as wheelchair users, and those who employ communication devices as well as those who speak unaided. However, given the exploratory nature of the study and the breadth of the research question, the project was limited to a relatively small number of participants in order to allow more in-depth analyses of each individual’s responses while still promoting meaningful interpretations of the aggregate data.

I sought participants from CP and disability-related advocacy groups and organizations, such as independent living centers, but also looked for participants who are not involved in these types of activities. I felt that these individuals might have a more diverse range of social and psychological experiences related to their disabilities (See Appendix D for recruitment flyer). I posted flyers in the two independent living centers that serve the city Chicago and the greater Chicago area, as well as in the local Mayor’s Office for People with Disabilities. I also sent flyers to the local chapter of United Cerebral Palsy and to physicians at local hospitals. Further, I identified several groups on Facebook that were geared towards individuals with CP, and posted my announcement on their discussion boards.
Finally, I sought participants from “The CP Group,” a diverse social and educational network of people with CP from across the country who meet annually to discuss issues pertaining to adulthood and CP. Prior to beginning my data collection I attended the meeting for two consecutive years in order to understand more effectively the issues that were important to adults with CP and also to establish relationships with some of the associates in the hope that they might later be able to participate in my study. Many of the individuals in “The CP Group” come from the east coast, Mid-Atlantic states, and so I anticipated that I would be traveling to that area to collect data as well as the greater Chicago region.

In the end, my study involved four participants from Chicago-based disability advocacy organizations, two participants through Facebook, four participants through “The CP group,” one participant who heard about the study through a referral from a physician’s office, and one participant through a referral from a friend working at a Chicago-based advocacy organization. At the time of the interviews, seven participants lived in the greater Chicago area, two lived in Maryland, two lived in Pennsylvania, and one lived in Ohio. All twelve individuals took part in the first interview and the diary portions of the study, eleven completed the follow up interview, and nine participated in the virtual focus group.

3. **Sample Demographics**

My final sample was comprised of twelve individuals, ranging in age from 26 to 49. Six men and six women participated; nine individuals self-identified as Caucasian, one self-identified as Latino, and two self-identified as African-American. Eleven held high school degrees, eight held college degrees, and two had completed
Master’s degrees. At the time of the study, six participants were employed in full or part-time jobs, and six were not employed. Three participants were married and two had children. Five individuals used power wheelchairs, four used scooters, and three were fully ambulatory. Six individuals had speech impairments, and two of these individuals used augmentative communication devices to aide in their communication.

a. **Initial Contact**

The flyer and listserv announcement provided very brief descriptions of the study, including a list of the activities that were involved, and instructed interested individuals to contact the researcher for further information. The majority of individuals contacted me via email, at which point I asked them their ages and whether they lived in the community in order to determine their eligibility for participation. If their answers indicated that they were eligible, I provided them with a more comprehensive description of the investigation, including the estimated time involved for participation and the compensation involved. If individuals indicated that they were still interested in participating, we arranged a mutually convenient meeting time and location. I also asked them several brief background questions related to their impairment status, their employment status, and their family status as a way of getting to know them a bit better prior to the actual interview.

D. **The Process of Data Collection**

1. **First Interview**

The first round of individual interviews took place in a variety of locations, most of which were agreed upon because they were mutually convenient for the participants and the researcher. Of the 12 interviews, two took place at my office at
the University of Illinois at Chicago, three took place at a local hospital, three occurred in participants’ homes, two occurred in participants’ place of work, and two took place at coffee shops/restaurants.

After meeting the participant, exchanging brief introductions, and reviewing the nature of activities involved in the study, I asked participants to read and sign a consent form (see Appendix D; see “Ethical Concerns” below for an extensive discussion of the consent process). In two cases, participants asked me to read the consent form to them because they said that reading was challenging; in the other ten cases, they read and signed the form without assistance.

On average, the interviews lasted approximately one hour, with the shortest interview lasting forty minutes and the longest interview lasting two and a half hours. All interviews were recorded (with participants’ permission) on two digital voice recorders. Two recorders were utilized in case one recorder malfunctioned during the interview.

All interviews were transcribed verbatim by a professional transcriber; my own disability made it virtually impossible to transcribe the interviews myself. However, in the consent form, I informed participants that an outside party would be transcribing the interviews. Immediately following the interviews, I uploaded the voice files to my personal computer and transmitted them to the transcriber through the secure file sharing program Sendspace. The transcribed files were then returned to me via email as Microsoft Word documents.

a. **First Interview Content**

I began the first interview by asking participants to tell me a little
bit about themselves, beyond what they had told me during the initial contact. This included basic information about their families, educational backgrounds, jobs, and recreational and leisure activities. Not only did this help me to get a broad sense of participants’ overall lives and personalities, but it also helped to “break the ice” and to facilitate a comfortable atmosphere before moving into the actual interview content.

Next, I utilized a brief script to introduce the topic and provide an overview of the first section of the interview:

- I’m interested in knowing about what it’s like for you when you interact with strangers or people who you don’t know very well during the course of your everyday life in your community. I am interested in knowing what it’s like for you to interact with others in very routine and even mundane situations like grocery shopping or riding a bus.

I followed this up with the first question:

- Can you tell me about how people generally respond to you and to your disability? I’m interested in knowing about both the good and bad experiences you have had when interacting with others.

If necessary, I provided a probe, asking participants to talk about situations where people had acted strangely or had treated them differently because they had a disability. I used this question to acquire a general sense of participants’ experiences without being too directive or invasive at the outset.

The second question was closely related but was more directive:

- During the course of your everyday life, can you tell me about certain types of situations in which you are treated differently because you have CP?

The goal of this question was to more specifically focus upon participants’ perceptions of how CP had affected their everyday interactions and to give them the opportunity to discuss any positive effects as well as negative ones. Probing questions asked participants to describe who was generally involved and how the individuals behaved, as well as how
participants felt about and responded to that behavior. I was anticipating that perhaps participants might discuss how they were treated differently by certain groups of people in their community (shopkeepers, bus drivers, etc.) but that they might, in some cases view this treatment as a good thing – for example, perhaps a participant might have had developed a friendship with a store clerk who regularly helped her with merchandise that was out of her reach.

The third question asked participants to provide concrete examples:

- Please think about a specific time when you felt that you were being treated differently because of your CP? It can be a recent experience or something that happened a long time ago.

My intention here was to transition from the general to specific, and, consistent with a phenomenological approach, to have each participant describe an experience as acutely as possible, both in terms of how the situation unfolded and in terms of how participants felt about it. In an effort to capture this level of thick description, I asked participants to “tell the story” of the experience. Probing questions, used as necessary were also designed to elicit descriptive details, and asked:

- What happened?
- Where and when did the experience occur?
- Who was involved?
- How did the experience make you feel?
- How did you respond to being treated differently?

In the fourth question, I asked participants to:

- Please think about whether there have been specific times where you have felt *devalued* because of your CP, or as though you were being viewed or treated as less of a person because of your disability?

With this question, I was moving towards the heart of my initial focus on the experience of feeling stigmatized. Up until this point, I had been careful not to be too directive or
leading and to focus more generally upon participants’ social experiences. However, after
getting a more general sense of where participants were coming from and establishing a
rapport with them, I wanted to begin narrowing in on my real interest without making
them uncomfortable. If participants indicated that there had been instances when they
had felt devalued but struggled to describe these experiences, similar probes were used as
in the above question to elicit descriptive details. In addition to capturing details about
their experiences, I was primarily interested in understanding how they made sense of the
experiences in their own minds and in whom they talked to and relied on for support after
these experiences occurred.

The last two questions were designed to more explicitly “try out” my overarching
research focus to see if my guiding assumptions resonated with participants. I wanted to
interrogate my assumption that, within mainstream society, individuals with CP are
among the least accepted impairment groups. Additionally, I wanted to see how this
translated into people’s lived experience. Therefore, I asked participants:

- How do you believe that people with disabilities are treated in general, and do
  you believe that people with CP are treated differently than people with other
disabilities are treated? How and why do you think that this is the case?

I designed this question believing that several of the participants in my study would have
frequent experience interacting with individuals with other impairments either through
educational, work, leisure, or activism pursuits. I therefore thought that that they would
be in a good position to consider, and might have some unique insight into, whether there
was a difference in the type of treatment they received and, if so, why.

In the final question, I explicitly asked participants about stigma:

- In my research, I am specifically questioning if and how people with CP
  experience stigma. I am defining stigma as the personal experience of feeling
different and socially devalued based upon a particular characteristic, in this case CP. I am wondering to what extent you have ever thought about aspects of your own life in terms of stigma, and to what extent you think that the concept of stigma is relevant to the overall experience of people with CP?

As with the last question, the intent here was to “try out” directly my belief that individuals with CP have frequent experiences of being devalued and that these experiences could most appropriately be understood in terms of stigma theory. I believed that at least some of the participants might have considered the experience of stigma in the course of their educational or advocacy pursuits, and that, again, they might have some insights into this topic.

2. **Diary process**

Upon concluding the first round of individual interviews, I introduced participants to the diary portion of the study. Consistent with my initial focus on stigma, I asked the first few participants to record weekly for four weeks any experiences during the course of their daily lives and interactions with others when they felt that they were being treated differently and/or experienced stigma because of their disability. I suggested to participants that they try to write a short paragraph about what occurred during these experiences and how the experiences made them feel. Again, the goal of this activity was to encourage participants to reflect upon experiences of feeling stigmatized or of being treated differently as soon as possible after those experiences occurred so that, consistent with the goal of phenomenological research, they might be able to provide a more in-depth descriptive account of their experience then they could during an interview setting long after the experience occurred. I anticipated that during the second interview, I would probe for even more details related to the experience. I provided participants with two made-up examples of diary entries, stressing that they were only examples and
encouraging them to be creative in how they expressed themselves. I also provided a copy of the interview guide I had used, so participants could easily recall the type of information I was interested in.

Participants handled the diary activity in a variety of different ways. For example, one participant wrote a diary entry every few days, whenever he had an encounter that related in some way to his disability. One wrote a few sentences each day about what she did and whom she spoke with; one wrote an entry each week about an event that triggered thoughts and feelings related to her disability, even if the event itself did not relate specifically to her disability.

Although I will address the findings from the first interview and the diaries much more thoroughly in the results and analysis sections, it is necessary to say here that the information that participants provided during both of these activities precipitated a significant change in my theoretical orientation and overall focus of my research. Whereas I had previously been primarily concerned with how the participants experienced stigma in their everyday interactions in their communities as a result of their CP, I expanded my focus to examine more generally their overall social and psychological experiences.

There were several reasons for this expansion. First, I found that in the initial interviews and diaries, participants had a hard time coming up with and describing in depth multiple instances of feeling stigmatized. Most indicated that they had, indeed, felt devalued at certain times, but they had difficulties recollecting the specifics of those instances. Second, participants’ feelings of devaluation related to CP tended to be more strongly tied to prolonged interactions and experiences in educational, familial, and work
settings than to everyday encounters in their communities. Third, and most significantly, several participants seemed more eager to discuss the positive aspects of their lives, particularly in terms of strong relationships with family, friends, and other members of the disability community. Although many participants clearly acknowledged having experienced a bumpy road, most appeared very confident and content with their lives and themselves as individuals with CP. As participants began to share their experiences and life stories, I became intrigued by how many naturally incorporated their CP into their narratives, how they had struggled so hard to defy others’ expectations and traditional beliefs about disability, and how their CP experiences had become integral and meaningful aspects of their identity. A few participants acknowledged that they did not like having CP and felt as though it significantly interfered with their relationships and/or with their ability to succeed in life. However, even these participants also indicated that they had managed to make a certain peace with their disabilities and with themselves.

Thus, returning now to the diary activity, after reviewing the entries of the first several participants, I decided that I would expand the focus of the assignment to actively encourage future participants to write about any thoughts and feelings they had related to their disability, rather than to simply focus on a social interaction or an external event. I felt that the assignment still remained consistent with my original goal of asking participants to reflect on their experiences outside of the interview setting; I simply expanded the focus of the content of those experiences. Even so, several participants still chose to write about specific events that triggered thoughts and feelings related to their overall disability experience, but a few participants reflected on very intriguing aspects of their experiences that were not related to specific events and/or interactions and that may
have not otherwise been addressed during the course of the study. For example, one participant wrote about his experience of being physically and verbally abused by his personal care assistant, while another wrote about his experiences of incontinence and having to wear adult diapers. I chose not to comment extensively upon or to probe for more information about participants’ diary entries as they were submitted. Instead, I reserved comments and questions for the follow-up interview, most of which I was able to spontaneously incorporate into the questions from the second interview guide.

The majority of participants submitted their diary entries via email each week. Two participants did not have access to a computer, and so dictated their entries to me by telephone. Another participant chose to dictate her entries as well because of her significant difficulties with typing. I initially asked participants to submit their first diary entry exactly one week after the initial interview, but finding it quite challenging to keep track of different participants submitting entries on different days, I ultimately asked everybody to submit their entries on Friday. In light of people’s busy schedules, participants sometimes missed a week, submitted two in one week, or took longer to complete the activity. However, each participant did ultimately provide four entries. Each week, I emailed participants personalized reminders to submit their entries and I also emailed acknowledgments when I received their entries. Not only did this help participants stay on track with the activity, but it was also instrumental in helping us maintain a strong and comfortable rapport with one another. As each participant completed the diary, I mailed his or her compensation for that part of the study.

3. **Second Interview Content**

I had originally intended for the second interview to follow up upon and to
focus more specifically and concretely upon the experiences of stigma that participants
described in their first interview and in their diaries. However, in light of the findings that
participants did not generally report experiencing stigma in the manner and degree that I
believed that they might, and consistent with my expanded focus on their overall social
and psychological experiences, I chose to use the second interview (and the online focus
group) to more thoroughly investigate the factors contributing to these experiences.

In framing my questions, I did frequently refer to and follow up on the
information they had supplied in the first interview and the diaries. This also served as a
way of “member checking” or verifying and ensuring that I accurately interpreted what
they had said earlier. Finally, it helped to maintain the continuity of the process and
rapport between myself and the participants. However, I did develop a single general
guide that focused primarily on participants’ psychological experiences; I utilized this
guide for every interview. In seeking initial approval for the research, I had told the IRB
that the questions for the second interview guide would emerge through preliminary
analyses of the initial interviews and the diaries. IRB had already granted permission to
submit the second interview guide as an amendment, and in the amendment I explained
this shift in focus.

Eleven of twelve participants took part in the second interview. One participant
missed his follow up interview and I was unsuccessful in repeated attempts to contact
him. With one exception, I chose to wait to begin the second round of interviews until
after all of the first interviews were completed. I wanted a chance to conduct at least a
preliminary analysis of the data before meeting with participants again, especially
because my research questions and focus changed so significantly during the course of
the first interviews and diaries. However, during the period between their first and second interviews, I maintained regular communication with participants to update them on my progress, and, with the one exception mentioned above, was able to easily re-contact them for the follow-up meeting.

As with the first interviews, follow-up interviews took place in a variety of locations. One occurred at my office at the University of Illinois-Chicago, three occurred at participants’ homes, two occurred at participants’ workplaces, and six occurred at restaurants or coffee shops. Upon meeting participants and becoming re-acquainted, I reviewed the nature of and activities involved in the study, re-iterated their rights as a research participant as outlined in the consent form, and asked them whether they had any questions or concerns about the project. Although I did not ask them to sign another consent form, I obtained their verbal assent to continue participation prior to beginning the actual interview.

The first two questions of the interview were:

- How would you describe, on a social level, what it’s like to have CP?
- How would you describe, on a psychological level, what it’s like to have CP?

My intention with the first question was establish continuity from the first interview (when I had asked primarily about social experiences), to gain a basis of comparison between the first and second interviews, and to encourage participants initially to think very broadly about their overall lives with CP. The second question introduced the psychological element, and encouraged participants to focus not just on what their experiences are, but also how they feel about those experiences.

The next group of questions was:
Tell me more about how you think your family experiences have influenced your feelings about having CP.

Tell me more about how you think your experience in school and with other children has influenced your feelings about having CP.

Tell me more about how you think your experience with friends has influenced your feelings about having CP.

Tell me more about how you think your experience with work has influenced your feelings about having CP.

Tell me more about how your experience with romantic relationships has influenced your feelings about having CP.

These questions asked participants to focus upon and explore how particular elements of their lived experience contribute to their general thoughts and feelings about having CP. I chose these areas because not only are they generally quite influential in shaping people’s overall personal experience, but also because in the initial interview and diaries most participants referred to (at least briefly) some or all of these factors.

The final group of questions was:

What do you think that your life would be like if you did not have CP?

How would you describe yourself to somebody who didn’t know you very well?

What, if anything, do you think you have in common with people who have other disabilities instead of CP?

How do you think that your gender and/or your race affect your experience with CP?

If there was a cure for CP, would you take it? Why or why not?

These questions were intended to elicit how CP affected participants’ overall identities and self-concepts. In the first two questions, I sought to determine to what extent CP was an integral and positive aspect of their identities and in the third question I
tried to gauge their actual and/or felt connection to the larger disability community. In the
fourth question, I wanted to understand how participants navigated multiple identity
statuses, and in the final question I tried to ascertain participants’ overall level of
satisfaction with their lives and the degree to which CP played a role in this satisfaction.

4. **Virtual Focus Group**

Upon concluding the follow-up interviews, I conducted a virtual (online)
focus group, in which eight of the twelve individuals in my sample participated.
Qualitative researchers often conduct focus groups either in addition to or in lieu of
individual interviews because of the “synergistic effects of interaction in enhancing
discussion of the topic” (Moloney, Dietrich, Strickland, & Myerburg, 2003, p. 274). With
the explosion of in-home computer use in the past two decades, social science researchers
are increasingly utilizing on-line focus groups as they serve many of the same purposes
as actual focus groups but also have the added benefits of convenience, reduced travel
costs and time demands, and increased participant comfort (i.e., anonymity) (Watson &
Lissitz, 2000). Moreover, since the Internet is frequently used as a mechanism for contact
and support among individuals with various health conditions, it has also proven to be an
effective tool for health care researchers to collect data. In this study, I envisioned that
the virtual focus group would function as an additional opportunity for participants, who
were able and willing to do so, to share their perspectives and experiences; it would also
allow them to interact with other individuals in the study. Finally, parts of the focus
group were more directive than the individual interview in that I utilized the forum to
conduct member checks – to revisit the major findings that had emerged through the
interviews and diaries and to see if they resonated with participants. Qualitative
researchers frequently use member checks in order to enhance the accuracy and credibility of the research findings. By sharing findings, and interpretations of findings, with participants as the project is still taking place, researchers have the opportunity to “learn a great deal about the accuracy, completeness, fairness, and perceived validity of their data analysis” (Patton, 2001, p.560). Additionally, they have the opportunity to follow up with participants to identify gaps in their data and to elicit further information.

At the same time, though, I was cognizant of the disadvantages and potential difficulties with an online focus group, including the difficulties of involving participants that did not have access to the Internet and the time requirements involved to develop and sustain a strong discussion. Further, it can often be challenging for the moderator to maintain control of the discussion, to keep the conversation focused upon the topic at hand, and to facilitate equal participation among everyone in the group; in other words, in an online versus an actual focus group, it may be more likely that some participants overpower the discussion while others (especially those who may be less familiar or comfortable with computers) just “lurk” in the background without commenting (Moloney et al., 2003). Finally, online focus groups promote a fundamentally different sort of communicative experience than do face-to-face interactions; for example participants do not have access to one another’s non-verbal gestures, tone of voice, and body language – all of which can be crucial components of a face-to-face conversation.

In the case of this study, I was concerned that the drawbacks of virtual focus groups might be magnified; in particular, I was concerned that some participants would not have regular access to the Internet or that the Internet may not be an effective mode of communication for them. Because of this, I worked to develop accommodations for
participants who still wish to be involved, including allowing participants to relay their responses over the telephone and then posting those responses onto the discussion board.

a. **Dynamics of the virtual focus group**

Of the twelve individuals in the study, eight took part in the focus group. Of the four participants who were not in the group, one was no longer interested in being part of the study. Another, as previously mentioned, had been lost to follow-up prior to the second round of interviews. A third was unable to commit the necessary time and energy to be involved. Finally, in an effort to capture more diversity in my sample, I recruited the fourth participant after the focus group had concluded.

The focus group began approximately one month after the second round of interviews ended. In order to facilitate participants’ continued involvement, I maintained regular contact with each participant during the period between the second interviews and the focus group. This brief interlude was necessary to develop (and gain IRB approval for) the focus group guide, which I derived from preliminary thematic analyses of the interviews and diaries.

The focus group lasted for four weeks, and I ran it through a Yahoo group account, taking necessary measures to protect anonymity and confidentiality. Each week the discussion revolved around a different topic. I posted a question on Monday morning, and posted follow up questions every morning throughout the week (or every other morning, depending on how many follow up questions there were per topic) through Friday. I did not post questions on the weekends, although participants sometimes accessed the board during that time to “catch up” on conversations that they had not had time to participate in during the week. Each morning, I sent individual notes to
participants’ regular email accounts, reminding them to check the board and to respond to the questions. In two instances, I called participants and they dictated their answers to me, which I recorded and transcribed verbatim. One of these individuals had trouble typing and found it easier to dictate their replies. The other was hospitalized halfway through the focus group activity and still wished to participate in the group but lacked access to a computer. Upon the focus group’s conclusion, I sent personalized thank you letters to each participant along with compensation for participation in this portion of the study.

b. **Content of the Virtual Focus Group**

As mentioned earlier, I centered the focus group questions around four major themes, each of which recurred throughout the individual interviews and the diaries. In the first week, I asked about their experiences with CP over the course of their lifetimes:

- Please imagine that you were asked by a child with CP and/or her parents to describe what it’s like to live with CP as an adult. What would you say? Why? What advice would you give? Why?

This initial question was intended to be broad and non-invasive enough to facilitate participants’ comfort with sharing in a group. Further, in the individual interviews, many described having mentored children or young adults at some point, and I thought that sharing these experiences would be both fun and informative.

I followed this up with two, more direct questions:

- Please discuss in a paragraph or two how your thoughts and feelings about having CP have changed over the course of your lifetime.

- Please address what factors contributed to this change? How do you believe that these factors played a role?
During the individual interviews, several participants revealed that they had undergone a significant transformation during young adulthood with respect to how they felt about their disability (a transformation that contained several striking similarities) and I wanted to further explore this phenomenon within the group forum.

The last question of the week was:

- Do you ever think about what your life would be like if you had never had CP? If so, what do you think it would be like?

Although I asked a nearly identical question during the second individual interview, I was once again interested in encouraging discussion and debate about it within a group setting.

To start the second week, I asked:

- Reflecting upon your life as a whole, please describe in a paragraph or two who or what has contributed the most to how you think and feel about your CP? You may discuss multiple people or things in your answer.

While I had not specifically asked this question during the interviews, many participants alluded to individuals who had been pivotal in this respect. In particular, several spoke of how family members and other individuals with disabilities had been instrumental in helping them to develop a positive self-concept. Thus, in addition to capturing more detail in this area, this question served as a sort of member checking as well. As a probe, I suggested that they consider what that person or thing had contributed to their understanding of their CP. The next question was:

- How you think your thoughts and feelings about your CP would be different without this person?
My goal here was to have participants reflect upon and discuss more explicitly the kinds of roles these individuals had had in their lives and how the individuals had shaped their views of CP.

The third week of the group centered around participants’ corporeal experiences. Although this study focused specifically upon individuals’ with CP social and psychological experiences, experiences with impairment, particularly as they related to physical pain and fatigue, emerged as a significant theme throughout the study. While interview findings suggested that these impairment experiences are related to participants’ social and psychological well-being, I wanted to more directly and thoroughly explore this relationship. Thus, the first question asked participants:

- Discuss how you believe that your physical experiences with CP affect your social and psychological experiences.

As a probe, I asked them to consider how pain, paralysis, drooling, incontinence, and other physical experiences affected their social interactions or their feelings about themselves.

Secondly, as many participants had previously suggested that their physical abilities had deteriorated with age, I asked them to:

- Discuss how you believe that these physical challenges have changed as you have gotten older.

In the last question of the week, I asked participants to:

- Discuss what steps you have taken to address these challenges (therapy, medication, etc). Have they been successful?

In addition to once again helping to elucidate differences between older and younger participants with respect to the physical effects of CP, and their consequent social and
psychological responses, I was hopeful that the question might engender an exchange of strategies and support.

I used the final week to focus upon what I believe to be a significant finding and theme of this research project: the experience of having CP not as primarily one of stigma and devaluation but also as one of resilience and finding/creating new life meanings. Specifically, I very briefly introduced my thinking to participants:

When I began this project, I wanted to focus on how individuals with CP experience stigma and social marginalization. But since I have gotten to know each of you and have been privileged with hearing your life stories, I’m beginning to think about the experience of having CP as one of resilience and finding and/or creating new meanings.

Then, as a way of member checking and elicitig more direct and concrete feedback on this idea, I asked them to:

- Please discuss in a paragraph or two how you agree or disagree with my assessment.

I followed this up with my final question:

- Reflecting on your own life experience, would you describe it as one of resilience and creating new and unique life meanings? Why or why not? How has having CP contributed in these ways?

Thus, acknowledging and drawing upon participants’ unique insight, I utilized my final bit of data collection to seek participants’ input on my new overarching theoretical framework.

E. **Analysis and Writing**

In accordance with phenomenological data collection methods, phenomenological analysis “seeks to grasp and elucidate the meaning, structure, and essence of the lived experience for a person or group of people” (Patton, 2001, p. 482). Although there are multiple perspectives on and approaches to phenomenological analyses that vary slightly
in their details (Moustakas, 1994; van Manen, 1990) most follow the same general process. The data I have analyzed came from the interview transcripts, the diaries, and the transcript from the focus group.

To begin with, I read each participant’s response data (two interview transcripts, diary, and focus group responses) several times, highlighting and then copying in a separate document any words, phrases, and sentences that related to his or her social and psychological experiences and/or related constructs (Patton, 2001, p.485). I disregarded all that did not seem related so that I essentially pared the data down to its barebones. In other words, I eliminated any little “asides” that I judged as not relevant to the primary content of what the participant was sharing. When I was uncertain as to whether something was related, I included it so that I could use it later if necessary.

At this point, I was not concerned with evaluating the relative merit or usefulness of certain units versus others for the understanding of the experience, but rather just with recording them into a separate document that would be more manageable then the original transcript. Patton (2001) refers to this as “horizontalizing the units, or laying them out for examination, with all elements and perspectives having equal weight” (486). For example: “My daughter helps me with my hair, but I wish I didn’t have to ask her for help,” was a unit. I then grouped similar units into clusters; these constituted the fundamental structures of a participant’s experience. For instance, when later on the participant said: “My husband wants to do some of the cooking, but I don’t like asking him for help,” then I cut and pasted these two units into the same cluster. When units did not seem to fit into a cluster, I temporarily set them aside until I finished examining all of the units. At that point, I re-evaluated whether they did fit into a cluster after all, whether
they stood on their own as potentially being important to the participant’s overall experience (perhaps even as contradictory evidence), or whether they should be eliminated from the analysis. When the clusters were complete, I then labeled them. For example: “Not wanting help from family members,” was a cluster.

Van Manen suggests that each time a new cluster emerges, the researcher should ask herself: “What does this cluster reveal about the phenomenon or experience being described?” and “How does this cluster contribute to a theme?” (van Manen, 1990, p.93). In his discussion of uncovering themes in lived experience, van Manen argues that “…phenomenological themes are not objects of generalizations; metaphorically speaking they are more like knots in the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes” (p.90). In this case, I examined clusters of experience in order to identify emergent themes in the data. In other words, I developed categories of words, phrases, and ideas embedded within the text that related to different aspects of a participant’s social and psychological experience. For example, the participant spoke extensively about wanting to be functionally independent, not only within her family but in the public sphere as well; thus, the cluster “not wanting help from family members” contributed to a broader theme of “wanting independence.”

After determining the overarching themes that seemed to define an individual’s experience with CP, I began constructing his or her “experiential description” (see chapter six). I wrote multiple drafts of each description as I initially found it difficult to identify what was most significant in, or to capture the fundamental essences of, each participant’s experiences. I had always wanted to limit these descriptions to two or three pages, but some initially were as many as six or seven. This forced me to revisit my
drafts several times and to re-evaluate what aspects really spoke to who the participants were and what their experiences were like. In a phenomenological investigation, the researcher should use quotes liberally as a means of showing, rather than telling, what an experience is like, but I found that my descriptions were reading more like news feature stories, biographies, or portraits rather than research results. In fact, I had originally thought of, and referred to, these pieces as summaries of who these participants were rather than descriptions of their experiences with CP. My choice to rename them as “experiential descriptions” was a conscious acknowledgement that I needed to remain true to my methodology and rigorous in my approach.

Thus, as I worked to pare down my descriptions to capture the essence of each participant’s experience, I similarly tried to improve the consistency of each description so that they all followed the same basic format and were therefore easier to read. This proved challenging as well, as participants had a vast array of life experiences and I was wary of streamlining the descriptions too much so that everyone’s experiences ultimately sounded the same, or that participants’ genuine voices were not readily captured. However, in the end, I believe that doing so not only made the descriptions easier for others to follow but also helped me to read across participants’ experiences in order to identify the emergent themes. Providing participants’ basic demographic information at the outset of the descriptions as well as information about their families and occupational status was an effort to at least provide some contextual background prior to discussing the fundamental qualities of their experiences. Quotes at the end of each description were designed to clearly and succinctly reiterate what stood out to me as the fundamental essence of each individual’s experience.
After constructing the experiential descriptions, the next step of my analysis was to examine the descriptions together in order to determine the major themes that emerged across multiple participants’ experiences. In identifying the emergent themes, I relied on the descriptions but also went back to my pared down versions of the transcripts and diary entries searching for commonalities among experiences and issues that continually resurfaced throughout the data. For example, many participants spoke about their families in several different contexts, demonstrating how their families have played very central and supportive roles in their lives. Thus, “the importance of family” emerged as a major theme in the data. Similarly, “the effect of impairment” surfaced as another theme; although participants were not explicitly asked about their bodily experiences initially, many chose to discuss these experiences extensively throughout the data collection process. While the thematic chapter is an attempt to integrate the experiential descriptions into a meaningful whole, I tried to avoid redundancy between the two and thus to make the chapter more than just the sum of the descriptions. I was careful to use quotations in the thematic discussion that I believed represented the experiences of multiple participants, or that served as counterexamples, while I reserved the more unique anecdotes for the experiential descriptions.

Finally, in the last step of my analysis, I scrutinized both the descriptions and the emergent themes to determine the major findings that emerged from the study. My discussion (see chapter eight) is an effort to compare and contrast experiences across participants, and to utilize the data as well as the literature described earlier in the dissertation to begin to infer why particular similarities or differences exist. This project is more focused on gaining a sense of the structures of participants’ experiences rather
than building theory about why they are the way they are. However, I do want to put participants’ experiences related to having CP in dialogue with one another in hopes of gaining more clarity about the underlying factors that influence these experiences. In phenomenological research, this is often referred to as “creative synthesis” and “imaginative variation.”

Although many phenomenological researchers flatly reject the term “validity,” most agree that “evidence from phenomenological principles is ‘valid’ when the knowledge sought is derived from descriptions that make possible the understanding of experience.” As such, “a continuing alteration of validity occurs as people articulate and describe their experiences” in such a way that the underlying structures can be comprehended, if not experienced identically, or even similarly. As Drew (2008) writes: “We incorporate our empathized views of others’ experiences as valid for them and therefore valid for us.” In other words, validity is achieved when meaning is effectively communicated. De Witt and Ploeg (2006) refer to this as “concreteness,” such that readers are situated firmly in the context of the phenomenon and can also, in some way or another, connect the phenomenon back to their own lifeworld.

In this study, concreteness was evaluated both through what is referred to in more traditional qualitative methods as “member checking” and “auditing” (Patton, 2001). In qualitative research, participants are considered integral partners in the research project; as such, I wanted to ensure that I was accurately representing their experiences and to seek their input on my analyses. Prior to the final write-up, I produced a brief description of the major findings from the study and emailed it to participants. I then asked to have a brief phone call or email conversation with participants so that they could provide their
input. I refined my analyses to reflect their comments and interpretations when I felt that it was appropriate to do so.

Likewise, I also asked two colleagues to conduct audits: to review selected interview transcripts and diary entries, as well selected experiential descriptions, emergent themes, and a brief summary of the major findings, and to compare their interpretations with my own. I selected one postdoctoral fellow in disability studies who is a highly skilled qualitative researcher, as well as a PhD student in disability studies who is also very familiar with qualitative research and who has CP. I was careful to select transcripts that I believed were representative of multiple participants’ experiences, as well as those that contained pivotal examples of their social and psychological experiences of having CP. I also worked to select transcripts that might contain some potential for researcher bias in interpretation, such as transcripts from interview participants’ whose experiences and/or personal and demographic characteristics I believe to be very similar to my own.

Kruger (1979) indicates that the criterion for validity is not “whether another researcher would use exactly the same words or would arrive at an identical description of data.” Instead, he suggests that: “Validity is indicated by whether such differences in wording may be intersubjectively understood to reflect similar meanings or essential themes to those which emerged throughout the original process of explication by the researcher.” Intersubjectivity, also sometimes referred to as “resonance,” denotes the idea that as human beings, as social beings, we always exist in relationship to one another (Drew, 2008; de Witt & Ploeg, 2006). Thus, rather than seeking a singular meaning of a phenomenon that has universal applicability, researchers must strive to “uncover the
intersubjective unity of experience between persons” (Drew p.275). I tried to promote intersubjectivity through concrete description and careful reflection; for example, readers should be able to clearly understand the experiences being described regardless of whether they themselves have cerebral palsy or have similar social and psychological experiences as do participants in the study.

F. **Ethical Considerations Throughout the Data Collection Process**

I had to carefully consider several ethical issues prior to initiating data collection, including the ability of individuals to give their informed consent to participation, the potential for individuals to suffer psychological stress as a result of participation, issues of confidentiality and access to data (particularly in the virtual focus group), and compensation for participation. The entire research process was reviewed and approved by the University of Illinois-Chicago Institutional Review Board (Protocol # 2008-0898).

Before starting the first interview with each participant, I asked that the participant sign a consent form (See Appendix D). In simple and straightforward language, this form detailed the procedures involved in the research study, the participant’s rights as a research subject, and measures which would be taken to protect him or her and the information he or she conveyed. Participants had a right to withdraw from the study at any time and without any negative consequences, a right not to answer any question with which he or she felt uncomfortable, and a right to remain anonymous and to have his or her personal information kept secure and confidential. Prior to the second interview and the virtual focus group, I again described the purpose of the research project, reiterated the participant’s rights as a research subject, and sought his or her verbal assent (in lieu of formal written consent) to proceed. All participants were able to adequately understand
the terms outlined in the consent form and to make an informed choice about whether or not to participate in the research activities. Two of the individuals asked that I read the consent form to them; the other ten individuals read the form independently.

The risks in this study were minimal, and consisted primarily of the potential for psychological discomfort as a result of discussing potentially sensitive information. Every effort was made to create a safe and comfortable environment for participants to share their thoughts and experiences, but, as indicated above, they also had the right to refuse to answer any question or to complete any activity. Further, they had the right to terminate their participation in the study at any time, for any reason, and without any negative consequences. Additionally, I gave participants my contact information and the contact information of my dissertation advisor, a clinical psychologist, in case they had any questions or concerns before, during, or after the research activities. All participants were given pseudonyms for the purpose of this dissertation, and pseudonyms will also be utilized in all future presentations and/or publications related to the study.

As a token of gratitude, participants received 25 dollars for each phase of the research activity which they completed or partially completed. Participants were given 25 dollars in cash at the conclusion of each interview; they were mailed checks for 25 dollars once they had completed their diaries and then again once the virtual focus group had ended. I chose these amounts because I felt that they were substantial enough to reflect an appreciation of participants’ time commitment and willingness to share their experiences but minimal enough not to be coercive, and thereby deprive potential subjects of a genuine choice of whether or not to participate.
In addition to the standard ethical considerations, several issues arose that were specific to individuals with CP, and indeed to my unique sample. For example, many of my participants required greater amounts of time and physical effort to complete the study activities, particularly if they utilized augmentative communication aides or if speaking was difficult. I had to account for this when estimating the time that would be required of them to complete the study, as I did not want to create excessive burdens for any of my participants. A couple of my participants chose to convey many of their experiences through their diaries because it was easier for them to type the information when they were not under the time constraints of an interview setting. For at least one participant this format also offered added privacy, as his personal assistant remained in the room throughout both of our face to face interviews. Additionally, in other cases participants asked to rest for a short time during the interview or to take a break so that they could receive necessary personal assistance with eating, toileting, etc. Finally, one participant began to have seizures right after our interview had ended and we were chatting while he was waiting for his ride. Although he had been having seizures regularly and it was determined that the onset of this episode was not related in any way to the interview, it was still distressing for both of us. Fortunately, we were in a very busy public place and I was able to get help immediately. An ambulance was called, but unfortunately his family members could not be reached to meet him at the hospital. The seizures had subsided by then, but the participant had become very agitated because the paramedics were infantilizing and ignoring him, and I think also because he was embarrassed that I had witnessed and was involved in the situation. My first concern was for his safety and well-being, and I tried to help as much as I could but unfortunately,
because of my CP, the paramedics did not pay much more attention to me than they did to him. He lived in a different state and I had planned to take a flight back to Chicago immediately after the interview. I was on the verge of canceling the flight so I could accompany him to the hospital when a family member was finally reached. I was prepared to stay with him, but he asked me to go and the paramedics assured me that everything would be okay and that the family member was on her way. So I left, promising to call him the next day. When I did call the next day, he seemed much better but rather embarrassed by the entire situation. However, since the incident his seizures seemed to be under much better control and our researcher-participant relationship resumed comfortably for the remainder of the data collection process.

G. **Researcher–Participant Relationship and Researcher Orientation**

Because qualitative research is inherently based in some degree of subjectivity, it is always very important to consider the role and orientation of the researcher. Although my research is clearly not auto-ethnographic, I have had to remain extremely mindful of my own “insider” experience of having CP and of how it has played a significant role in nearly every aspect of the research process. For a researcher to “belong” to the community where she conducts research does require careful attention to her own perspective and careful consideration of her own abilities as a researcher. I acknowledged in the introduction that my own life experience served as the impetus for this project; however, I also acknowledged earlier that the focus of the project evolved significantly as I discovered that the experiences of my participants did not, in fact, match my expectations, expectations which had been based largely upon my own experience.
Being an insider can bring certain benefits, but it can also pose challenges, both in the data collection and analysis process. Dwyer (2009) puts it well when she writes in her article, “On Being an Insider-Outsider in Qualitative Research” that “As a qualitative researcher I do not think being an insider makes me a better or worse researcher; it just makes me a different type of researcher” (p.56). I do believe that having CP myself has contributed a certain attentiveness, commitment, and overall depth to the project. I further think that it allowed me to establish a rapport with participants that I would likely not have otherwise had, and that several participants saw me as a sort of “kindred spirit,” as someone who could really empathize. In many situations, this worked to my advantage as several participants seemed to open up to me, as if they almost forgot that I was a researcher and instead viewed me as a friend. In a few cases, however, my position seemed to present itself as a disadvantage, as other participants seemed to automatically assume that I would be able to personally identify with their experiences and that they therefore did not need to elaborate significantly upon them. In these instances, I had to walk a fine line between revealing enough about myself to maintain the rapport while simultaneously redirecting the attention toward them and encouraging them to more thoroughly describe their own experiences. Moreover, I had to be very careful that any information I revealed to participants about my own experience was not in any way “leading,” i.e., that it did not inadvertently bias them to discuss their experience in a particular light. This came up a few times in instances when participants did not seem to understand the question or concept as I presented it, and so I was tempted to provide an example from my own experience as a way of providing clarity. However, in order to
prevent potentially biased responses, I refrained from doing so and instead simply tried to re-present the question in simpler or just different terms.

In reflecting upon the information participants have shared with me and considering how several did not describe experiences of stigma in the ways that I had anticipated they might, I cannot help but wonder if participants refrained from sharing more not because they believed that I already intuitively understood their experiences, but because they were trying to impress me. Perhaps my status as a researcher with CP was actually in some ways problematic as some participants may have, even subconsciously, compared themselves to me. In the presence of a seemingly happy, successful PhD candidate, perhaps participants felt uncomfortable revealing their true thoughts and feelings in a way that they would not have had I been a non-disabled researcher. Another possibility is that some of the participants (particularly the older ones) chose not to talk extensively about their experiences and feelings of devaluation because they felt a desire to protect me.

For my part, however, throughout the analysis process, I have worked hard to adopt a perspective of *epoche*, where “the researcher looks inside to become aware of personal bias, to eliminate personal involvement with the subject material, that is, eliminate, or at least gain clarity about preconceptions” (Patton, 2001, p. 485). Of course, in this case, it is impossible to eliminate personal involvement, since I have always and will always have CP, but I have taken measures to “become aware of personal bias” and “gain clarity about preconceptions.”

As Patton point out, *epoche* is: “An ongoing analytical process rather than a single fixed event.” Moreover, he maintains that: “The processes of *epoche* epitomizes the data-
based, evidential, and empirical (vs. empiricist) research orientation of phenomenology” (p. 485). In other words, I have had to continually revisit and carefully examine my own biases throughout every phase of the data collection and analysis process in order to ensure that I have accurately and fully captured participants’ experiences without a significant trace of my own. Moreover, through journaling and discussions with my own family and friends, I have worked to understand why participants in the study might not have experienced stigma in the way that I have and the way that I therefore expected them to.

This has been particularly difficult in cases where I have had profound experiences of stigma during the actual data collection process. Because I traveled extensively to meet with participants, I had numerous encounters with strangers in airports, hotels, restaurants, taxi cabs, etc. Further, because I traveled by foot (as opposed to the scooter which I usually use to get around Chicago), I struggled significantly to walk to and through all of these venues while carrying my luggage. Additionally, I struggled to make myself understood to individuals who did not know me and who perhaps had had very limited or no interaction with people with cerebral palsy. Although the majority of individuals whom I encountered during my travels (like on a daily basis here in Chicago) treated me very appropriately, there were also numerous occasions when I was either disregarded or treated condescendingly because of my CP. “Put your change away, honey” was a common response I received as I purchased fast food in the airports and train stations, as was “you should really let someone push you in a wheelchair” as I walked through the airport.
In one particular instance, I had just finished a long interview with a 50 year-old woman with CP who could not think of a single example when she had felt devalued or had experienced stigma. Upon leaving her apartment, I called for a taxi and then called my mom while I was waiting. I was still on the phone when the cab arrived, and when I told the driver what hotel I wanted to go to he ignored me, appearing not to understand me and repeatedly looking me over, as though he was very reluctant to pick me up. However, he seemed to understand me fine when I said into the phone, “I’ll call you back, Mom,” because he beckoned for my phone, demanding to talk to her. He appeared anxious and distressed when I abruptly ended the call without letting him speak with my mom, even after I very clearly repeated my destination. But instead of starting the car, he then said that the ride would cost at least twenty dollars and asked if I had enough money to pay him. Here I was, a doctoral candidate traveling up and down the east coast to do my dissertation research and because of my disability, a cab driver didn’t think I knew where I was going or that I would be capable of paying my own fare. Admittedly, I was physically and emotionally exhausted by that point, but I was also infuriated by the infantilization that I had just experienced.

After first collapsing in tears upon entering my hotel room, I began to wonder how a 50 year-old woman with CP similar to mine could have possibly never experienced these types of situations. Furthermore, I had also interviewed a woman earlier in the day who had also claimed not to experience these situations. Were participants not being honest about their experiences; were they selectively forgetting or repressing? Was my sample unique in some way and not representative? Or is it just my own experience that is unique and not representative? These are some of the many questions and issues with
which I have struggled throughout the research process. I recognize that in qualitative research, the researcher is the primary instrument, and that through having CP, I do have a unique vantage point. Yet, I have always worked to remain mindful of the fact that my task is to fully and accurately capture the experiences of the participants in my study, and not my own.

H. **Chapter Conclusion**

This chapter has described the methods I used to collect my data, and has provided a rationale for why I selected these methods. Additionally, it has discussed the analysis procedures and ethical concerns, and has addressed some of the personal challenges that I encountered as a result of being a member of the group whose experiences I was investigating. The following chapter will introduce the individuals who took part in the study and will provide a description of each participant’s experience.
VI. EXPERIENTIAL DESCRIPTIONS

A. Chapter Summary

In this chapter, I will provide descriptions of each participant’s experience with cerebral palsy. The purpose of descriptions is to introduce the reader to who these participants are as individuals, to capture the essence of each of their experiences, and to highlight the fundamental ways that CP influences each of their lives. The data come primarily from the initial and follow-up interviews, but I have also incorporated information from diaries and from the focus group as well, particularly from participants who utilized augmentative communication and for whom the interview process proved slow and cumbersome. Although these descriptions, in many cases, do include brief commentary, thematic in-depth analyses of participants’ experiences and comparisons among experiences will be reserved for the following chapters. Participants are described in the order that I met them for their initial interviews.

B. Miles

Miles is a 40 year old Caucasian male who utilizes a motorized wheelchair and communication board. He works at a large center for independent living, and is very involved in disability advocacy. Miles describes himself as an outgoing person who likes to have fun. He enjoys movies, sports, and traveling. Yet, when he goes out, oftentimes people will ignore him. “Whenever I am out with my friends in a restaurant,” he says, “the waiter or waitress will ask my friends, ‘What does he want to eat?’ As if they don’t want to take the time to figure out what I am saying.”
Although Miles recognizes that these situations are not unique to him, and refers to them as “social barriers,” he still considers them to be “very frustrating.” He believes that interacting with young people is often easier “because they were reared to be more accepting,” and can relate to technology more effectively. For example, he often uses the texting feature on his cell phone in order to communicate with strangers when he does not have his communication board.

He attributes his high self-esteem and strong sense of self-worth to his family and upbringing, noting that his parents, and even his extended family members, always encouraged him to participate in activities with his non-disabled peers, even if he could not do everything in exactly the same way as they could. Miles says that his high self-esteem helps to protect him from internalizing discrimination, but that it is something he has to work at continuously. Having been involved in the disability community since college, he goes to Washington DC every spring to participate in protests. Miles has friends in both the disability and non-disability communities, and says that although attitudes towards people with disabilities are improving, there is still a lot of work to be done. He feels that people with disabilities all share fundamental similarities in that they all like to have freedom and independence.

Despite his current leadership position in the Disability Rights Movement, Miles hated grammar school and high school because he felt isolated being among only peers with disabilities when he felt that he had more in common with able-bodied students. However, once he arrived at college, Miles was able to make friends with able-bodied students as well as students with disabilities, many of whom were active in the Movement. Although Miles has many friends and a strong support network, he finds romantic relationships to be “complex” and says that, in his opinion, two people are more likely to engage in a relationship if they have the same disabilities. But he still struggles to define his places in, and his allegiances, to the
disability and the non-disability communities. Although he currently has a very close female friend with CP, he acknowledges that, prior to meeting her, he used to like able-bodied women more. “I guess because I was segregated growing up,” he says; “I feel bad because I feel that I was betraying my people.” Still, he feels that if he were able-bodied he would be married by now, and that perhaps he would also be a journalist and would play sports. “I would take a cure for CP,” he says, “but I have friends and a good life.”

C. **Juan**

Juan is a 40 year old Latino male who is ambulatory, single, and currently unemployed. He attended a “handicapped school” until his third year of high school, when he transferred to a regular high school where “he couldn’t get along” and dropped out after a few months. Although he went through vocational training, the job that he found paid so little that he quit after five years and is now living on government benefits in Section 8 housing. However, he wants to go back to get his high school degree and is considering taking classes to become an interpreter.

Juan refers to himself as a “loner,” and feels like society looks down on him. But he has also learned not to let other people’s attitudes bother him. “People treat me differently because of disability,” he says. “You can see it in their eyes. It’s like a weird stare, like – I don’t know. Like I shouldn’t be outside, you know?” However, he then adds: “I used to let that bother me, but now it don’t bother me, cause I’m here to stay. I’m not going anywhere. I got to live my life and not worry too much about strangers.”

However, Juan does appear distressed by how he is treated by his family. “I can also see it in my family’s eyes,” he says. “They won’t come out and say anything, but you see it in their eyes. It’s not that they’re ashamed. But you’re supposed to encourage [your kids]. And I felt like I really wasn’t encouraged.” Juan also feels like he is devalued when around his brother and his
brother’s friends, who often just ignore him. “I don’t really speak to nobody, and nobody speaks to me really. That’s how I feel. I don’t have nothing important to say so – I don’t know. The only time they don’t blow me off is when I say something real sarcastic.”

Juan also finds dating to be a challenging experience because of his disability. He sometimes attends parties where he chats with women and asks for their phone numbers, but it seldom leads to more. “I don’t know. I don’t get the vibe like – how can I say it? Like we’ll be chatting for too long.” Juan did describe a period several years ago when he spent a lot of time exercising and was in very good shape physically. “I lifted weights for three years straight and I was at my best – I’ll give the females credit. They didn’t care about the disability. It took the focus off having CP; they didn’t really care about the disability. So I plan to get back with the weights.”

In many ways, Juan appears to identify more with the Latino community than with the disability community. With large tattoos on his arms and a nonchalant swagger about him, he seems to want to convey a sort of “macho” attitude despite his CP, and he expressed very little emotion during the interviews. Even so, Juan indicated that he is making an effort to become more outgoing and to connect more with people with disabilities. He does volunteer work at a local disability organization, and since his friend from high school passed away, he has been trying to reach out to his former classmates and encourage them to get together more often. Further, when asked if he feels that he shares commonalities with other disabled individuals, he responds: “We struggle. We struggle but we keep going. We got to try – I guess we got to try harder to let the public know that we’re out here. I don’t know. Like we shouldn’t be tossed aside or something. So we got to try harder for them to know that we’re out here, that we’re people too.”
Sara is a 29 year old Caucasian female who utilizes a scooter, is single, and is seeking her Associates degree. Sara is deeply committed to the empowerment of youth with disabilities, and attributes her own disability consciousness to her parents who have always been her biggest advocates. She also believes that having a mentor with a disability and having worked at a local independent living center have also been instrumental in building her self-confidence and shaping her sense of self. “It showed me that there are other people with disabilities who are working, who are empowered, who are proud of themselves, even though they had a disability. Like, if I have a problem, go, and be like, “Who else has had this problem and how have you dealt with it?”

Yet Sara also struggles for validation and acceptance within the larger society. She feels that she is often treated differently as a person with a disability and is not always recognized as the independent, competent adult that she is. In particular, Sara says that she is sometimes asked intrusive questions about her disability, or is treated condescendingly by others when she is out in public. “There are times when I just – I want to feel normal. And when you have a disability, people do still tend to look at you as not normal. And so when they come up to me and ask me that kind of stuff, I do find it a little insulting. It’s like they are doubting my intelligence.”

Sara has had difficulty finding and maintaining strong friendships. Having transferred high schools prior to her junior year, she lost most of the friends that she had grown up with until that point. Additionally, having taken time off from college for health related issues and to participate in various internships, she laments the fact that it has been difficult for her to make new and lasting friendships. Although she is now working on her Associates degree, she says that students tend to scatter their own separate ways as soon as class has ended, making it
difficult to get to know people. Sara has managed to build somewhat stronger relationships within the disability community, although, being fairly young herself, she has often felt that older individuals think of her more as someone to be mentored than as an actual peer. Developing friendships with younger individuals tends to be difficult as well, as Sara believes that she is sometimes inadvertently put in the role of mentor to those who have less developed social skills and/or overprotective families.

Sara also sometimes has trouble gathering the self-confidence necessary to actively seek and pursue romantic relationships, noting that: “[Romantic relationships have] been difficult sometimes, because non-disabled guys still - I think sometimes they want what’s the most attractive, and they think that someone in a wheelchair isn’t going to be as attractive.” Still, she is confident that the right relationship will come with time and patience. Additionally, structural barriers also sometimes prevent her from fully participating in her community alongside her non-disabled peers. In particular, inadequate accessible transit service often means that she arrives late to class, or does not make it at all. This also restricts her opportunities to meet people, socialize, and have fun outside of class.

Thus, despite her age, Sara is, in many ways, still transitioning into adulthood; she is also experiencing many of the ups and downs so common to this transition. However, even with the obstacles that Sara has encountered, she doesn’t believe that she would ever choose not to have CP. “I have changed a lot of people’s ideas about people with disabilities, a lot of people’s opinions,” she says. “And I think that that is more beneficial than taking away the disability, because my life has been a little bit harder. I think that I’m happy with – you know – me.”

E. Susana
Susana is a 39 year old Caucasian female who utilizes a scooter and has a mild speech impairment. She is married with two teenage children and works as the coordinator of a program that seeks to empower girls and women with disabilities. She says that from the time she was a high school student, her mother, who has post-polio syndrome, encouraged her to demand the same rights as her non-disabled peers. Susana would like to have more opportunities to teach young people about disability, and to be a mentor for disabled kids. “When I get that opportunity,” she says, “I love it, because I preach like ‘be true to yourself, don’t try to impress anyone. Be yourself.’ If I could get a handle on grammar school kids, like fourth, fifth graders, I would try my damndest to make them realize it’s okay to have a disability, that you need to be true to yourself.”

Although Susana was very scared about leaving home after high school, her parents sold their house “so my brother and I would not move back home. But you have to understand, they did that in a positive light. They wanted me to be independent.” Like her parents, Susana says that her husband and children “don’t see [her] disability,” but rather just accept her for who she is. “I have responsibilities, like any other mother and wife does,” she says. “I don’t get out of it. And if I fall or drop something, okay – they step over me. If there’s no blood, they step over me.”

She is very involved in the mainstream community as well, especially with her church and the local PTA, and she works hard to project an image of herself as a strong and competent woman. “When I was little,” she says, “people treated me like a little disabled girl. But I’ve proved to people that I’m in the community, and I’m knowledgeable. I kind of make people feel like it’s okay to approach me. You know, we’re in a society where people look at the outer side
too. I might feel more pressure to look a certain way because of my CP…I don’t know…I just want to look good.”

Yet Susana says that she has not experienced much devaluation in her adult life: “I wouldn’t put myself into a situation where I would feel demeaned. I control my life. And I control who I let in, or who I don’t. I feel comfortable with myself…I know myself…I’m very secure. So I don’t even give [jerks] a second look.” She has a strong network of friends who frequently go out together on weekends. “We just hang out and talk,” she says, “and bitch about our husbands of course. My friends get me drunk, like any other person, and they still bring me home to my husband.”

Susana has never considered what her life would be like if she did not have CP, nor would she want a cure for CP “because this is my life, and I like my life right now.” She briefly tried Baclofen to reduce her spasticity, and although her family noticed a difference, she did not. “And it made me tired,” she says, “so here I sit, and to me, I’m not doing so bad.” Then she adds with a grin, “I’d rather be a – gimme a beer! And then I’d get a buzz too!”

F. Alex

Alex is a 40 year old openly gay Caucasian male with CP who utilizes a motorized wheelchair and an augmentative communication device, and works for a state disability organization. He says that having a disability is “a challenge at first, but once people get to know me, it’s awesome [because] they see me as Alex.”

At the same time, however, he also suggests that some people fear him because of his disability and do not take the time to listen to what he is saying. “I would love to talk with no disability,” he says. “Sometimes people avoid me because I can’t talk, and sometimes I avoid them because it takes too much energy to type.” Whether it is calling hotels to reserve meeting
space for his job, or ordering food at a restaurant, Alex often encounters ignorance from his
communication partners. Although he often makes meticulous preparations, (for example, by
pre-programming his communication board before he calls to make a reservation), he laments
that people “don’t get that I am the person making decisions.” On one occasion, Alex was
checking into a hotel and the clerk refused to accept his credit card, believing that it had been
stolen. When asked how this incident made him feel, Alex replies: “I am forty-four, and this is
my life.” He adds that age and experience makes it easier to understand and accept these
situations, and that other’s attitudes do not affect the way he sees himself because his “family
and friends say that it is the other people’s stupidity.”

Although Alex is able to effectively negotiate public misperceptions about his disability,
he has had periods of depression, for which he is on medication and regularly sees a therapist. He
attributes his depression largely to a lack of intimate relationships, as well as his deteriorating
physical condition, which prevents him from socializing as much as he would like. “My
disability does stop me from meeting men,” he says. “And being gay does add a lot of struggle.
Having a disability is one strike for people, and being gay is another.”

Alex also wishes that adults with CP received more attention in medicine. “Our
disability is so intense,” he says, “but it’s not talked about among professionals. Medication is a
huge issue for us. We either don’t get enough, or we are over-drugged. I think our age group is
the testing ground for medications, and sometimes that’s good, and sometimes not. We are a new
frontier.” Alex has struggled for years to find the right combination of medication he needs, but
he believes that there are many, many individuals with CP who are living in institutions, are
unable to communicate, and are not receiving basic care, including pain management.
Finally, Alex is very concerned about the prevalence of abuse among people with disabilities, especially people with CP. Having been the victim of physical, emotional, and financial abuse at the hands of his aides, he notes how vulnerable people with disabilities are, particularly when they have such complex personal assistance needs as he does. Ashamed at his own weakness, and not wanting to burden those he loves, Alex hid what he refers to as “a hellish situation” for over three years. He writes in a diary entry: “I am a person with cerebral palsy who could not survive twenty-four hours without any human contact. Therefore, being mouthed off by this girl, was it safe for me to make even the simple statement, an attitude change needs to happen? If I wanted not to eat, drink, get my medication, and not maintain my job intact, yeah it would have been safe.” Alex had been leading workshops for several years, even throughout the period of his own victimization, on preventing the abuse of people with disabilities, and reveals that he “felt like a hypocrite [when my aide was abusing me]. [I had] a fear of my life coming apart.” However, since the abuse was revealed, he feels like he is finally getting his life back on track. “My brother is supportive,” he says; “I now have eyes on me that people are not aware of.”

Despite the multiple challenges he has encountered, Alex still considers his CP to be an integral and positive aspect of his identity. “Let’s be honest,” he says, “it is the only life I have known. I think having CP has made me a better person. I do not think I would work with people with disabilities or would be as grounded had I not had CP.”

G. Kate

Kate is a 36 year old Caucasian woman who is ambulatory and has a speech impairment. She runs two nonprofit organizations: an acting company for youth and young adults with disabilities, and a disability awareness training project that works to educate grade school students about what its like to live with a disability. The ideas for these programs were born out
of the isolation and ridicule that she personally experienced in middle and high school and that still deeply affect her. “Kids made fun of the way I walked and talked and ate,” she says. “I would sit by myself at lunch. It was difficult. One of my best friends from grade school went to the school, but I never saw her.”

By the time she reached high school, Kate was suffering from depression: “My mom knew that I was just not myself,” she recalls, “And I felt socially isolated, so she pulled me out. And I took the rest of the year off, and I got treated for depression, and other things.” Kate completed the remainder of high school at a different school, where she found a few friends and, despite her speech impairment, became involved in the choir. College was even better, because she received more educational support, met a more diverse group of students, and had a boyfriend. Looking back on her high school experience, Kate reflects that: “I think it made me who I am. ‘Cause I left the school, and I educated kids about disabilities, and if I never went through that experience, I probably wouldn’t do what I do now.” Later she comments that: “I think [my work] gives me a sense of purpose. I think it’s kind of my mission in life.”

Although Kate believes that she is generally well accepted within her small town community, her significant speech impairment and unique body posture make some people uncomfortable. “Some people don’t know what to do, and they don’t know what to say,” Kate comments. “I don’t think a lot of people know what CP is… Basically people don’t want to take the time to listen.” On the other hand, Kate has also found that some people are very invasive, asking questions or offering assistance when she does not need it. She frequently blames herself for appearing awkward in her movements, and works with a psychiatrist to overcome her guilt and self doubt. “CP is hard,” she acknowledges. “I mean, I think that there are certain social situations that you go through that other people don’t have to go through, and so learning how to
deal with them is helpful.” Kate really values her membership in the CP Group, an organization for adults with CP that meets every year and has an active Internet listserv. “I’m always sad when I come home,” she says, “because you have a great period with these people, and then it’s over. But she also wishes that the CP Group attended more closely to issues related to psychological well being, stressing that: “Social and emotional issues are so critical, and they don’t really understand that. Because I remember growing up, there wasn’t a lot of support for me. Like friendships and self-confidence and self-esteem. And I just think that’s so important. It’s just so critical.”

Kate is very close to her family and has a few really good friends from grade school and from her acting programs whom she feels that she can really talk to. Still, she would like to have a more active social life and also to have a boyfriend. Thus, although Kate recognizes that she has been able to do a great deal of good as a result of her disability, she clearly has also experienced social devaluation as well. This discrepancy has led her to question her own identity and has caused some emotional angst. “I do think about CP a lot,” she says. “What if I didn’t have this? What are people thinking? I want to move into Kate who happens to have CP, and I don’t think I would be who I am without CP, but yeah, I’m stuck with CP defining me sometimes.”

H. Megan

Megan is a 50 year old Caucasian woman who uses a scooter, is single, and works as a math tutor at a community college. Megan’s describes her experience with CP as “not a major thing” and as “just a small part of who she is.” She has a strong network of friends through her church and characterizes herself as easy to get along with, as a good listener, communicator, and teacher, and as “damn proud to be 50.” She was also very, very close to her parents up until their
death, and attributes her self-esteem and success in life to them. “They stood back, and they let me figure things out. And if I needed help, I knew that all I had to do was ask, and they’d help. They were just great parents and I love them to death.”

As she ages, Megan feels increasingly self-confident; she “sees [herself] as normal” and, indicates that, as an adult, she has not experienced much differential treatment as a result of her CP. However, Megan has, throughout her life, experienced significant internal conflicts; these have resulted in periodic bouts of depression. She attributes these periods to her former perceptions of CP, her physical limitations, and overall feelings of incompetence. “The CP would be bigger than I was, and I thought that people were looking at the CP, and they weren’t looking at me. But it was all my perception. My self-perception was getting cockeyed. Where I was projecting that people were looking at the CP, because that’s what I was seeing the most from myself.” Although Megan attributes her depression to her self-perception and claims not to have experienced much stigma or discrimination in her life, she also describes later how she was denied a teaching position after graduate school because her supervisor didn’t believe that she was capable of teaching special education students.

Over the years, Megan has had significant difficulty finding romantic relationships; she again attributes this to her own anxiety and low self-esteem rather than to social prejudice. “Part of it [is because of my disability],” she acknowledges. “A lot of it is fear of the unknown, [and] I’m making CP a big part of it. And by that, I mean I’m hiding behind it. It’s not being fair to me. And it’s not being fair to any guy who might be interested.” But with age, Megan has gradually learned to be content being on her own. “It’s just easier sometimes. I mean, yeah, I would like to have a companion, and to have someone to share stuff with. But it probably is not
She notes that fatigue also often prevents her from going out and putting herself in situations where she could meet new people.

However, despite her fears around dating, Megan says that she now feels very comfortable around people and generally satisfied with her life. “I could talk to virtually anybody,” she says, and she is happy to answer questions about her disability. But, she points out that the people she interacts with the most rarely notice the CP. “With the students I’ve worked with…They just see me. And if anybody brings it up, I do.” Even with the challenges she has encountered, Megan sees her disability as an integral part of who she is. When asked what she thinks her life would be like if she did not have CP, she replies, “I would not be the same person I am today. My life would have been just a totally different thing. And it’s part of who I am, and I’m happy with it.”

1. **Jesse**

Jesse is a 40 year old African American male who is married with a son and works as a tax analyst. Although he has a very mild form of CP that mainly affects his left arm and often his impairment is barely noticeable, Jesse has struggled throughout his entire life to be fully accepted and integrated. During his childhood, Jesse’s family worked to normalize him and to promote his full inclusion. “I’ve always tried to be a part of, you know, the general population,” says Jesse. “My parents never, like, put me in that situation. So I’ve never really thought about [associating with other disabled people]. I’ve been forced – ‘get out there, get out there,’ so I’ve never really had friends that have CP, or have a disability, just because usually when I’m in a room with people, I’m the only one with it.”

However, as a child, Jesse was often ridiculed by his non-disabled peers because he could not play sports or complete his work as quickly. “When I was going through school,” he says,” I
realized that I could not do things like everybody else. I couldn’t play baseball. I couldn’t play basketball like everybody else. I thought everybody had the same problem I had, but that wasn’t true.” And as an adult, Jesse has encountered significant discrimination in the workplace. He used to try to conceal his impairment during the hiring process, but says that this plan backfired on him once employers would assign him tasks that involved a lot of typing, which he couldn’t complete as quickly as everyone else. When he finally had to reveal his CP, employers “felt like they had been taken.” “I would not tell them,” he says, “because I was trying to assimilate. I was trying to be like everybody else.” Jesse has since decided that it is better to disclose his disability at the outset of the hiring process, and says that he chose to work for the state because, as he puts it, “There, they have to hire you. I mean, they’re not going to discriminate against you because of your disability.”

Jesse describes how he has also, once he actually gets hired, felt ostracized by his co-workers and he says that he has even been openly ridiculed for his slow typing speed. “They would always consider me a liability…they always made me feel like I was inferior.” Jesse believes that there are many tasks that he could do within his current job that would highlight his strengths rather than his challenges, but that his supervisors are frequently unable to “think outside of the box,” and his co-workers often get jealous when he is given different assignments.

Although Jesse attributes most of the discrimination he faces to his disability, he acknowledges that his racial status may play a role as well. “It’s like you’ve got to get over two hurdles to get to the real person that you’re sitting in front of sometimes. Because if I’m sitting in front of somebody who doesn’t have CP and who is not black, I may – I don’t know how they feel about me as an African American male, and then I don’t know how they feel about me,
African American male with CP. So once you get past the black and then you get past the CP, then there’s a chance that we can have a true relationship.”

However, Jesse does have a very good relationship with his wife. “She’s been very supportive,” he says. “She understands what I need. She understands I can’t do everything, and she’s always willing to help out.” Both he and his wife have worked to make their ten year old son aware of his father’s abilities as well as his limitations. Jesse believes that having a disability has forced him to use his mind and has given him motivation to get an education and to work hard. “It has been a big part of my life,” he says. “This is who I am. I’m almost forty years old. I’ve done this forever.” But apart from his family, Jesse has found it very difficult to build relationships, particularly with other men. “I put up that shield. I don’t allow myself to get involved with too many people. Because, ultimately, I know they’re gonna let me down.”

Thus, Jesse seems to be caught in a sort of no-man’s land between the disabled and able-bodied worlds. Like many other individuals with very mild impairments, hidden disabilities, or chronic illnesses, Jesse doesn’t believe that he has much in common with other disabled people, or that he would be readily accepted into the disability community. “I keep to myself mostly,” he says, “because I really don’t find there’s people like me. I would love to change that. But I haven’t found a way to become friendly or be accepted in someone else’s world, because of the CP.”

J. Steve

Steve is a 43 year old Caucasian male who uses a motorized wheelchair, lives in supported housing and does assembly work at a supported employment center for people with disabilities. He enjoys watching sports, spending time at bars, and going to different places and events around town. Steve believes that people generally respond well to him, and that he is
rarely treated differently because of his disability. However, his social interactions are usually limited to a small group of friends and acquaintances, most of whom he regards as “normal,” which he defines as “a hundred percent walking and being able to get around more.”

He spends a lot of time around other individuals with disabilities at work, but says that he rarely talks to them about the disability experience. “I really don’t talk to people about it,” he says. “It’s a lot easier that way. I really don’t get in that kind of business. Most of the people at work have disabilities, but I don’t ask them what their disability is.” It seems that rather than naturally choosing to integrate into the disability community, he has been placed in a segregated and paternalistic environment with other individuals who do not necessarily identify positively as disabled.

Although Steve appears to be generally satisfied with his life, he appears, particularly in contrast with some of the other participants in this study, not to be very introspective regarding his experience with CP, and to have an attitude of resigned acceptance towards his disability. He says that “having CP is not fun because it’s hard to walk” as well as to do basic activities of daily living like dressing and undressing. He also adds that “I really can’t do stuff like other people. Like a lot of people play tennis and soccer. I can’t do that. It’s hard to watch people do it. When they play soccer or do stuff outside, I watch them and it’s hard for me to watch it, because I can’t do what they can do. It’s hard sometimes.”

Steve thinks that if he could walk better, then he would be able to get around more easily and would not have to spend so much time waiting for Paratransit, which is often late picking him up. He also believes that having a disability makes it more difficult to meet new people, especially women, and that if he did not have CP he could talk to new people more naturally without relying on his friends to help him start a conversation. He often prefers to spend time
alone because, as he puts it: “It’s a lot easier to get stuff done. I mean like, because I don’t have
to worry about waiting for some other people. If you go by yourself, then you’ll be able to get
there.”

In talking about sports and hanging out with his friends at bars, Steve seems to want to
assume the role of the average working-class Joe. Although he enjoys visiting strip bars with his
friends, he is not interested in having a girlfriend, claiming that it is “too much hassle. They bug
you. They bug me. And they just want to do stuff. Some girls want to have sex all the time, and
they – I don’t want to do that.” Although Steve does not consider his CP to be an integral part of
who he is, he acknowledges that there can be benefits to having a disability. “You get in stuff
faster [when you have a disability]. Like a bar – sometimes bars make you wait in line. A lot of
times they make you get in first in line. And I get better seats. Better seats at places. Hockey
games, or sports, or whatever.” Ultimately he just accepts his disability for what it is, although
he says that he would take a cure. “I deal with it. But without CP, it’s a lot easier to get around.
It would be a lot easier in my life. I’d love it [if I woke up one day and didn’t have CP]. I’d be
jumping for joy.”

K. Danielle

Danielle is a 33 year old Caucasian female who uses a wheelchair. She is married, and is
the mother of five year old twins. She works full time as a personal assistant coordinator in an
independent living center, and refers to herself as an “empowered disability rights activist” who
has learned “not to take shit from anyone.” Danielle has struggled to get her own mother to see
her as a capable, independent woman. “I don’t think she has ever really accepted the fact that I
have become this empowered disability rights activist,” she says, “and I don’t think it’s a death
sentence to have a disability.”
Despite being empowered as a person with a disability, Danielle often still struggles to feel empowered as a parent with a disability. As a mother of twins, one of whom also has a disability, Danielle sometimes feels as though she’s on an emotional roller coaster. “Cause I feel like I have to show – work a hundred and a half times harder than your average individual.” Later she says, “I’m too permissive. I want to be able to do everything for my kids, so at times when other parents would draw the line, right, I may not. Because I have to make up for my disability. I said I was an empowered individual with a disability and I was proud of having a disability. But damn, you throw this cork at me and it’s kinda like, ‘whoa, I have a lot to learn.’” Danielle is also concerned about others’ perceptions of her abilities as a parent, and says that there have been times when she has been out with her children and strangers were surprised to realize that she was the parent. “When they were first babies, I’d go to the grocery store with my then child care provider who was in the home, and people would say, ‘Wow, you look like you have your hands full.’ And she’d say, ‘No, actually she does.’ And people’s eyes, ‘Oh my god.”

Danielle also gets frustrated with people’s everyday lack of consideration for her needs and those of other people with disabilities, whether it be people running into her wheelchair, blocking her path when she is headed to the train, or just talking over her. “I’ve had people tell me I’m angry,” she says. “That I’m angry about being a disabled person. Poor me. But if I speak passionately about something, I’m angry. Right? Because I’m disabled. I tend to speak loud. And from my stomach. And if I have to repeat something four or five times, I’m going to get pissed!”

However, despite personal conflicts and social obstacles, Danielle recognizes that her time working in the disability rights field, as well as her roles as wife and mother, have transformed her identity and have strengthened her sense of self. “It’s not easy,” she says. “I feel
like I have internal demons that I deal with a lot. But I realize now that I can change the world for a lot of people.”

L. **Drew**

A 26 year old Caucasian male who is ambulatory and has a speech impairment, Drew recently began a Master’s program in special education, and hopes to serve as a teacher and a mentor to youth with CP. “I found that working with the disabled has helped me accept my own disability,” he says of his experience as a teaching assistant. “I don’t know how common that is, but I decided I wanted to go into Special Education. I like working with all kinds of disabilities, but I especially like working with kids who have CP. There’s something special about CP.”

Drew’s experience with CP can be described as one of positive disability identity and pride. As a child, he was frequently ridiculed by his classmates at school and even now he sometimes encounters prejudice and discrimination from strangers because of his unique speech and manner of walking. However, he says that he does not take these reactions personally, and that he is usually able to “block those experiences out of [his] mind.” “Some people just look down on disabled people,” he comments. “Some people think because we walk different and talk different that we are not as good as them. And we need to change that. I don’t know how, but we need to change that.”

Drew believes that he has become less self-conscious with age, but he also admits that having successfully emerged from a significant period of depression a few years ago, or what he calls a “nervous breakdown,” significantly changed his outlook on life. During his senior year in college, as he was preparing to embark on a teaching career, he inexplicably began having seizure-like incidents. At the same time, his professors began to express concern about his ability to teach special education because of his own impairment. “I guess it was really hard on me
physically and mentally,” he recalls. “I started to have depression really bad, and I tried to kill myself. It’s not something I’m proud of, but I did it.”

Drew acknowledges, however, that his experience of depression has really helped to improve his perspective and outlook on his future. “I didn’t worry about what people thought of me as much as I did before.” He says that medication and psychotherapy have helped considerably, as did simply getting out of the situation that he was in. Even so, his seizures continue to wreak havoc on his life and prolonged his return to school. In addition to negotiating his seizures, Drew also has difficulties with incontinence and has recently decided to wear diapers in order to control this problem.

Fortunately Drew has a strong support network, including his mother and a best friend who also has CP. Although he feels comfortable talking to his mom, he believes her non-disabled status prevents her from entirely understanding his perspective. However, in describing his relationship with his friend, Drew says, “We are like brothers, you know…we are bonded. He’s a couple years older than me. We can talk about anything. Work, projects, cerebral palsy, you name it. We don’t have to explain anything to each other. He’s my rock.”

Overall, Drew believes that having CP plays an enormous role in who he is. “It’s been part of me my entire life, and it will be with me until they put me in the ground. I can’t imagine life without it.”

M. Betty

Betty is a 45 year old African-American woman who uses a wheelchair and has a speech impairment. While Betty herself is not gay, she describes herself as an ally of the gay community, a gay rights activist, and a “very, very stubborn person” who gets along with all types of people. Although she considers herself to be very independent, she feels that family,
friends, and even strangers, are often too overprotective of her; they constantly remind her to be

careful of traffic, advise her to stay indoors because of the cold, and tell her what sort of people

she should, and should not, spend time with. “People are kind of condescending,” she says,

“mostly wherever I go. Until I set them straight. I tell them, ‘I’m 45 years old, and I’m an adult’

and they would not like it if other adults talked to them like that, you know? And once that

happens, then it’s okay.” But she acknowledges that these comments sometimes wear on her. “I

feel frustrated, and aggravated, and irritated. I don’t feel bad about myself. I just feel – I don’t

want to be bothered with what they are saying anymore.”

However, Betty did not always feel so self-confident. Thirteen years ago, she experienced

a huge emotional and spiritual turning point while listening to a church sermon on forgiveness.

“It’s hard to put it in words,” she admits, “but that did change my whole outlook on things. I

used to give in to other people’s fears when I used to compare myself to normal women. I used

to settle for things that I shouldn’t have been settling for. All of that changed for me. I don’t do

that anymore. And now I speak out more. People don’t know how to handle my response

because they are so used to the way I was that they’re not used to the way I am now.” Whereas

until that point, Betty frequently felt devalued by others’ ignorance and condescending attitudes,

she now says that: “Nobody can ever devalue me. I am the only one who can devalue me. If they

try to do that, I will set them straight. I don’t want those kind of people in my life. I don’t let

them get to me.” Betty says that she has not had much luck dating men because, since her

“awakening,” her standards have become higher, and she wants to find someone whom she can

really settle down and feel comfortable with.

While Betty has no hesitations about speaking up for herself among strangers and casual

acquaintances, handling the delicate relationships within her own family has proved significantly
more challenging. She believes that her mother has always kept her in a position of dependence in order to maintain control of her social security checks. As Betty has recently begun to assert her own needs and wants, her mother and brother have consistently worked to quell them. Everything came to a head when they issued false allegations against her personal assistant (PA) and were able to get her fired. “She woke me up,” says Betty of her PA. “She woke me up. She woke me up, and she put a fire in me.” She describes how her PA encouraged her to become more independent and to start making her own decisions. Betty says that her mother and brother are so angry by her desire to be independent that now her home is like “hell.” Although she wants to open her own bank account, and ultimately move into her own apartment, she says that asserting her independence in front of her family “is like starting World War III,” and that she does not have anyone to provide her with the physical, emotional, and social support that she needs.

Despite her constant trials with her family, however, Betty enjoys her life and would not change having CP. “Normal people are kind of boring,” she says, “because we always had to be creative. And I think CPs do a lot.”

N. Chapter Conclusion

This chapter has provided brief descriptions of each participant’s experience with CP. Clearly, each participant’s overall lived experience is highly complex and is influenced by a multitude of factors, including, but not limited to, gender, age, race, sexual orientation, personality, socioeconomic status, and employment situation. It is also influenced by interactions with family members, romantic partners, co-workers, and even strangers or casual acquaintances in the community. The next chapter will discuss the major themes that emerged across participants’ experiences.
VII. EMERGENT THEMES

A. Chapter Summary

In this chapter, I describe the common themes that emerged across multiple participants’ experiences. As explained in the methods chapter and evidenced in the experiential descriptions, I have expanded my focus of this dissertation from a focus on stigma to a more general exploration of participants’ social and psychological experiences. This includes both positive and negative experiences. For example, while I discuss experiences of devaluation and depression, I also address experiences of empowerment and the development of a positive disability identity.

B. Devaluing and Challenging Experiences

1. Devaluation in the Community

Throughout the interviews, diaries, and focus group, participants spoke about experiences of devaluation in the community. Miles, a disability rights activist who utilizes a motorized wheelchair and who relies upon an augmentative device to communicate, provides a particularly poignant example of an instance when he felt treated differently.

I was going to a party in my motorized wheelchair. I got lost, so I saw a woman on the sidewalk and asked her for directions. After a few minutes of having a pained expression on her face, she said to me, “Wait”, and she went back into her house. Five minutes later, I heard a squad car coming towards me. I took off in my wheelchair right away. The woman got so freaked out that she called the police.

While Miles now relates the incident with laughter, he did not find it very amusing at the time. “All she had to do was take the time to listen to me,” he says. “That would be it.” He says that he finds instances like this to be “very frustrating” and hard to deal with sometimes. “I get pissed off,” he admits. “If I were able-bodied, it would not have
happened.” At the same time, however, Miles believes that his high self-esteem helps to protect him from this sort of psycho-emotional disablism (Reeve, 2008). He attributes this characteristic to his family and his upbringing. Still, his self-esteem does not always come easily; “I have to work at it,” he says. This shows that even seasoned disability rights activists who intellectually understand the root of their mistreatment nonetheless struggle with handling it on a day-to-day basis. Similarly, Danielle, also a disability rights activist, describes how, when she is out with her children and her personal assistant, people frequently just assume that the children belong to her assistant and not to her.

If I’m out with friends, [strangers] automatically assume that the children aren’t mine. When they were first babies, I’d take them to the grocery store with my childcare provider, and people would say to her, “Wow, you look like you have your hands full.” And [the childcare provider] would say, “No, actually she does.” And people’s eyes, “Oh my god!”

Although her children are now school-aged, others’ misunderstanding and discomfort still persist:

I went to curriculum night for both of my kids, and the parents would move out of the way, as if they were in the way, instead of, “Hey, we have a child in the same class. It’s nice to meet you.” You know? I’ve found that the parents who have been around the school a long time, and have older kids than I do, are sort of more receptive to the idea. But for parents with kids my own kids’ age, it’s gonna be a little challenging.

Additionally, Danielle worries about the impact this will have upon her children:

I certainly hope it doesn’t preclude my kids from having friends and going to play dates and birthday parties. I know last year I went to a birthday party at a friend’s – one of my kids’ friends’ houses, and it wasn’t accessible. It made it real difficult for me, because I can walk, but I have to worry about if there are stairs to take them to the bathroom. And so I literally have to go with somebody – my husband, you know. So that’s kind of interesting.

Moreover, Juan also believes that even when strangers refrain from making comments, they are often uncomfortable around him because of his disability. “It’s a weird stare,” he
says, “Like I shouldn’t be outside or something.” Juan attributes this staring to lack of interaction between people with and without disabilities; “They see something they haven’t seen before, and they don’t know how to respond to that, so they treat us differently.” Betty has been told directly that she should not be out on her own because it is too cold or because there is too much traffic. “People are kind of condescending,” she says, “mostly wherever I go.”

While many participants in this study are older and feel well integrated into one or more communities, several of the younger ones still seem to be looking for their niche. They appear to be significantly more vulnerable to others’ negative attitudes and differential treatment. Sara admits that she often gets annoyed when she is alone and strangers come up and ask her what happened to her or treat her as though she is a child.

If you want to get to know me, then find stuff that interests me. It’s not just about my disability. Ask me what I do for fun. Ask me that kind of stuff. Don’t ask me, “How did you get in the chair? Because it’s kind of like, “Do I ask you why your hair is brown or why your eyes are blue?” I think that other people are always like, “Oh, it’s so great that you’re out!” and “It’s so great that you’re doing this!” And I’m just like – it’s my norm. It’s what anyone would do.

Sara believes that her gender and her youthful appearance also contribute to people’s patronizing attitudes. She describes having been in bars where waiters refused to serve her because she looked too young and also because her unique gait made her seem as though she was intoxicated. Similarly, she refers to incidents when she has been out by herself in her scooter and policemen remind her to obey the traffic signs, as though she did not know any better. Sara believes that she is particularly subject to people’s condescending attitudes when she is out with her parents.

Sometimes when I go to [the grocery store] with my parents, I pick up some stuff for myself because that’s what I do, and then I go and I get in the line. I’m right in the line behind my parents, but the cashiers are always like, “Oh, it’s so good that
you’re buying some of your own stuff for yourself.” And I’m just like, “Why would that be good?”

Likewise, Drew, the youngest participant in the study, also feels that people are more likely to treat him differently when he is out with his family versus when he is alone.

I think it happens more when I’m with other people. I think when I’m by myself; people assume that I’m higher functioning. When I’m out with my mom and my sister, people think they are taking care of me. But when I’m on my own, I think people see me.

Participants with speech impairments appear particularly prone to experiencing differential treatment in the course of their everyday interactions with others. Several describe how they believe that they are not taken seriously because they cannot communicate in the “normal” way; frequently, they are assumed to have cognitive impairments and to be incapable of being on their own or making decisions. Alex relates an incident when he was checking into a hotel room and the desk clerk refused to accept his card, believing that it had been stolen. It was not until he called in his personal assistant that the matter was resolved. When asked how he handles these incidents psychologically, Alex replies matter-of-factly: “I’m forty-four, and this is my life.” He seems to possess a sort of ambivalence and resigned acceptance to these experiences. On one hand, he is aware of them and even bothered by them in the short term; on the other hand, he is experienced and self-assured enough not to dwell upon them excessively but rather to ultimately accept that they are an inevitable part of his everyday life with CP.

Similarly, Kate tells of an instance when she was alone in a restaurant eating a sandwich, and a stranger came up, handed her a fork, and walked away. She describes herself as sometimes being a “messy” eater and believes that the stranger was genuinely trying to be nice. Even so, Kate was very bothered and conflicted by the incident,
seemingly interpreting it as not only an example of condescension but also as evidence of her own social awkwardness:

I was really upset. I took it in for a while. I was really upset. I blamed myself a lot. I felt so bad about it. I didn’t feel good about the situation at all. I don’t know. I was just hurt by it. He was ignorant.

Even in the absence of such mistreatment by others, several participants experience difficulties with living day-to-day in a culture where the needs and desires of people with disabilities are so frequently ignored. Although they are not always intentionally denied opportunities, many participants described how simple ignorance, lack of physical access and others’ unwillingness to make slight accommodations all contributed to their sense of being excluded from participation in the mainstream. Multiple participants described how non-disabled individuals often seem uncomfortable around them, with some expressing a sort of nervous over-politeness, and others just trying to move away as quickly as they can. Others referenced incidents when non-disabled people simply make false assumptions about their abilities to participate or even their interest in participating.

For example, Danielle feels that she is not included in “moms’ nights” with the other mothers from her children’s school because the other women simply assume that she does not drink alcohol and therefore would not be interested in going to a bar with them. “I don’t drink a lot,” she says, “but I could still go and have a diet coke.” She also comments upon people’s lack of concern for her accessibility needs:

Every day it’s a struggle to make the train because somebody stands in front of me. So I’ll say, “Excuse me? Excuse me? Excuse me?” And about the fourth time, I’m like, “Move!” And they’ll look back at me like, “Huh! Who taught you your manners?” And I’ve literally said to them, “Don’t look back at me cause I asked you to move about four times! Just fuckin’ move!”
Similarly, Sara believes that her disability has made it more difficult to build and maintain friendships, and that fellow students at her college frequently appear uncomfortable when interacting with her, or else they shy away from her altogether.

People are just kind of – they’re standoffish. And it makes your education process more difficult, when you have to always feel like you have to be the one who is friendly first. When I’m in a class sometimes, I’ll have to be the first to say, you know, “Hello,” or “Can you help me with this?” I feel like sometimes it’s more difficult to get involved with group activities, because people – I feel like they’re still kind of afraid or something.

Her problems are magnified by larger, systemic barriers, like limited accessible transportation, that sometimes prevent her from attending class altogether and having the flexibility to go out whenever she chooses and socialize with her classmates.

Paratransit only runs from like eight to five during the week. There’s no service on the weekends. So in the winter I don’t have the same ability as I do in the summer, to get out and go. And sometimes I do feel like I’m getting cabin fever, and I just want to get out, and it’s difficult.

Interestingly, Jesse, who of all the participants in this study has the mildest form of CP, also seems to experience the most social stigma. Jesse walks and speaks without difficulty; only his right arm is significantly affected by his impairment. However, he has had substantial difficulties finding and maintaining employment (despite having two Master’s degrees), and also with formulating genuine friendships. Jesse appears to be stuck in a sort of “twilight zone” between the disabled and non-disabled worlds, particularly in the employment arena where he often requires minor accommodations to successfully perform his job functions. He finds career building to be particularly challenging, especially when he is at a social networking event and people realize that he is different because of the trouble he has with navigating the scene while holding a drink and/or a plate of food.
I’m dressed like everybody else is dressed. I think I brushed my teeth. It’s just a matter of them not being comfortable, and it’s the uncomfortableness that makes it for them, so then they just don’t want to be bothered. Because I’m not like them. So then they figure that since you’re different, I don’t want to be bothered. Or it’s – you’ve got issues, and I don’t even want to take a part of your issues, so they’ll move on.

If employers realize that he has a disability, they often will not even consider asking him for an interview. When possible, Jesse used to do whatever possible to conceal the fact that he had CP, but he says that this plan ultimately backfired on him once he was hired and had to ask for accommodations or was unable to perform certain tasks (particularly typing) with the expected speed and proficiency. Now he is upfront about his disability, but he says that this strategy hasn’t been very successful either.

I went to this job, and he really liked me until I told him, in the interview, that I had cerebral palsy. He said, “One moment.” He went around the corner to talk to his boss, and I heard them talking. He says, “How did he get in here?” Talking about me. “How did he get in here? Now you know, we have to send him for the second interview, because if we don’t, we’re going to get sued.”

When asked how that made him feel, Jesse replies: “That just led me to believe that no one wants you. I felt like the lowest thing on the earth.”

However, the stigma does not end when Jesse does find that seemingly elusive job. It is often a constant struggle to get the necessary accommodations, and even when he does, he is often treated poorly by coworkers who believe that Jesse is not pulling his equal weight.

I’ve come to understand, or what I’ve experienced is that people get jealous. “Well, he’s not doing that! Why isn’t he doing that?” Or: “Why do I have to do all this, and he gets to do that? Why does he get to do this, and why I can’t I?” And then they go back and tell the boss, and then it’s, “Jesse, you’re gonna have to do some of this, because your coworkers…” And, “I can’t have this…” So then you’re back to square one.
Jesse’s difficulties within the job also limit his opportunities for social integration outside of work. His co-workers’ jealousy and resentment mean that he is often excluded from social events and so does not have many chances to develop genuine, meaningful friendships. This is compounded by the fact that Jesse has trouble participating in those athletic activities around which male friendships frequently revolve, and also that when he has tried to trust people in the past, they have frequently let him down.

I really don’t have a true friend. I have yet to find that true friend, and once you get to my age, finding a friend is probably – it’s probably a lost cause at this point… You have to be able to trust people. I’ve been there, where people have used the CP against me. Or you think you’re friends with somebody, and then you walk into a room and you see them talking about you, or making fun of you. I mean, how do you react to that? How do you react to that? You’re like “Is this what friendship is about?”

Participants were asked if they felt as though people with CP were devalued even more than individuals from other impairment groups. They had mixed opinions about this. A few believed that individuals with CP are treated similarly as those with other disabilities. Juan, for example, says: “I feel that everybody with disabilities, they are treated the same,” and Sara responds:

I don’t know if we’re treated differently. I think that all people with disabilities are treated just about the same. So I mean, CP is just another – kinda like spina bifida, or…being paralyzed. I think that we all kind of get looked at kind of the same.

However, other individuals, particularly those with a significant degree of impairment, disagree. Miles says: “It depends on the level of your CP. If you are more able-bodied, you have fewer problems, but if you are more impaired, then it’s different. It all goes back to society.” Alex also believes that the presence of a speech impairment affects how an individual is treated: “We are significantly devalued because of our speech disabilities. Look at how much time it takes for a conversation.”
Although Danielle does not have speech impairment herself, as an employee in an independent living center, she works with many individuals who do:

Yes, I believe [people with speech impairments] are treated differently. I think a lot of times people who aren’t disabled look at people with speech disabilities as, like, dumb. Not dumb, just take time to listen to me. And so one thing that I teach is disability etiquette. I talk about the example of somebody who has a speech disability, and it’s okay to ask a person to repeat, not to assume you know what they said.

Drew also believes that, for people with CP, the presence of speech impairment is directly linked to others’ perceptions of their intelligence:

When people hear me speak, they automatically think I’m mentally retarded. I have an undergraduate degree and you are working on your PhD. It’s how you communicate in this world [that determines] how they’re treated. But even among disabled people, people with CP are looked down upon. Even among disabled people, I have found.

Later he adds:

I have made the comment before that CP is treated like the lowest life form on earth. But I don’t really know. Sometimes it seems that way. Sometimes it seems like we are treated like less than maybe a person with a learning disability, or a person with a visual impairment…because our disability is more visible. You can see it. And parts of our disability are not socially appropriate. We are more socially inappropriate than others. Some of us are incontinent. Some of us are not able to walk. [We have] a lesser position in the disability hierarchy.

2. **Early Experiences of Devaluation**

Although this study is specifically focused upon experiences during adulthood, it became clear as participants were sharing their stories that social experiences during the formative years of childhood and adolescence played an important role in how they saw themselves and related to others even as adults. As young people, many struggled to fit in with their peers and to come to terms with the reality of being different. Many experienced rejection, isolation, and even ridicule throughout their childhoods.
Susana, 39, was only mainstreamed once she reached high school. She describes how difficult it was to achieve social integration when, because of school rules, she had to have her own aide:

In high school, every disabled kid had to have an aide. And in high school, you know, you want to be cool, and you want to hang out, and everything. And I always hated, hated my aide so much. I used to ditch her, and I used to complain about her. Because I thought I was like everyone else. My friends and I wanted to go outside the building which was not allowed. And it was almost like having a mother, because you get these older women.

Although Susana still managed to find friends, and was able to have many of the same social experiences as all of the other students, she remembers how hard it was to realize that one of her “friends” was only a friend of convenience.

When I was growing up, I had a quote unquote friend, and she – we grew up together. Her family knew my family. Mom and Dad were good friends with her parents and stuff. And as years go on, I found out that she was my friend when it was convenient to her. When she was bored, she was my friend. When she had nothing else to do, she was my friend. But when she went out with her friends, she didn’t want me around, because I hindered her. Years later, when I was in high school I was in a play. And after the play, they were having a cast party, and I helped with the crew, and stuff. So I went. I got there, and she said, “You weren’t invited.” And I had to call my mom, very humiliating, and I stood by the door while she went on with partying and stuff. And I left.

Sara also relates a similar experience of feeling left out during her junior year of high school. She had what she thought was a solid group of friends, until her family moved and she had to change schools:

Everyone stopped calling me, and I didn’t understand why. I was like, why did this happen to me? These people said they were still going to be my friends. I was supposed to go to prom with them. No one ever called me to tell me what was going on with it, or nothing. So I didn’t even get to go to my prom, because of that.

In fact, Sara says she had social difficulties all throughout her schooling:

When I was in grade school, the kids would make fun of me because of the way that I walked. I had a lot of teachers who were negative… I’m sure that it’s gotten
better now, for students with disabilities. But when I was going to school, kids would make fun of me. It was harder to make friends, cause they didn’t always understand, or I didn’t want to try to keep up.

Although Drew did manage to develop a solid group of friends by high school, he too says that elementary and middle school were difficult:

I just – I got made fun of, you know? There were a lot of different names for me in school, and none of them were very nice. That did something to me, you know? [This was] mainly in elementary school. By the time I got to middle school, and high school, it kind of fizzled out. Like by high school, kids pretty much left me alone, you know? I developed a group of friends, and you know, I pretty much came into my own.

Jesse was also ridiculed throughout his childhood and adolescence:

I went to a private Lutheran grade school, so it was mostly the same kids throughout my education. So, from preschool to eighth grade, some people left, some people came, but the core group was always there. So some days it was good, some days it was bad, because they knew that they could pick on me. You know, when they were looking for somebody to bully or pick on – I was the man. Because they knew I couldn’t fight back.

Kate’s mother actually pulled her out of school in her sophomore year because she was so unhappy. During this time, she began treatment for depression.

I went to a regular school all my life. Catholic school. I loved [elementary school], because all my friends treated me just like everyone else...But where I went in junior high school, again an all-girls private Catholic school, I hated it. Because the kids made fun of the way I walked and talked and ate. Like I would sit by myself at lunch. It was difficult. All new kids. One of my best friends from grade school went to the school, but I never saw her.

Kate continues:

And all new kids and it was just awful. But then, the spring of my sophomore year, I just couldn’t do it any more. My mom knew that I was just not myself, and I felt socially isolated, so she pulled me out. And I took the rest of the year off, and I got treated for depression, and other things.

Following some time off, Kate started at a different school. She says that this was a significant improvement because she got involved in the choir and managed to make a
few friends. Additionally, she was able to transform her own experience into something positive by developing her own non-profit disability awareness training for elementary, middle, and high school students.

On the other hand, Miles says that as a child and adolescent attending a segregated school for students with disabilities, he felt very isolated among his peers because he had more in common with non-disabled students. It was not until college, when his association with other disabled students was voluntary rather than forced, that he developed genuine and meaningful friendships with other students with disabilities, and eventually became involved in the Disability Rights Movement. “The way you feel about yourself is your friends,” says Miles. “If they have a high regard for you, then you feel better about yourself.”

Participants generally report that their middle and early high school years were the most difficult. Although many were teased in elementary school as well, they did not experience the same intensity of rejection that they did later on in school. However, by the time they reached their junior and senior years, many had started to develop their own identities and found a few friends with whom they shared common interests; this continued through their college years. Others, though, particularly those who attended smaller schools, actually found college to be the most difficult. Megan says:

I didn’t notice that I was disabled, really, until college. I mean, yes – “I’m in a wheelchair. They’re all walking around.” Duh. But I didn’t consider myself disabled, because my classmates, by high school age, accepted me for me. My classmates accepted me for me, and my core friends had no issues with me, with the disability. Again, it’s just there, but it was not a main topic of conversation. It had to be acknowledged, but so did other things.
However, she adds that making friends in college was difficult not so much because of students’ negative attitudes but rather because of the sheer number of students, and that ultimately she was able to meet a few students with whom she became very good friends.

3. **Devaluation in the Family**

A few participants described feeling that their families’ inability to understand the disability experience resulted in very strained and uncomfortable relationships. As Juan describes:

I can also see it in my family’s eyes. They won’t come out and say anything, but you see it in their eyes. It’s not that they’re ashamed. I don’t know how to describe it. Probably more like disappointed or something. I don’t know. That’s what I get. I wanted to challenge myself, but they would say like, “You can’t do that because of this or that,” and that’s not how you’re supposed to treat your kids. You’re supposed to encourage them. And I felt like I really wasn’t encouraged.

He attributes his loner personality and his difficulty developing relationships to his upbringing:

[The women] would have come up to talk to me, but I didn’t – I guess I didn’t pick up on that, because of my childhood. My family kind of screwed me up. Let’s put it that way. It’s like, they didn’t want me to be outgoing, so when I’m supposed to be outgoing, I’m not. My family kind of screwed me up like that.

Similarly, Danielle explains how her mother has always treated her like a child because of her disability, despite the fact that she graduated from college, holds a good job, and has children of her own:

My mother was never very supportive. I don’t think she has ever really accepted the fact that I have become this empowered disability rights activist, and I don’t think it’s a death sentence to have a disability. My mother has always been like, “Oh, poor you, you could have worn high heels, you could have…”

She continues by revealing that:

Even now, I still think she sees me as a ten year old. When she found out I was pregnant, she said, ‘Poor Tom, now he has three children -- you and the babies.’
Never said that, you know, my husband was my husband because he chose me. That’s done some damage to my psyche.

Despite her mother’s attitudes, however, Danielle has, as she says, become “an empowered disability rights activist” with children of her own. Similarly, although he says that he has been “screwed up” by his family, Juan has, over the years, been able to formulate his own identity, to successfully combat his family’s undermining of his abilities, and ultimately to make peace with himself as a person with a disability. For example, he used to “just accept it” when his brother’s friends made fun of the way he walked, but now he fights back with sarcasm, saying that the friend let his girlfriend walk all over him. “He has no place to talk,” says Juan, “because although my disability is on the outside, his disability is on the inside.”

Since the death of her parents, Megan maintains a very tenuous relationship with her brother and her sister-in-law, who believe that she was overly dependent on their parents and that she could not manage her parents’ affairs as an equal partner:

He said that he was afraid that when Daddy died, that I would shrivel up in a ball, shrivel up in a corner, and just give up. And I said, “I got news for you. I did not shrivel up and die when Mom died. I’m certainly not going to do that.”

Further, Megan recalls how her brother and sister in-law assumed that she wanted them to take care of her:

My brother said, five hours after we buried our mother, that, “You can come visit us anytime you want to, stay as long as you like, we have plenty of room, but don’t even think of moving in with us, cause we will not take care of you, like our parents took care of their mothers.”

Megan says that she was ultimately able to convince her brother that she could not only take care of herself but also serve as co-executor of her parents’ estate. Although they
will never be the closest of siblings, they now talk on the phone two or three times a year, and he now acknowledges her independence.

Finally, in the most striking example of family conflict and lack of support, Betty indicates that not only do her mother and brother not believe that she is capable of living on her own but that they have intentionally worked to keep her powerless and dependent so that they can benefit from her social security allowance. Betty says that when she finally found a personal assistant who encouraged her to take steps to become independent, whether it was picking out her own clothes or moving out of her mother’s house into her own apartment, her mother and brother arranged to have the assistant fired. Betty describes her living situation as “hell” and says that broaching the subject of her independence “is like starting World War III.” Betty wants desperately to find a way to open a bank account and get control of her own money but does not have the physical or emotional support to do so.

However, Betty has remained strong and determined in the face of this fierce battle, and she is determined to find a way to assert her independence. Like Danielle and Juan, she seems to have transformed a significant family conflict into a source of inner strength. She says that her family used to be able to put her down, but a recent spiritual awakening, coupled with her personal assistant “having lit a fire under her,” has led her to realize that nobody can make her feel inferior, or less of a person, because she has CP. “Nobody can ever devalue me,” she asserts. “I am the only one who can devalue me.”

A couple of participants, however, generally have supportive families, yet they suggested that there are sometimes limits to non-disabled individuals’ ability to
understand and empathize with the experience of having CP, no matter how close a relationship they might have with those individuals. As Drew explains:

I love my mom. There’s been many, many, many times of my life that she has been there for me, when no one else has been there for me. And I love – I really love her. But she doesn’t like the ways I’ve handled some things related to my disability. So I don’t think a non-disabled person can really understand a disabled person… I am not angry with her in any way. She just doesn’t get some things.

When asked to provide an example, he reveals his disappointment by her lack of encouragement of his desire to become a teacher:

She is able-bodied, so it’s easy to take my side when it’s something stupid, like someone is rude to me at a restaurant. But when it’s something complex, it gets complicated. Like my mom has never really come out and endorsed me as a teacher. I don’t really think she’s sure if I can teach or not.

Other participants similarly describe their parents’ love and support, but simultaneously suggest that as non-disabled individuals, their parents’ inability to know what it is like to have CP sometimes creates tension and misunderstanding. Sara says:

Sometimes I still don’t think [my mom] fully gets it. So sometimes it makes it a little more difficult to talk to her [about how people react to my disability], just cause sometimes she’ll be like, “Well you have to just explain it,” and sometimes I’m just like, “Mom, I don’t want to explain my disability to everyone.”

4. **Impact of Devaluation**

Several participants in this study report having had problems with depression at some point in their lives and many attribute their depression to social effects of CP. For example, Alex has been in counseling and has taken medication on and off for fourteen years. “For months doctors have tried to get the right cocktail of medications for me,” he writes in his diary. “Sounds easy to do, [but] I am 44 with cerebral palsy, and have clinical depression. Nope, it’s not so easy.” Alex says that his depression stems largely from his lack of romantic relationships as well as his rapid
decline in physical functioning. For several years, he also drank heavily, and believes that he might have committed suicide had it not been for his young niece and nephew living next door; “I didn’t want to scar them for life,” he says. Since that period, however, he has found a good psychiatrist, who he believes can truly understand his situation, and the right combination of medications. In closing a diary entry, Alex writes:

Fast-forwarding to today, I am thrilled to say that I think we have the right combination of medications. It took about eighteen months but life is looking good...we are flying good with my physical health. I am feeling really good emotionally. And every night, it is an awesome feeling going to sleep alcohol free.

Megan, the oldest participant in the study, says that she also “struggled with depression for a long, long time” and that she continues to take medication. Her depression began in college when she first began to feel like she was different from the other students. “When my self-perception shifted from Megan being first and CP being second in little letters, to CP being first in huge gigantic capital letters, and Megan being second in small letters, that’s when I got depressed.”

That was the first major depression, to the point where I woke up on Good Friday and said, “You know, if I just take something, then I could be with Jesus, and all this would be over and done with, and I’d be out of this pain.” And the second I thought that, I said, “No way, uh-uh. Nope, you’re not gonna do that. If God wanted you, he would have taken you twenty-two years ago, when you were two pounds, eight ounces, and fourteen inches long. He didn’t want you then; you have no right to do anything to make you go up to him now.

Although Megan has never been that close to suicide again, she has been in counseling throughout her life, and it was not until after her parents died that her perception of herself changed to the point where she recognized herself as a strong, capable, and independent woman. Like Alex, Megan believes that her depression stems largely from her lack of relationships as well as the effects of her impairment -- that as she ages, it is
becoming increasingly harder to move around and to get her body to cooperate with her. At the same time however, she believes that aging has also helped her to feel more confident with who she is and the lifestyle that she leads:

The older I get, I think the easier it is, mainly because I haven’t really broadened my social circle. And I’m not looking for a boyfriend, or a husband, or anything like that. So I think I’ve taken that pressure off of myself.

Drew, the youngest participant in the study, believes that his depression can be traced all the way back to how his peers treated him during his elementary school years. He says that being teased so much in school led him to doubt himself as a child:

I think having cerebral palsy is having people treat me like they have treated me, or make me question myself more than the average person. This isn’t the case anymore, but when I was younger, I used to second guess everything I’d do. Like, should I have done this? Should I have done that? Am I good enough? Did they understand me? Do I have an odor? Do I have this? Do I have that?

He continues:

I wasn’t as confident. I don’t think that was related to my CP. It was related to how other people treated me. I think if people didn’t treat me the way they treated me, I wouldn’t have had a problem, you know? I am better now. I am better now about second-guessing myself. I have grown up, and matured.

As Drew progressed through school, he was able to make a solid group of friends and gradually developed more confidence. He says that as he and his peers aged, they became more accepting of him and that they found common interests. However, this confidence was once again tested when he began a Master’s program in special education and discovered that his supervisors did not believe that he was capable of working with children. During the same period, Drew had to grapple with the onset of an inexplicable seizure disorder:

My senior year in college, I started having these seizure-like incidents, and then I finished my senior year, having these incidents. And I guess it really was hard on me physically and mentally, as you can imagine. The doctor didn’t really know
what was going on, you know? So I got into my Masters Program and the faculty started to play this game where, “We don’t think you can teach, because you have CP.”

Drew says that the combination of these two incidents led him to spiral into a deep depression:

It just got to be too much. And I started to have depression really bad, and I tried to kill myself. It’s not something I’m proud of, but I did it, you know? And I was hospitalized in a psychiatric hospital.

But Drew also experienced a lot of personal growth as a result of this ordeal. He says that medication and counseling really helped him, as well as just leaving the “toxic” environment that he was in. He has since enrolled in another university and has been enjoying his in-service trainings: “Because of this, my perspective on things kind of changed, you know? I just didn’t worry about what people thought of me as much as I did before.”

Finally, Kate has also had significant issues with depression. Her first bout began in high school because she was always being teased by her peers. Work with a psychiatrist and the right medication allowed her to successfully finish high school and college, but she became depressed again once she graduated college, “I think because I didn’t know what I was doing, you know?” But like Drew, Kate is driven by her passion to work with children with disabilities, and starting her own acting company and continuing her disability awareness program have been instrumental in her ability to negotiate the psychological effects of having CP. However, she is still being treated for depression and anxiety.

‘Cause CP is hard. I think that there are certain social situations that you go through that other people don’t have to go through, and so learning how to deal with them is helpful. I want to move into Kate who happens to have CP, but I’m stuck with CP defining me sometimes. I don’t think I would be who I am without
CP. I wouldn’t be who I am. But you know, I do think about CP a lot. What if I didn’t have this? What are people thinking? I do that a lot.

It seems that for many of these participants, depression has frequently stemmed from other’s negative attitudes, as well as a lack of or feared loss of control. While impairment itself plays somewhat of a role in their overall social and emotional health, participants seem to be largely concerned with the ways other people react to, or would potentially react to, their bodies when they are not necessarily as controlled as non-impaired bodies. Fear of having a seizure, of being incontinent, of eating messily, or of displaying spasticity in front of others leads participants to doubt themselves and to question their position as worthy members of society. This seems to be particularly true for younger participants and those who were ridiculed often during childhood and adolescence. Several of the participants in this study, especially when they were children, have been told in one way or another that they do not measure up to acceptable standards. Whether they were constantly told by their parents that they need to more effectively control their bodies through therapeutic intervention or were bullied by their peers and ridiculed for being different, these messages can have profound effects upon how individuals think and feel about themselves even as adults. As adults, they frequently continue to strive for control: control over their bodies, control over interactions with others, and even control over how they think and feel about themselves. They accomplish this control through various means, including carefully choosing whom they interact with, avoiding potentially unpleasant situations, trying to completely immerse themselves in an alternative (disability) community, using alcohol and drugs, and even, in a couple of cases, contemplating suicide. While some strategies are more benign than others, they all
represent attempts to gain control and find a sense of peace in a world that is not designed for them.

Moreover, although several participants discuss how psychotherapy has been helpful in dealing with their depression and struggle for control, a couple also alluded to how their therapists have reinforced the idea of disability as a personal problem rather than as a broader social issue. For instance, when Megan expressed anger and frustration with her disability, her therapist suggested that she was simply looking at her disability in the wrong light, and that she was giving it too much power and blaming too many of her problems on her CP when she should just be moving past it. However, Megan’s narrative suggests that she has, indeed, encountered significant disability discrimination in multiple aspects of her life, particularly in terms of her employment opportunities and her lack of romantic relationships. When Kate described to her therapist how hurt she was when a stranger handed her a fork because she was making a mess with her sandwich, the therapist advised Kate not to waste time being too bothered by the incident, and to just attribute it to the stranger’s stupidity. Thus, rather than acknowledging and attending to her felt experience of stigma, she was advised to take control and put the incident behind her. Kate was also encouraged to work with an occupational therapist to develop more “normal” eating patterns. Once again, the therapist was, in effect, blaming the problem and her reaction to it on the individual rather than addressing her feelings of marginalization.

5. **Experiences with Impairment**

   Although this study did not focus specifically upon their impairment
experiences per se, participants’ relationships with their bodies emerged as an important
theme, significantly affecting their social integration and overall psychological well-
being. Several participants feel that CP is speeding up the aging process such that they
are experiencing deterioration of bones and muscles at a much earlier age as compared to
their non-disabled peers. Seizures, incontinence, drooling, spasticity, and impaired speech
are among the factors cited as interfering with daily life and social interactions. However,
while participants expressed frustration with these issues, they seem to handle them with
the same adeptness and resilience that they demonstrate in so many other facets of their
lives.

A couple of participants commented on how physical problems related to their CP
prevent them from doing everything that they want to do. As Sara puts it:

I’m having knee problems now. And that is changing my life. Because I can’t do
the things that I used to do as easily. And I have to kind of change my mindset on
how to deal with that, and how to deal with the fact that I can’t walk as far as I
used to. When I go out with friends, I have to make sure that either there’s a place
for me to sit, or that I have my scooter, to accommodate for that. And that’s
different.

Later, she expresses frustration that her body and function seem to be deteriorating more
rapidly than most people’s and that she faces obstacles when relying upon her scooter.

I think that wear and tear happens to everyone. I feel like it’s happening to me
sooner, which I don’t feel is completely fair. It’s frustrating when I have really
bad pain. And I want to go out and hang out with people, but there are obstacles.
Not all the places that I want to go are accessible to the scooter, that kind of
stuff… It means I have to do more research which can make going out a project
instead of something fun. I wish more people understood the importance of things
being accessible. I have the right to have fun just like anyone else.

Megan also speaks of the frustration that her body often simply will not cooperate with
her when she is in a hurry to be somewhere or do something.
I have – what I call a ‘full body spasm’, where everything just goes “nyee!” and it’s hard to move. It’s the proverbial “C’mon. We’re late, we gotta get goin’, I gotta move, c’mon, like, go!” And the body says, “Um, no, I think we’re gonna go our speed, not the speed that you wanna go.” And you end up wrestling with your legs, trying to get them to do whatever you want them to do, when they’re not doing it on their own. But that gets extremely frustrating, and sometimes that can be a catalyst to, “God, I hate my CP.” But it doesn’t last as long as it did ten, fifteen years ago. Ten, fifteen years ago, that would have put me in a downward slippery slope, into a depression. But now, I keep telling myself, “This is today. You know tomorrow is gonna be different. So just hang in there with it today.”

Alex talks about the adverse effects of aging, and how it limits his opportunities for social participation, particularly in terms of his ability to communicate and to control his body movements.

Declining in ten years freaks me out. I think back ten years and I could do so much more like stay up for sixteen hours. Depression runs in my family, however I think my disability is a stronger factor. Aging rapidly and losing control has contributed to my depression. Like ten years ago, I would have done this [interview] much easier. My spasticity is going off the chart. I feel so out of control that I sometimes isolate myself.

Several participants talk about the importance of body image, particularly when they were children and adolescents. As Miles comments:

Growing up, I was self-conscious for my body movements. As a teenager, your top priority is the opposite sex and dating, and your body image is everything. I always felt that my drooling and spasticity was a turnoff to women - both disabled and able-bodied.

But Miles believes that age has really changed his attitude. Despite others’ view of him as too disabled to be on the street by himself, Miles has a remarkably balanced view of himself. He is at once a proud disability activist, and is also unashamed to admit that having a disability can be quite difficult at times. Moreover, while he is committed to and passionate about his work, he speaks about having many other traits and interests in life, which he wants others to acknowledge as integral to whom he is as an individual.
As I became more successful in life I became more positive about my body movements, or lack thereof. My sudden spasms, my speech and other irregular muscle movements have become part of me, my identity. And yet, this isn't all of me. I've got other valuable features to me than my CP.

Several participants describe of the importance of exercise in maintaining their mobility and function, and a couple work regularly with a physical therapist. Interestingly, they express a variety of different attitudes towards working out at a gym. Sara, for example, comments that:

I definitely think that I need to get myself in some type of exercise program, or something. But I feel like sometimes going to a gym, especially with people without disabilities, would be intimidating. Because you're the only one with a disability and people are going to be looking at you or staring at you, and being like, “Why are you even here?” Like, “Can you do this?” I mean, that’s gone through my head when I’ve thought about going to a regular gym.

Susana, on the other hand, has attended a gym for many years, and considers working out to be an important part of her routine and one that is essential for maintaining strong physical and mental health, as well as an attractive appearance. Unlike Sara, who is young, single, and still growing into her identity as a woman with CP, Susana is older and much more settled. Married with two children, Susana has seemed to develop greater confidence in herself, particularly in terms of her physical appearance.

I love my gym. I go twice or three times a week. I know people there. We joke, I work out, and we bullshit. It’s great. I don’t allow my husband to join that gym. That’s my thing! I want to look good. Yes, I am into myself. But if I’m not into myself, who will be? And don’t get me wrong. I’m not conceited. I just like looking good. I’m very much involved in real life.

Similarly, for Juan, exercise has been a very important part of his routine:

[If I didn’t have CP] I would probably be in the Marines, or be a Special Forces type of person I guess, or a bodybuilder type of person. Something like that. I’ve done weight lifting in the past. And I’m trying to get back on it. That was an experience all in itself.
He continues by describing how he first started working out as a way to appear more attractive to women, and says that his efforts were initially very successful:

I’d say when I was at my best when I lifted weights for three years straight. I’ll give the females credit; they didn’t care about the disability. They just came at me. Let’s put it that way. So they didn’t really care about the disability. It took the focus off having CP. Yeah. It took the focus off. Which was nice, but the attention was a little much. They were attracted to my fitness I guess. They didn’t care too much about the disability.

But then he says that because he is fundamentally a very shy individual, the attention he received eventually became too overwhelming:

You can tell by the reactions that they were interested. I guess it kind of freaked me out. I got too much attention. It freaked me out. And so I stopped. I was not prepared for that type of reaction.

A couple of other participants regularly attend physical and/or occupational therapy to combat the deleterious effects of their impairment and to facilitate their social participation and overall well-being. Megan, for example, regularly works with a personal trainer, and although she gets frustrated that her pain and fatigue often prevent her from attending choir practice, she has learned to take one day at a time.

Drew has recently experienced two particularly problematic effects of his impairment; both have affected his social integration and his psychological well-being. First, his problems with incontinence have grown worse, to the point where he now wears diapers. Although he now feels more comfortable in diapers and says that they actually make his life much easier, getting used to the idea was difficult and caused a great deal of tension between him and his mother. As he writes in his diary:

There is a major stigma in this culture having to do with incontinence and diaper usage that many people with CP have to deal with. I know this better then most because I have my own incontinence issues; while they are not as severe as some people’s, they are there and have been there my entire life. As a child, I was made fun of more for incontinence than for any other disability related issue. At home
we tried I don’t know how many things to better my control; none worked. I was not allowed to use diapers or any other protective product for fear it would make me lazy. From my point of view it is easy to see how people like myself could become ashamed.

In describing these issues to other participants via the online discussion board, Drew says:

The part of my CP that has affected me the most psychologically is incontinence. It is not total but it is to the point that I have regular accidents. I remember in school, they teased me more about my accidents than about any other thing. After a while it got to my head. Plus my parents were not really supportive. They half thought my accidents were due to laziness, and not CP. It took a long time to realize I wasn't a lesser person because I had accidents. A couple of years ago I started to wear adult diapers to help manage my accidents. I wish I would have done it a long time ago; it has made my life a lot easier.

In addition to his issues with incontinence, Drew has recently developed a seizure disorder that has delayed his start to a Master’s program in special education, and has even prevented him from volunteering in the schools. Although he has had extensive testing, as of yet doctors have been unable to successfully diagnose him, and so his life remains on hold:

I’m not volunteering a good deal, because of my health. My seizures have gotten bad again, pretty much out of the blue. It just doesn’t make sense. Sometimes some things in life really don’t make sense…. They wax and wane; they are really unpredictable. They are disrupting my entire life. I have no choice but to put things on hold, while we try to figure these out, you know? I’m hoping to get back in school in January, but it looks like that’s not going to be easy. I just have to wait and see.

C. **Positive and Empowering Experiences**

Despite the challenges that some report, participants also describe many positive social experiences that promote their empowerment and overall well-being.

1. **Community Integration**
   a. **Integration into the Mainstream**
Despite having experienced devaluation in their communities, participants also discuss instances when they felt well integrated. Susana, for example, has a supportive husband, two children, and a strong network of friends, all of whom accept her for who she is. She does, from time to time, encounter people who appear uncomfortable with her CP, but says that she tries not to associate too much with those individuals who she believes cannot see past her disability and treat her differently because of it. She says:

I wouldn’t put myself into a situation where I would feel demeaned. I control my life. And I control who I let in, or who I don’t. And I’m lucky for that. I’m lucky that I could see that. This sounds stupid, but I blow jerks off. Because I know what I am. And I feel comfortable with myself. So I don’t even give them a second look. They take quick looks at me. They walk away. Their demeanor is unsettled. It’s not approachable.

Instead, Susana focuses on maintaining those relationships she already has. Married with two adolescent children, she is active in her church and her local Kiwanis club. Additionally she has a small but strong network of female friends in her neighborhood that she has known since her children were young and with whom she regularly goes out.

Likewise, Megan is also involved in her church and says that people in the congregation are very friendly and supportive. When the current pastor assumed his position several years ago, he renovated part of the church to make it more accessible, and when Megan was in the hospital over the holidays, her friends in the choir drove to pick her up and take her to services on Christmas Eve.

b. **Integration into the Disability Community and Disability Identity**

Several participants are very involved in the disability community, and seem to rely largely upon fellow advocates for social support and for finding
meaning in their lives. Danielle, who works at an independent living center, feels like her job has really helped to empower her as a woman with CP and to facilitate her integration into the disability community:

I wanted to be able to achieve getting a job on my own. Wasn’t in my field of study necessarily, but I was able to tell myself, and tell my peers – I’m telling a different story, of life with a disability, and I find the disability rights movement to be empowering. And when I can make a change in someone else’s life, then I feel good.

Likewise, Miles also works in the disability community and is involved in disability activism, and Sara and Kate both strive to empower youth with disabilities – Sara through her involvement with youth and feminist leadership groups, and Kate via the creation of her own non-profit theater company for children and adolescents with disabilities. Drew is pursuing a degree in special education and several years ago started a book club for individuals with developmental disabilities, and Susana also works to empower girls with disabilities. As Danielle indicates in the above quote, each of these individuals, in his or her own unique way, is defying the traditional accepted wisdom of what it means to be disabled in our society. Instead, they are each working to carve their own paths and to challenge people’s assumptions of what they can and cannot do.

Thus, through their interactions with other disabled individuals and their affiliation with disability-related causes, these individuals are able to find their own niche within a larger society that has often rejected them. A couple of the younger participants talk about the mentors that they had found in the community. Sara says:

I think that [doing disability advocacy] helps a lot [to deal with my disability], because it showed me that there are other people with disabilities who are working, who are empowered, who are proud of themselves, even though they have a disability. Until I got involved with the disability community, I really was kind of lacking that. So I mean, that helped immensely with just giving me an outlet. Like, if I have a problem, go and be like, “Who else has had this problem...
and how have you dealt with it?” [Now I want to stay in disability advocacy] cause I think that it’s important, and I think that it’s good to have someone who really is passionate about it, and knows why it’s important.

And Drew adds:

I think what I have in common with other people with disabilities is that I know what it’s like to be looked down upon, and I know what it’s like to have – to have accommodations – need accommodations, and I know what it’s like to be in special classes and go to a special school. And I also have a great deal of empathy, so I – even if I see a person with a disability, even if it’s not CP, I just – I just look inside myself.

In addition, Drew speaks about the limits of non-disabled people’s understanding of the disability experience.

In a perfect world, disabled people would have their own little planet. But it doesn’t work like that. We have to adjust our own living space, and we have the non-disabled people thrown in, and that is a pain in the ass.

Drew says that he relates well to people with disabilities in general, but that he feels particularly connected to other individuals with CP. “There’s something special about CP,” he says. “I don’t know why. But I seem to bond more with people with CP.” Drew’s best friend also has CP, and Drew describes him as being like a brother, saying:

We grew up together. We lost touch for a long time, and we were reunited through work a couple years ago, and we just picked up like we never were apart. We are like brothers, you know, and we are bonded, you know. He’s a couple years older than me. We can talk about anything. Work, projects, cerebral palsy, you name it. We don’t have to explain anything to each other.

Not surprisingly, each of these individuals expressed a strong sense of comfort with who they are as disabled individuals, as well as a feeling of solidarity with other members of the disability community. Danielle remarks:

I realize now that I can change the world for a lot of people. You know, not single-handedly, but there are a lot of us that feel that discrimination among people with disabilities is wrong. It’s okay to live with a disability. It’s okay to have a romantic life with a disability. I’m not some animal with a horn sticking out of my head.
She continues, describing her integration into the disability community:

It has strengthened my identity, and it has helped me to go back to my family members who have said, “I’m sorry you have a disability,” and say “You know what? I’ve accepted it. Now you have to too.”

Sara also describes how becoming involved in the disability community has strengthened her identity:

Once I got involved with [the independent living center] and their youth program, that’s when I really started to feel empowered, because those programs are so unique. They’re not everywhere. And they teach you about having pride in yourself, and that kind of stuff. I was twenty-five years old then. That’s when I was like, “Okay. I’m gonna be fine.”

2. Positive Experiences with Family
a. Parents

Participants generally seem to consider parents to be a very important factor in allowing them to get where they are now, from the moment of their diagnosis with CP up through the present day. They express gratitude that parents refused to “give up on them,” even when they were warned that their children might not amount to much. Megan says:

[At the diagnosis], they said the damage was diffused over my entire brain. It wasn’t just localized in one area. And they said, “Take her home, give her lots of tender loving care, but don’t expect too much. She may not amount to much.” So my folks took me home, and thought otherwise. Put me into OT, PT, speech.

In a couple of cases, parents ignored medical advice to keep their children in segregated settings and instead insisted that they grow up and be educated alongside their non-disabled peers. As Jesse describes:

My parents helped shape me into who I am as a person today. When they found out about my CP, they were determined to prove the doctors wrong. The doctors suggested that my parents place me in a special school with a limited curriculum. My parents chose not to take that advice. I appreciate everything my parents did
for me. Even with my difficulties relating to others. I was able to earn two masters
degrees, married with a child, and I own a home.

Although many parents often pushed their children very hard to be independent,
and their children did not always appreciate it at the time, as adults the participants
generally express gratitude. Susana says:

Mom and dad would push me in life. The day after high school, they moved me to
DC. They knew that New Jersey wasn’t accessible to me. So when I got to DC,
every time that I called home, wanting to come home, they said no. I thank them
everyday.

Megan, too, describes how her parents pushed her, but also how they tried to give
her every opportunity and treated her like a “normal” child:

They acknowledged it and saw to it that I would have the best physical,
occupational and speech therapy available in the county where we lived. They
treated me like Megan, their daughter who happened to have CP. They didn't
make a big deal about my CP. I followed their lead. In high school, I was different
but I didn't consider myself different. I was in a wheelchair and no one else was
but I didn't consider that different; I just considered it part of me and I didn't let it
get in the way of doing what I wanted to do. CP is CP, you know. You deal with
it.

Later she describes how her parents always treated her like her brother:

They said: “You’re Megan. You’re just like your brother. We’re going to treat
you just like your brother. You’re not gonna get no special preferential treatment.
If you do something out of the ordinary – if you’re naughty, we’re gonna punish
you”

Sara also relates how her parents have always treated her like her siblings:

I think that my parents worked pretty hard to make sure that I was encouraged just
like the rest of my siblings to go out and date, and go out and make friends, and
you know, go out and do all that stuff.

And Miles discusses how his parents’ constant encouragement and faith in him really
helped to bolster his self-esteem and to foster a secure sense of self as a person with a
disability. He says:
My parents, especially my mother, played a vital role in helping me to feel good about myself being a person with CP. She used to tell me, "Miles, you can do anything once you put your mind to it." When I was growing up, my parents used to take me out in public as other parents would do with their able-bodied kids.

b. **Role of Other Family Members**

Miles also points out his extended family’s role in helping to build his self-esteem:

They always included me on family vacations with my cousins. My cousins treated me like anybody else without a disability, having fun in the swimming pool and the summer strolls to the park. Looking back now, I feel my cousins also played a key role with my positive self-esteem.

Kate’s older brothers have also been very supportive of her, helping her to establish her own non-profit acting group for youth with disabilities and housing it within their own summer camp business. They have also helped to facilitate and arrange her disability awareness trainings in various schools and summer camps around the area. She says that her brothers and parents are protective, but not overly so; although she still lives at home, Kate has her own space and is encouraged to come and go and do as she pleases.

Additionally, Alex discusses how his brother encouraged him to move from Texas to Maryland, where the brother and his family lived, in case Alex needed support. His brother built a small cottage on his property so that Alex would still have independence but would be near his family in case he needed anything. Alex also credits his brother for helping him to escape an abusive situation he was experiencing at the hands of his personal assistant, despite Alex’s reluctance to reveal the extent of the situation. He writes in his diary:

I was living as if I was still eighteen hundred miles from family. Meaning while [my brother] and myself had regular interaction, he did not know what was going on. It is pretty scary to both of us that this was happening basically under the same roof. I take 99 percent of the responsibility for not telling him. I was so
the mind set that he had two children, a wife, and responsibilities; I did not want to put anything else on him.

However, Alex says that his decision to finally reveal the abuse (and the ensuing discussions he had with his family) spurred a significant change their relationship:

[I realized that] he and his wife, six years ago, made a decision to incorporate me into their life. So our relationship has changed. First and foremost, we communicate everyday, be it me e-mailing with issues, or having face-to-face conversations. We make it a point to talk in private. Also, with my ok, my sister in-law manages my financial issues, and my niece and nephew are suddenly making their presence apparent.

In closing his diary entry, Alex writes:

While this has confirmed that I must think of myself as a man with a disability who needs increasing family support, God has blessed me with a family willing and prepared to provide it.

c. **Marriage**

At the time of data collection, only three participants, Jesse, Susana and Danielle were married. All three had been with their partners for several years, and all had experienced relatively healthy, stable relationships. Still, for each participant, the experience of CP presented some challenges. For example, Susana says:

When we got married, we made a pact. If he cooks, I will clean after dinner. And I said, “Fine,” because that’s how my brother and I were. “You cook lunch, and I’ll do the dishes.” But I didn’t know that chefs are the messiest person in the kitchen, so – it takes me like a half hour to do the kitchen. But when I get tired, he doesn’t really care. He’s like, “That’s your duty.” Or if I don’t feel like doing something else, he says, you know, “Come on, you’re the mom. Get your son up.” You know? Or things of that nature. He doesn’t see my disability.

Although Susana occasionally wishes that her husband acknowledged her limitations, she says that overall she’s glad that her husband sees past her CP:

So it’s good and bad. I’m his wife. I’m a mother too. I have responsibilities, like any other mother and wife does. I don’t get out of it. And if I fall or drop something, they step over me. If there’s no blood, they step over me. So that’s the good part. But the bad part is when I’m like tired, or I have a cold – even a cold
runs me down a little more. So I have to push myself a lot. I think at some level, deep down, they have sympathy. But they don’t show it. And that’s just a part of their personality. We’re not a sympathy family. You know, I like it. I would not like it the other way. I would be so miserable.

Similarly, Jesse does not believe that his disability plays a big role in his relationship with his wife. At least initially, Jesse had been able to conceal his impairment in other romantic relationships, and he was reluctant to reveal it when they started dating for fear that she would reject him. Even though he now considers his wife to be his best friend and says that he can talk to her about anything, he also describes how at the same time, he still sometimes feels a need to prove his abilities to be a good husband, son, and provider. For example, when the couple was re-doing their kitchen, he first tried unsuccessfully to re-sand the floor himself, even though his wife suggested that they hire a contractor. Jesse admits to knowing that trying to sand the floor himself was probably not a good idea, but says that the project did not seem to be that difficult and that he wanted to prove to himself and to his family that he was a good provider and a strong and capable man. Thus, even in seemingly solid marital relationships, the stakes of acceptance may be so high for individuals with CP that they may have a need to fulfill socially prescribed norms as a way to continually prove both their competence and their worthiness.

d. **Parenting**

Three participants in the study have children: Jesse has a preteen son, Susana has a teenage daughter and a preteen son, and Danielle has five-year old twins: a son and a daughter. For each participant, having CP has influenced their style of and feelings about parenting, albeit in different ways. Although Jesse felt like his CP had relatively minimal influence, he expresses regret that he cannot play ball or always help
his son with projects as well as other fathers might be able to. Yet he is also amazed by how understanding and accepting his son is:

He always wants to go out and play ball, so I would have to catch the ball in the glove, and take the glove off, and then throw the ball back to him. So at that point, he realized something was different. But he’s understanding. He’s like, “Okay.” That’s one thing about my son – he’s taught me that he loves everybody. He’s one of the most loving people that I’ve ever met, and it’s like, “Wow, I created this human being.” But he understands, and he always tries to help me out whenever he can. He realizes that I can’t do everything.

Similarly, Susana is also very impressed by how her two children have so naturally accepted her disability, and have taught many of their peers to do the same:

I guess I explained what CP is at some point when they were young. But other than that they are around people with disabilities. My daughter volunteers [in disability related events] so she’s very much involved. They both are, in my life. I hear that sometimes kids ask my daughter about me. And she tells them. And then the kids that grew up with me, could accept – you know, disability now is not taboo. You know, it’s not.

She continues, saying:

When you have kids, they just accept you and they are taught – you’re the mom, you do have a disability, but it’s no big thing. They know, and they know how to push me, trust me. But they know the limits. They do know.

Susana says that although her children are willing and even eager to assist her with everyday tasks, she is wary of asking her children for too much help:

My daughter, who is twelve, is very helpful. Maybe too helpful. I want her to be twelve, not eighteen. And that’s hard. That line. Sometimes I ask her to do my hair, to put it in a ponytail. She does it a lot. I will ask her to do some stuff. I try not to, but she’s able- bodied. Instead of spending ten minutes, I can have someone do it in two seconds. And I have to be very careful about that.

Finally, Danielle, mother of five year-old twins, is still learning to walk that fine line between being too permissive and too controlling. In the past, she has let her children “have the run of the mill” a behavior that she attributes to “trying to make up” for her disability. Subsequently, she says that her children have not seen her either as an
authority figure or as their protector. After working with a child psychologist, she has learned how to more effectively stand her ground, and not just to delegate the disciplining to her husband. She says that having children has made her re-think her disability experience:

> I know the first time we talked I said I was an empowered individual with a disability and I was proud of having a disability. But damn, you throw this cork at me and it’s kind of like, “Whoa, I have a lot to learn!”

D. The Question of a Cure

At the end of the second interview, in an effort to better ascertain their sense of disability identity and the extent that their beliefs about the disability experience are consistent with those of the mainstream, non-disabled community, participants were asked if they would take a cure for CP if offered one. Analyses indicate mixed responses to this question. Some report that even though they are generally satisfied with their lives, they would accept a cure because it would make life easier. Alex, who has a very significant impairment, but who has also previously described CP as “awesome,” responds: “Hell, yes, I would take a cure.” He suggests that it would be easier to communicate and would decrease his physical pain. Similarly, Miles, who is very involved in disability activism but also has a significant impairment, says that even though he has “friends and a good life,” he would still accept a cure. Steve says that he would like the opportunity to get around without difficulty: “It would be a lot easier in my life. I’d love it [if I woke up one day and didn’t have CP]. I’d be jumping for joy. I’d walk around.” Finally, Juan, who is less impaired, expresses his belief that:

> Everybody with a disability would take the cure if there was a magic pill. Because, I don’t know, people always want to improve, get better, and that’s just the public. So people with disabilities – I know that they’re the same as
everybody else, so they want to get better, just like everybody else. That’s how I feel.

However, most participants in this study, even those who feel that CP had made their lives more challenging, say that they would not want a cure for CP. Susana comments that:

I would be the six thousandth person to take the pill. And if I ever get to the six thousandth, and I see the damage that they did, I don’t know. This is my life, and I like my life right now.

She continues by explaining how she used to use a spinal cord stimulator in her back, but that she never noticed much of a difference in her walking or her posture, and that it made her tired:

I just said screw it. First of all, I never saw a difference. [My husband] and my family did. And once you don’t see a difference, it becomes a pain in the ass... [My family saw] better walking, better speech. But I never saw that. So to me, it was just a pain in the ass. And who knows if it works anymore? And I tried, you know, the pill to calm my face – calm my spasticity. And it made me tired. So here I sit, and to me, I’m not doing so badly.

Sara points out that having CP has made her who she is, and that in the process she has helped to change people’s perceptions:

I have changed a lot of people’s ideas about people with disabilities, a lot of people’s opinions. And I think that that is more beneficial than taking away the disability, because my life has been a little bit harder. So I don’t think that I would. I’m just kind of so focused on what I’m doing right now, that I really don’t think about it that much.

Of all of the participants, Drew is the most adamant about not wanting a cure, suggesting that to want one would be to invalidate the individual he is now:

This is how I am. I’ve always been this way. So I wouldn’t change it. That would be saying that who I am is wrong, you know? That would be saying that they are right. The other people that say I’m not good enough, that I’m just some piece of shit. It’s like saying that they are right, you know? And I’m not gonna do that, because they’re not right. They’re not right.
Even several participants who have experienced significant discrimination and/or psycho-emotional conflicts say that they would not want a cure. Kate, for example, acknowledges that she has thought a lot about what her life would be like without CP but that, like Sara, she believes that she has been able to make a difference in others’ lives because of her disability, and that without CP her life probably would not be as interesting. And Jesse acknowledges that although having CP can be a challenge, at this point in his life, he is who he is.

I guess it would make my life a little bit easier, right? But this is who I am though. I guess I’ve done this forever. I’m almost forty years old. I’ve done this forever. So I wouldn’t know how to be. I’m too old to be something else right now. You know what I mean? I am who I am at this juncture. My world is what it is. So for me to go to some other world right now would be kind of difficult.

E. Chapter Conclusion

This chapter has outlined several themes that emerged from the data collection process, and has discussed some of the similarities and differences among participants’ experiences. The following chapter will provide a discussion of the primary findings of the study and will situate those findings in terms of the larger bodies of literature on adults with CP and disability studies.
I am Cerebral Palsy
My friends call me CP
People who have me have good lives
They have different lives but they’re still good lives
They have friends
Go to school
Work Jobs
Get married and have families
They get to see life in another way then people without me
They are able to inspire others
I am not disease or illness
I am not like Cancer or AIDS
I never did any harm
and certainly never killed anyone
People who have me are just different
Different types of people make the world interesting
Do not try to cure me
Because I am a part of the people who have me
Destroy me and destroy part of them as well
Children like me shouldn’t be made to undergo intensive therapy to “improve”
Or withstand countless surgeries
Parents should accept children how they are
If they can’t do that they’re the ones with the problem
People with me deserve the same rights as everyone else
If they don’t get them, then they should demand them

Drew
Participant
A. **Chapter Summary**

This chapter presents the major findings from the research, explores possible rationales for these findings, and works to situate the findings in terms of the broader literature on the social and psychological experiences of people with disabilities in general. It also describes the project’s limitations and implications, and suggests future directions for research into the experiences of adults with CP. As the experiential descriptions, the thematic discussion and even the poem illustrate, there are many variations, complexities, and even contradictions in the ways participants articulate their lived experience of having CP. Negotiating physical, social and
internalized barriers seems to be an ongoing process for many participants. Nevertheless, most
employ a wide variety of strategies to create lives that they define through their narratives as rich
and meaningful.

B. **The Experience of Stigma**

The first major finding from the study is that participants do not define their experience
of having CP primarily in terms of stigma, and that the experiences and feelings of stigma that
they do discuss, or that they imply, are often quite complex. While instances of stigma and
devaluation do certainly appear across the data, what has struck me the most is how participants
continually reject the traditional narrative of life with CP as one of constant hardship. Instead,
many are working to reframe their stories in ways that emphasize their connection to others as
well as their overall strength and resilience. Contrary to literature suggesting the importance of
developing disability-appropriate values, even the participants who strive to attain “normalcy”
and mainstream values seem to have negotiated their lives in ways that work for them. However,
in many cases, this negotiation is continuous and often precarious. For Miles, finding
camaraderie at a disability rights rally is coupled with a stranger calling the police when he stops
a stranger to ask for directions. For Danielle, the reward she derives from matching another
disabled individual with a skilled personal assistant is coupled with getting trampled on her way
to the commuter train. For Drew, the joy he finds in teaching is coupled with the frustrations he
feels in trying to convince his superiors that he is fully capable of doing so. As is the case for
non-disabled individuals, life for these participants is full of ups and downs; the difference,
however, is that these individuals seem to have to work much harder to achieve and maintain
social acceptance.
Even so, the question remains as to why participants do not report experiencing as much stigma as I had anticipated that they might. There are several possible explanations for this. First, perhaps people with CP in general simply do not experience much stigma. Second, perhaps individuals with CP, as a group, do experience a significant degree of stigma, but individuals in this particular sample, primarily because of their demographic characteristics (e.g., education level), do not. Third, perhaps some of these participants do not report experiencing stigma because of where they are from and the sorts of situations they find themselves in. For example, a few participants are from small towns where they rarely interact with individuals whom they do not know. A fourth possibility is that immersion into the disability community has helped to buffer these individuals from feeling stigmatized. Fifth, it is possible that participants in this sample do experience stigma, but that they are not being honest about their experience. Within this scenario, there is the possibility that either participants are intentionally withholding their true feelings from me as the researcher, and/or that some participants have become adept at controlling and concealing their feelings in general, even from themselves, and that they have no peer group to help frame their experience in terms of social oppression.

It is possible that adults with CP generally do not experience stigma because they have learned, throughout their lives, not to internalize others’ negative attitudes towards disability. As indicated in chapters three and four, existing literature provides a very complex picture of how adults actually think and feel about their disability experiences; the results of this study also illustrate this complexity. Crocker and Quinn (2000) point out that:

Understanding the experience of stigmatized people requires that we understand the collective representations that these people bring with them to situations. Whether collective representations held by members of devalued groups are shared by those in valued or advantaged groups, they may cause situations to have different meaning for different groups. This suggests that research on the experience of stigmatized persons should not only document the collective representations that stigmatized and
nonstigmatized individuals bring with them to situations, but should also explore how these collective representations affect the meaning of situations for these two groups. We cannot assume that the same situation will mean the same thing for stigmatized and nonstigmatized people. (p. 177)

In other words, it is possible that individuals with CP, as a group, do not see themselves as many others see them. For example, a cashier may count out change for a customer with CP because he or she may view the customer as incapable of calculating it; however, the customer might simply interpret this as a friendly gesture. Recall that Watson (2002) describes how, for some individuals, disability does not factor into their identity one way or another. Perhaps this is true for many individuals with CP, particularly those without strong ties to the disability community.

A second possibility is that individuals with CP as a group generally experience a lot of stigma but that this particular group does not. This introduces an important concern about sampling strategy in this investigation, and one that arises not only in other disability-related research, but often in qualitative research in general. Qualitative researchers, and especially phenomenologists, typically seek participants who are likely to be articulate and to provide thoughtful and detailed information about their experiences. In any project, but particularly in disability related research, this may limit the scope of the sample to participants who have higher socioeconomic status and are fairly well educated. Indeed, in the present study, six of the twelve participants were employed at the time of data collection and eight of twelve held a college degree. These percentages are significantly higher than for the U.S. population of individuals with CP as a whole (Ruthowski & Riehle, 2009). Although level of education and socioeconomic status would not likely be direct factors in buffering these individuals against stigma, they may function as indirect factors. Many of these individuals are from families where they grew up feeling valued and were taught to have high self-esteem. Several participants also suggest that
their families had the knowledge and the financial resources to seek educational, therapeutic, and social opportunities to which many children with disabilities might not have access. Indeed, some, like Miles and Megan, discuss how their parents have instilled in them a high level of confidence and self-esteem, and have taught them that they are just as valuable as their non-disabled siblings and peers. Another reason that participants may not have reported experiencing stigma as readily as I expected is because, as a group, they tend to be a bit older. The younger participants in the study, those who are under the age of 35, (like Sara, Drew, and Danielle) more readily describe stigmatizing experiences than do the older ones like Megan, Susana, and Kate, who were over 35. Ironically, having grown up in more mainstreamed environments, in the height of the Disability Rights Movement, and with more access to equal opportunity, may have actually made younger participants more aware of their marginalized status.

A third possibility is that some generally remain in comfortable, familiar situations where they do not often encounter people whom they do not know. This is especially likely for participants such as Kate and Megan who have always lived in small towns and are likely to see the same individuals day in and day out. Whether it is fear, a lack of resources, or just a general satisfaction with their current life that prevents them from venturing out into different environments, they have remained in familiar and comfortable situations. Both Kate and Megan have trouble coming up with instances when they feel stigmatized; however, at other points during the interviews they also describe how they sometimes have trouble “putting themselves out there” and suggest that they are afraid of being rejected. Kate, for example, discusses how she has often stood alone in the corner at parties, and Megan explicitly states that her own fears have prevented her from going out to meet men.
Those participants who are able to readily describe instances of experiencing differential and/or devaluing treatment tend to be from a large urban area where they are perhaps more regularly exposed to a larger and more diverse group of people. For example, both Sara and Danielle express frustration with individuals on the commuter train that either ask invasive questions or refuse to make room for them. Sara and Danielle, unlike Kate, Megan, and Susana, frequently leave their comfort zones to explore new environments and to have different kinds of experiences. While Kate and Megan drive around their towns, Sara and Danielle rely on public transportation to get them to and around their city; they are therefore forced to interact with more people on a regular basis. Danielle may also have to interact with more people on a regular basis because she is the mother of young children.

A fourth possibility as to why individuals in this particular sample do not report experiencing extensive stigma is that they have come to see disability discrimination as a larger social phenomenon, so that they do not internalize the devaluation that they experience. For example, Drew describes being able to put these instances out of his mind almost as soon as they occurred. It is not that he does not recognize experiences of devaluation when they happen, but rather that he is able to chalk them up to societal ignorance and prejudice rather than to a personal shortcoming. In fact, his own experience of being devalued has increased his personal commitment to working with other disabled individuals. He wants to ensure that people with disabilities are more accepted for who they are rather than being made to fit into the mainstream or to fulfill others’ expectations of normalcy. Moreover, his bond with another, slightly older, individual with CP has been instrumental in his ability to see his personal experiences of devaluation as part of a broader social issue.
Likewise, through her work in a center for independent living and her involvement in the Disability Rights Movement, Danielle has overcome her mother’s perception of her as weak and dependent; instead, she has built a successful career and family, and has come to identify herself as a strong, proud, and independent woman “who doesn’t take shit from anyone.” Juan, too, has defied his parents’ expectations of him and is working to build an independent and meaningful life, saying that he wants to show his family, and himself, that he can be successful. Juan’s determination to succeed is, in fact, largely fueled by his attempts to prove his family wrong; he even says that he wants to learn to drive partially because his parents scoffed at him when he first expressed an interest in doing so. Thus, not only have participants managed to find other support systems when their families have proved unhelpful, but they also sometimes use their families’ doubts as motivating factors.

Fifth, it is possible that while participants actually do experience stigma, they are not being honest with me during interviews. It is possible that they do not want to admit their real feelings to a researcher, and, despite my attempts to create a rapport with them and a comfortable environment conducive to sharing, they want to appear strong in front of me. My own position as a researcher with CP could either contribute to or hinder this effort. On one hand, my having CP perhaps helps them to open up to me because they see someone who could sympathize and genuinely understand their experiences. On the other hand, my status as a doctoral candidate, and as someone who tried to appear professional and confident, could make them want to impress me and not to want to admit how they really felt. Additionally, they may want to project to the public their capacity to be valued and integrated into the mainstream.

Finally, it is also possible that, for many participants, claiming not to experience stigma is part of a larger, lifelong effort to appear strong in front of others and to exercise control over
their lives. That participants as a group do not readily report experiences of devaluation, or internalization of that devaluation, is particularly interesting in light of Reeve’s (2006) argument that: “For many disabled people, it is the barriers that operate at the psycho-emotional level which have the most disabling consequences on their lives…the experience of exclusion, prejudice, and the reactions of others can adversely affect someone’s emotional well-being” (p. 106). I had expected that her argument would be especially relevant for individuals with CP whose embodied experiences often differ from the norm more so than individuals with other kinds of impairments and who are considered among the least socially accepted of impairment groups (Yuker, 1988; Thomas, 2000). However, participants’ narratives suggest that, throughout their lives, they have become adept at negotiating others’ attitudes towards them and working to resist psycho-emotional oppression. Unlike individuals who have acquired impairments later in life, or whose impairments may be relatively minimal, it appears that many of these individuals have struggled to gain social acceptance from a very early age and have developed strategic systems to try to protect their ego. Susana, for example, says that she just “blows jerks off” when she thinks that they are devaluing her, and Drew imagines a planet with just disabled people, as he has come to regard many nondisabled people as a “pain in the ass.”

C. The Influence of Family

The effort to seek acceptance and gain control seems, for many participants, to have begun at an early age, and leads to the second major finding from this study: that participants’ families play a major role in how they think and feel about their disabilities, especially with respect to their attempts to establish control. Many participants report that their families are the single most important influence in supporting them and helping them to “lead a normal life.” However, they similarly suggest that their families have frequently encouraged them to control
their feelings about having CP and even, in some cases, aspects of their impairment experience, so as to appear as “normal” as possible. Olkin (1999) notes that oftentimes children with disabilities are indoctrinated into a “conspiracy of silence” regarding their disability – it is not discussed except in the context of medical or therapeutic intervention. (p. 96). She further describes how, without proper knowledge and support, families can internalize society’s negative views of disability, and pass those views down to their children rather than teaching them alternative ways to conceptualize disability. Olkin argues that these negative understandings of disability are often reinforced in children’s minds as they become exposed to other children with disabilities: “Thus,” she writes, “the greatest source of comfort and understanding—other children with disabilities—is the avenue children carefully eschew” (p. 100). Miles, for example, discusses how, as a child, even though he attended a segregated school, he was reluctant to socialize with other disabled children because he did not feel as though he had anything in common with them. It was not until he got to college, and was free to associate with both disabled and non-disabled students, that he began to befriend others with disabilities.

Olkin points out that while parents often are trying to do the right thing by treating their disabled child like a “normal” child, this can often have a negative effect as it denies a fundamental part of his or her identity. “By treating children with disabilities as ‘normal,’ she writes, “we are implying a badness associated with disability” (p. 101). This, in turn, puts significant pressure on children with disabilities to try to be as “normal” as possible and to deny their thoughts and feelings related to their disabilities; participants’ narratives suggest that they feel this pressure even as adults. For example, when participants are asked about whom they have relied upon for support after experiencing devaluing interactions, most say that they rely on family members. However, they also indicate that family members frequently encourage them to
ignore the situations and to move on with their lives. For example, when a hotel clerk refused to accept Alex’s credit card because he believed that it had been stolen, Alex’s brother told Alex “that it was the person’s stupidity” and that he should not worry about it. Similarly, Sara often confides in her mother about situations where she feels rejected, and while her mom expresses sympathy to a certain point, she ultimately advises Sara not to dwell on these situations.

Even Jesse feels that his wife eventually becomes frustrated when he describes his troubles with professional networking; “She just assumes that, ‘oh, you need to get out there and do it. Just get out there and do it.’ Or, ‘you need to go out and make new friends….it’s as hard as you make it.’ She tries to put it off that it’s me.’ It is likely that, even during the data collection process, some participants’ claims that they do not experience stigma or their reluctance to directly discuss their feelings and experiences of devaluation are rooted in this “conspiracy of silence” that Olkin describes. If they have always been told to control their thoughts and feelings related to their disabilities, then openly bringing them out and discussing them during an interview would likely be much more difficult.

For some participants, however, their families’ lack of support has actually provided the necessary motivation for them to succeed and to prove themselves to their families. For example, Juan’s parents’ belief that he can not drive a car has made him all the more determined that he can, if he puts his mind to it. Additionally, his brother’s mocking of the way he walks has led Juan to realize, and to articulate to his brother, that he actually has many strengths that his brother does not. An absence of family support has also led several participants to seek support from alternative sources, such as the disability community, and for some individuals, immersion in the disability community has provided the necessary strength to resist their families’ oppression. For example, Danielle explains that her work in disability advocacy has allowed her
to stand up to her mother, who often treats her like a child, and to say: “I’ve accepted my
disability, now you have to too.” After many years, with encouragement from her personal
assistant and friends with disabilities, Betty has also finally begun to stand up to her mother, and
to seek greater control over multiple aspects of her life, from choosing what clothes she wears to
how she spends her social security income. In fact, a couple of participants suggest that, to them,
the disability community functions similarly to a family. Drew says that his best friend, who also
has CP, is like a brother to him, and he also refers to other members of the disability community
as his “brothers and sisters.” Although most participants say that their families are supportive of
their efforts to integrate into the disability community, some, like Betty, believe that their
relatives feel threatened and try to hinder these efforts.

D. The Experience of Depression and Disability Community as Antidote to Depression

This leads into the next series of findings from this study: that several participants report
having experiencing depression during adolescence or young adulthood. Moreover, for some
participants, integration into the disability community has been instrumental in their efforts to
successfully negotiate their depression. Conversely, participants who have not become involved
in the disability community seem to have had a harder time negotiating this depression. Although
adolescence and young adulthood is a difficult period for many individuals, disabled and non-
disabled, it seemed particularly trying for individuals in this study. King, Gathers, Polger,
Mackinnon, and Havens (2000) found that young adults with CP frequently define success in
terms of feeling a sense of belonging and purpose in life. Participants in my study reported
having had difficulties on both fronts. Particularly in high school, many felt rejected by their
peers, and once they reached college they were not only faced with the challenge of building
social networks but also of separating from their families and formulating their own identities.
Several initially wanted to leave college and return to their families, and others, like Megan, even contemplated taking their own lives. She explains how after attending a small school where everybody knew and accepted her, being on a large university campus was a complete culture shock. Not only did this environment make it much more difficult to meet people, but getting around was physically much harder as well. Although Drew, in contrast, was more socially integrated in college than he had been in high school, his efforts to build a career as a teacher were nearly thwarted by professors who could not see past his disability. After eventually learning to navigate her university, making several good friends, and ultimately obtaining a Master’s degree, Megan also relapsed into depression after she was told that she could not teach because she had CP. Kate, who initially struggled with depression after experiencing ridicule in high school, also became depressed again after college as she contemplated her future and feared continued rejection.

Participants have negotiated this rejection in a variety of ways. Some, like Susana, Megan and Kate, appear to have dealt with this rejection by working to change their own attitude. Even when they encounter disability prejudice, they frequently seem to either pretend it does not exist, try to shrug it off, or blame themselves for feeling bad about it. For instance, Megan describes how she eventually realized that “her perception was cockeyed,” that she had been making CP “bigger than it was” by blaming her lack of relationships and low self-esteem on other people’s attitudes towards her rather than on her own fears. However, although Megan does not talk directly about it in the context of feeling devalued, her narrative indicates that she has, in fact, experienced what appear to be many instances of disability-related rejection throughout the course of her life.
Megan admits that she has been in counseling since college, and perhaps her parents’ efforts to normalize her coupled with the therapy she has received has led her to interpret her feelings of rejection as a personal shortcoming rather than a very real and often very difficult part of being disabled in our society. In a similar vein, when Kate felt bad after a stranger handed her a fork in a restaurant because he thought her eating was messy, her therapist suggested that Kate not worry about it because the stranger was “ignorant and didn’t know about CP.” Reeve (2000) suggests that therapists often perpetuate the notion that individuals with disabilities need to be strong and to move beyond their feelings of rejection, and if they have a hard time doing so, it is somehow their own fault, i.e., that their perception is cockeyed. She points out that:

Counselors are subject to the same negative images and stereotypes of disabled people as the rest of society. The attitudes and prejudices can adversely affect the nature of the client-counselor relationship when the client is a disabled person—there is sometimes oppression within the counseling room. (p.699)

She goes on to describe how many counselors still see disability as an individual problem and do not realize the magnitude of oppression that disabled individuals can face. “Counseling,” writes Reeve, “cannot fix disability because ‘disability’ is a problem created by society and not the individual, although it can help someone to explore the ways in which they are being disabled and how they feel about it” (671). Reeve calls for a new approach to disability counseling where therapists would “look at disability from the social model point of view and to help disabled clients move away from blaming themselves for being socially excluded” (677).

It seems that participants who have most successfully moved past their depression have done so by integrating into the disability community and/or developing alternative support networks that view disability as a broader social issue. Miller and Major (2000) point out that: “People with strong group identities may be more likely to recognize the role that their stigmatized status plays in causing their outcomes. They therefore may be more likely to
attribute outcomes to prejudice than those who are less group identified” (p.261). Moreover, as noted by Wright (1960) and Gill (1997, 2001), it is through this group identification that people with disabilities typically adopt alternative values that celebrate difference and emphasize resilience in the face of oppression.

Supporting this contention, Miller and Major argue that:

The benefits of interactions with similar others include validation of beliefs and attitudes, mutual need gratification, mutual understanding, and compatibility, as well as provision of emotional and instrumental social support. By affiliating with similarly stigmatized others, stigmatized people gain a respite from prejudice (p.256).

Sara and Drew, for example, both describe how, when they are around other people with disabilities they frequently feel more comfortable than when they are among non-disabled people, like they “don’t have to explain everything all the time.” Of the participants in this study, those who are integrated into the disability community seem to feel the most free to express themselves to others.

Notably, involvement in the disability community does sometimes appear to heighten participants’ awareness about the oppression encountered by disabled individuals in general and themselves in particular. For example, Miles and Alex are older, seasoned activists who are able to acknowledge that regardless of whose “problem” disability is, it can manifest in very personal ways and at times can be very hard to negotiate. Being so connected to the disability community, they continually witness the difficulties of living in a world that is not typically designed with disabled individuals in mind. For them, admitting that others’ attitudes and behaviors often wears on them is not admitting to personal weakness or to failure, but just to the fact that a hostile social climate towards people with disabilities can sometimes have intensely personal ramifications. Nonetheless, for participants in this study, immersion in the disability community ultimately seemed to strengthen their resilience and provide them with additional support needed.
to combat this oppression. Participants like Sara and Danielle note that the disability community offers a sense that “it’s not my problem, it’s society’s” and a recognition that “it’s okay to have a disability… I don’t have a horn sticking out of my head.”

For participants like Juan and Betty who come from less supportive family environments and are just beginning to immerse themselves in the disability community, it offers not only a sense of belonging but also a place to seek practical support and advice; for example, Juan volunteers at an independent living center as a way to get much needed job experience and Betty has sought assistance with assuming control over her money. Exposure to and interaction with other disabled people has helped both Betty and Juan to assert their value as individuals; it has similarly strengthened their confidence when interacting with others, including members of their own families.

E. The Place of Impairment

Another major finding is that participants’ impairments play significant roles in their everyday social and psychological experiences. Participants’ discussions of impairment often seem to reflect how they view their overall disability experience, and several participants wanted to talk extensively about their experiences with impairment even after I tried to make it clear that this was not the primary focus of the interviews. Susana, Megan, and Kate seem to battle their impairment in an effort to integrate into the mainstream as much as possible. Kate’s declaration that: “Sometimes I hate CP,” and Megan’s description of trying to get her legs to move can each be viewed as signs of struggle for control over their often non-compliant bodies. Susana, too, emphasizes her desire to look good and to keep in shape, noting her opinion that others with CP could do more to look better. She also comments that she does not like having her picture taken because certain features related to her CP tend to look exacerbated in photos. Susana’s
statements parallel Tighe’s (2001) finding that women with physical impairments often compare themselves to non-disabled women, feeling a need to “keep up” with non-disabled society, even to the point of exhaustion, in order to prove themselves as healthy and capable. For Juan, working out and building muscle also serves as a way of removing the focus from his CP and instead emphasizing his masculinity. Effectively controlling and even striving to “overcome” impairment is an instrumental part of how many participants define success. For example, Juan said that although he has a cane and his doctor has said he should use it regularly, he does not want to use it unless he absolutely has to. Susan Wendell (1996) suggests that this need for bodily control stems from a pervasive cultural myth that can have particularly dangerous ramifications for individuals with disabilities. She writes that:

> The price of illusion that most of us are in control is the guilt and stigma we inflict upon those whose bodies are out of control. I believe that it is a major contributor to the stigma of disability... Imagine the self-doubt and psychological pain that this inflicts on people who want to get up and walk away from a wheelchair… (p.106)

In analyzing several participants’ narratives, it appears that this struggle is particularly relevant for individuals with CP, whose impairment experience is often highlighted by a loss of control over their bodies, be it through drooling, seizures, incontinence, or severe spasticity. Alex and Miles, the two participants with the most extensive impairments, also are the two that most readily acknowledge the difficulties inherent in negotiating impairment and also that life overall can often be quite difficult. Alex, in particular, seems unabashed in his admission that his deteriorating physical condition frustrates him to the point of serious depression, primarily because of the physical pain he experiences but also because his physical condition restricts his opportunities to go out and socialize as much as he would like. “My spasticity is off the charts,” he says; “I feel so out of control that I sometimes isolate myself.”
However, a few participants have re-negotiated their impairment effects in ways that really seem to work for them and allow them to live fuller lives. For example, Drew has ultimately decided to use diapers as a means of controlling his incontinence, and, despite his family’s protests, he says that not having to worry about the possibility of accidents has given him a certain freedom and flexibility that he previously had not enjoyed. Likewise, Sara and Danielle’s decisions to rely more extensively on wheeled mobility rather than walking give them more energy for other activities. To a large extent, they have forgone trying to assimilate into the mainstream and to do what is most socially acceptable in favor of doing what works best for them and provides them with the greatest freedom.

Jesse, however, is at the other end of the spectrum; with his relatively minimal impairment, he feels an intense amount of pressure to fit into the mainstream. In some ways, for Jesse, impairment actually restricts his social opportunities and his chances to integrate among his colleagues more than it does for participants with far more significant impairments. While those working in the disability field are not likely to be excluded from a softball game after work, Jesse has been. While many other participants readily receive the necessary accommodations at work, Jesse has to fight for them and risks not being hired or losing his job due to his simple requests. Finally, whereas Jesse’s failure to redo his kitchen floor by himself serves as a stark reminder of his limitations, other participants might see it as no more of a failure than not flying to the moon. Thus, although Jesse, like the other participants, has made certain accommodations regarding activities he cannot do, the limitations imposed by his impairment are often more blatant than they are for other participants. Further, his associates also feel free to openly discuss and even to ridicule his challenges in ways that they might be less likely to do in front of someone with a more extensive impairment, and he is often forced into
situations where he has to explain to his co-workers and even to his wife and son, what he can and cannot do. Whereas other participants may be able to more comfortably integrate their impairment into a lifestyle that may be a bit different from the norm, but that ultimately suits them nonetheless, Jesse battles with his impairment on a regular basis in order to fit into the mainstream.

1. **Speech Impairment**

In particular, the presence of speech impairment appears to play an important role in the experience of several participants. Specifically, participants with speech impairments report more instances of devaluing treatment than do participants without speech impairments. Further, they often attribute these experiences to others’ impatience or refusal to even try to understand what they were saying. When asked generally if they believe that individuals with CP are treated differently than individuals with other types of impairments, many participants respond that the presence of a speech impairment is a defining factor in how people with CP are treated. A few participants who do not have speech impairments even suggest that they are treated better than most individuals with CP precisely because their speech is “normal.” Drew believes that, in the minds of others, a speech impairment is strongly associated with intellectual impairment. “When people hear me speak,” he says, “They automatically think I’m mentally retarded. So it’s how you communicate in this world that determines how you are treated. Even among disabled people, people with CP are looked down upon.”

Utilizing an augmentative communication (AC) device can compound these challenges. In analyzing multiple narratives of AC users, Politano (2007) found that many potential communication partners just ignore them altogether, even when users go to sizable lengths to capture and maintain their attention. She similarly found that even when communication partners
do make the attempt to engage, their behaviors are frequently guided by misperceptions. “People
don’t just ignore us,” said one, “they patronize us, think we’re stupid, and maybe fear us too. …
They don’t hear us” (p. 51). Likewise, both of the participants, Miles and Alex, in this study who
use communication devices describe instances of feeling ignored, misunderstood, and devalued
when interacting with unfamiliar others. They also both describe instances of being treated like
criminals when engaging in everyday activities. Miles was almost apprehended by the police
after asking directions in an unfamiliar neighborhood, and Alex was accused of credit card theft
when checking into a hotel. Both men describe feeling very frustrated by the experiences, but
also indicate a kind of resigned acceptance; as Alex puts it “I’m forty-four years old, and this is
my life.”

Highlighting the importance of context, however, it is noteworthy that in this study,
individuals with speech impairments also tend to be more connected to the disability community.
It is possible that among individuals with speech impairments, only those connected to the
disability community found their way into my study, but it seems that individuals with more
significant levels of impairments (including speech impairments) are particularly likely to seek
out the disability community because they have more difficulty fitting into the mainstream.
Despite Drew’s contention that “even among disabled people, people with CP are looked down
upon [because of how they communicate],” in this study, participants with speech impairments
are more likely than those without speech impairments to hold important roles in the disability
community, especially in terms of their contributions to disability advocacy. Having a more
significant impairment (and particularly a speech impairment) seems to result in greater
credibility and hence an elevated status in the disability community. As discussed above, this
frequently helps to buffer participants from the devaluation that they encountered in the
mainstream. For instance, in talking about how he copes with situations like having the police called on him, Miles points to his allies in the disability community, remarking that: “The way you feel about yourself is your friends; if they have a high regard for you then you feel better about yourself.”

F. Placing the Findings within a Phenomenological Framework

These findings all describe the way that participants fundamentally relate to and interact with the world around them, and supports Hughes and Paterson’s (1997) assertion that “the social is embodied and the body is social” (p. 336). They demonstrate that not only do individuals with CP often interact with the world in unique ways because of their impairment, but also that CP frequently shapes others’ perceptions and ways of interacting with those who have CP. For participants in this study, interactions do not seem to be primarily structured in terms of stigma, although experiences of devaluation are certainly evident throughout many participants’ narratives. On the contrary, for many participants, interactions with the world are frequently shaped by disability identity and a strong sense of disability community. Nonetheless, this study demonstrates that both impairment and disability matter at an individual level and an interactional level.

Each of Merleau-Ponty’s fundamental categories of lived experience – time, space/motility, speech, and sexuality – is evident throughout participants’ narratives. For example, many participants discuss how their thoughts and feelings about having a disability have changed substantially over time. Several speak about the challenges they experienced with their peers during childhood and adolescence. The cumulative effects of these challenges, combined with the pressure of moving away from their families and transitioning to adulthood, led in several cases to the onset of depression during participants’ early twenties. In many of
these instances, however, this depression precipitated more positive disability identities and connections to the disability community.

Space also figures in participants’ narratives, as many address the difficulties of trying to physically navigate a world that does not readily accommodate different kinds of bodies. Danielle’s admonishment to fellow commuters to “just fuckin’ move” is indicative of how frustrating it can be to wheel through a crowded area surrounded by others who are completely oblivious to alternative modes of mobility. Similarly, Sara’s discussion of how she feels trapped during the winter months when the snowy sidewalks prevent her from using her scooter shows how inaccessible environments can have very real consequences for people with disabilities. Even when environments are wheelchair accessible, the ways in which participants’ bodies move in and through space often results in alienation and isolation, highlighting the role that impairment can play in social interaction and psychological well-being. For example, Drew points to his seizures as a contributing factor in his depression; they have also caused him to delay his plans to attend graduate school. Further, he cites difficulties with incontinence as a point of contention between him and his mother. However, participants also described the importance of accessible, welcoming spaces (like disability organizations) as spaces of community building.

The importance of speech and communication has emerged as a major finding in this study as it has contributed to participants’ challenging interactions with others. Participants frequently feel ignored or looked down upon because of atypical speech patterns and augmentative communication; Miles and Alex have even been treated like criminals. As Drew notes: “It’s how you communicate in this world [that determines] how you are treated.”
However, challenges with communication in the mainstream often result in closer connections to and greater involvement in the disability community.

Finally, issues related to sexuality recur throughout many participants’ narratives. Many discuss the importance of being attractive and desirable, and several express concern and uncertainty about how others’ perceptions may affect their ability to find a romantic partner. Even the participants who are married suggest a desire to fulfill traditional gender roles, and to have their masculinity or femininity validated both by their partners and by others. For example, Susana stresses the importance of having her husband see her as a capable wife and mother, even when she was tired or sick, but she also wants to generally project herself as a fit and attractive woman. Juan’s bodybuilding efforts are designed to attract female attention, and in visiting strip clubs, Steve seeks validation of his masculinity from both his male friends and from the female employees. To have a partner and/or to be seen as capable of giving and worthy of receiving love is not only something participants seem to genuinely desire and to value, but also something that many utilize to project their value to the outside world. However, those involved in the disability community seem somewhat less concerned with this, and several have partners or are searching for partners who are also in the community. These participants are more likely to emphasize the importance of having partners with similar values.

G. The Influence of Gender, Race, and Ethnicity

In selecting the sample for this study, I tried to capture as much diversity as possible in terms of gender, race, and ethnicity. The final sample included six men and six women, but consisted of nine Caucasian, two African-American, and one Latino participant. Both women and men seem to express a sense of pressure to conform to gender norms. This is consistent with Thomas’ (1999) assertion that: “We all live out lives which are profoundly shaped by gender”
and her extensive research with disabled women that indicated that: “Whether or not their lives followed traditional gender pathways (and most did), their narratives were constructed with explicit or implicit reference to public narratives about what it means to be a woman” (p. 85). For example, in this study, women express more concern than men with wanting to appear attractive and desirable. Susana, in particular, stresses a strong desire to look good and to be fit, and even expresses some frustration with other disabled women who she believes “could try harder” to accentuate their appearance. Danielle and Megan similarly describe their wish to lose weight, and both Susana and Danielle spoke extensively about wanting to fulfill traditional expectations associated with being a good wife and mother. Susana is adamant that her husband and children do not treat her any differently or “let [her] get away with anything” because of her CP. Even when she is sick or fatigued, she is always expected to pull her weight, and she asserts that, although it can sometimes be challenging, she would not want it any other way because hers is “a no-pity family.”

Similarly, Danielle seems very concerned that others view her as a capable wife and mother, a concern that she suggests stems from her own mother’s excessive criticism and tendency to treat her like a child. Danielle acknowledges that becoming a wife and mother entailed a “big learning curve” and that she has had a lot of trouble setting limits for her young children because she often feels that she needs to compensate for her impairment by giving them too much freedom. She explains that, until recently, she depended on her husband to discipline her children, but she eventually felt that she was appearing weak in front of them and that this was ultimately doing them a disservice. Through working with a family therapist, Danielle has come to view herself as a much more capable parent, which has, in turn, strengthened her relationship with her children and her husband and has helped to enhance her own self-esteem.
Of the male participants, Jesse, who has the least significant impairment of all of the participants in the sample, also seems to be the most concerned with fulfilling traditional gender role expectations. He speaks extensively about not having male friends and of feeling excluded from traditional male group activities, like participating in sports. He comments that he wishes he could more effectively play catch with his young son, and that it is important to him to provide for his family and maintain his house. For example, in an attempt to demonstrate his masculinity, he worked diligently but unsuccessfully to re-sand the floors himself although his wife repeatedly suggested that they hire a contractor.

Steve, a bit like Susana, seems to rely on gendered activities as a way to seek inclusion and acceptance. He describes spending time with male neighbors at a bar near his house where he often watches sports and drinks beer. Occasionally, he attends live sports events with them or even goes to strip clubs. Steve is adamant that he does not typically associate with other individuals with disabilities outside of his sheltered workshop; after work, he seems to want to be “one of the guys.” Similarly, Juan seems to use weight lifting, tattoos, and a shaved head as ways to conform to traditional Latino gender norms and to take the emphasis off of his disability. He describes how, during the period that he was working out intensely: “Women came at [him].”

In this study, more male than female participants are active in the disability community, and participants who are active in the disability community seem less concerned with fulfilling gender expectations, perhaps because they feel accepted within this subgroup and were not as concerned with subscribing to mainstream ideals. In other words, they do not feel as great a need to conform to stereotypical gender norms as a way of seeking acceptance from the larger society; as disabled activists, they have already accepted themselves and their CP. Additionally, as the disability community strives to embrace diversity, broader issues of social justice and equality
are often emphasized, including gender equality. More attention is being paid to the common experiences of socially oppressed populations as it works to strengthen alliances with other marginalized and activist groups, including women and feminists (Ostrove et al., 2009).

Because of the limited diversity in this sample, it is difficult to draw any firm conclusions regarding how race and ethnicity specifically affects individuals’ social and psychological experience. In looking at the experiences of the three racial/ethnic minority participants, it appears that socioeconomic background, rather than race and ethnicity per se, is a more important indicator of experience. Although no questions were specifically asked of participants regarding their socioeconomic status, I was usually able to infer it through our conversations. The majority of participants attended college and appeared to have come from families savvy and financially secure enough to seek out good educational and therapeutic services for their children. This suggests that the majority come from at least middle class backgrounds. Two exceptions to this seem to be Juan, who is Latino, and Betty, who is African-American. Both seem to come from less educated and economically advantaged backgrounds. Juan himself never finished high school and does not currently have a job; most of his family is still in their mother country and his brother, who is in the U.S., is employed in manual labor. Juan talks extensively about how he feels that his parents are ashamed of him and do not see him as an independent and capable person. Likewise, Juan also speaks about being ridiculed by his brother and his brother’s friends because of the way he walks. As discussed above, by working out, getting tattoos, shaving his head, and generally creating a more macho persona, Juan seems to strive for acceptance both from his family and from the larger Latino community. Wong-Hernandez and Wong (2002) note that:

Many Hispanic men have been culturally taught that it is their responsibility to provide for their families and being strong is considered an important male attribute. Acceptance
of disability may therefore be more difficult for a Hispanic male than for clients who perceive their roles less stringent. (p. 11)

However, Juan is also learning to challenge people’s perceptions of him as weak and incapable through his efforts to connect with the broader disability community, where he is steadily gaining self-confidence as well as a more positive disability identity.

Likewise, Betty has also started to reach out to the disability community after what she describes as years of verbal and emotional abuse by her family, who attempt to control her life and her finances. However, even outside of her family, Betty seems to have experienced more stigma than many participants in this study. She discusses much of this stigma in relation to her involvement in the African-American community, whose members she describes as condescending. For example, she describes how several members of her church have scolded her for going outside when it is cold or have warned her to be careful of cars when she is crossing the street. Although other participants in this study have discussed similar experiences, Betty seems to experience these incidents more frequently and acutely. Individuals with whom she typically associates may feel an inclination to be more protective and may have different understandings of disability. For example, King (1998) argues that:

Even as they encounter unequal treatment in the larger society, African-Americans with disabilities may experience exclusion and stigmatization within their own cultural communities. More ironically, the exclusion and discriminatory treatment of African-Americans with disabilities may occur regularly within the black church—historically, a haven of affirmation and acceptance for the disenfranchised. (p. 1)

Nonetheless, the combination of a supportive pastor, an encouraging personal assistant, and exposure to the disability activism community has helped to “light a fire under [her],” inspiring her to demand more freedom from her family and to assert herself among members of the African-American community.

H. **Methodological Considerations, Implications, and Future Directions**
1. **Methodological Considerations**

The methods used in this study raised a number of issues that should be addressed. First, midway through the data collection process, I expanded the scope of the investigation from an examination of how individuals with CP experience stigma to a more general focus on their social and psychological experiences, with an emphasis upon their resilience and ability to construct lives that they define as rich and meaningful. One of the advantages of qualitative research is that it allows the investigator to rework her overarching questions and theoretical framework according to the data that participants provide. However, it also creates challenges for researchers who must sometimes unexpectedly, and quickly, change course in the middle of a study without necessarily having much time to analyze this decision. I believe that in this case my decision to expand my focus was a good one, in that it not only allowed me to gain a richer insight into multiple aspects of participants’ social and psychological lives, but it also offered a way to more fully capture how participants do experience stigma and how they effectively negotiate some of these issues. Nonetheless, I felt a certain amount of pressure to complete my data collection as quickly as possible while participants were still engaged in and committed to the project. Thus, I did not have time during the data collection process to really broaden the scope of my literature review. At the same time, however, I felt that my own background in psychology and disability identity combined with my advisor’s expertise did allow me to ask worthwhile questions. I certainly felt that it helped to garner more meaningful responses. Moreover, I did not feel as though participants were at all jarred by the change in course. Indeed, from the beginning I had described my research to participants as a study of individuals’ with CP social and psychological experiences and did not even bring up the term “stigma” until the end of the first interview.
Second, the diary portion of the study brought its own challenges to the project. Related to the need to broaden the focus of the project beyond stigma, participants did not describe their experiences of devaluation as clearly or in as much detail as I had originally believed that they would. This made the diary activity especially challenging and somewhat unclear for many participants. Actually, I made the decision to expand the focus of the entire study after the first several participants expressed confusion over what to write about. I initially asked participants to focus on awkward interactions with others in the course of their everyday lives, but many said that they could not think of any. Thus, after encountering this with four or five participants, I expanded the assignment by asking them to write about anything that came to mind related to how they thought or felt about their CP. Although some only wrote a sentence or two a week, others actually provided very rich information, much of which was not touched upon in the initial interview; this also provided the impetus for several questions in the second interview. Further, I believe that the diary allowed some participants to share information with me that they might not have felt comfortable sharing face to face and/or that was difficult to convey verbally because of speech impairment issues.

Third, the sample I used was not representative of the population under investigation. I have already explained some of my concerns about the sample in the discussion section, namely that it was very homogeneous in terms of education level and socioeconomic status. Although the nature of the study and its exploratory methods called for participants who would be able to think deeply and communicate effectively about their experiences, it is difficult to transfer results to the larger population of individuals with CP. Additionally, the sample consisted primarily of individuals who were either associated with disability advocacy or of those who had sought out a CP related support group. These individuals are perhaps from distinct ends of a spectrum in
terms of how they think and feel about having CP. Although I tried to recruit participants from a variety of locations, and was somewhat successful in doing so, most were from one of these two groups. Nonetheless, as an exploratory research endeavor, this project has provided important initial insights into the social and psychological experiences of adults with CP.

Fourth, my own experience with CP affected my interactions with participants and undoubtedly affected my interpretations of the data, despite my efforts to approach the data openly and with minimal bias. While I do not consider this to constitute a limitation, and indeed believe that my own experience with CP contributed to the strength of the data analysis, it is nonetheless important to consider the effects of my research position. I feel that our shared experience frequently helped me to establish a strong rapport with participants, but I occasionally worried that they were not always fully honest with me with how they felt about their experience. Perhaps this was because they believed that I intuitively understood their experience, because they did not want to appear weak or vulnerable, or, particularly in the case of older participants, because they somehow wanted to protect me. Also, because I was a researcher (disabled or not), perhaps they viewed me as a messenger of their stories to the public, and thus wanted to project an image of themselves (and people with CP in general) as strong and capable individuals who are not readily fazed by others’ negative assumptions.

Relatedly, perhaps participants had become so adept at controlling their feelings about devaluation and working to appear strong that they simply could not express how they really felt. I was particularly concerned with Megan’s degree of honesty; she told me several elaborate stories of what amounted to be significant discrimination. However, when I probed for more details about how these experiences made her feel, she had very little to say beyond “It’s difficult, but it’s life.” In considering why some participants were so reluctant to share more
details about how they felt about these experiences, it is possible that they were simply not used
to sharing their feelings about CP; on the contrary, they may have become quite skilled at
concealing them. Megan was one of the participants who spoke about how hard her parents had
pushed her in life to be as “normal” as she possibly could. She also talked about how her
therapist had suggested that she was blaming her anxieties on her CP. It may not be surprising,
therefore, that she was reluctant to, or simply could not, express herself more than she did.
Similarly, Kate also had relatively little to say about experiences that I interpreted to be very
devaluing, such as when the stranger in the restaurant handed her a fork to eat her sandwich;
however, she did comment that both her mother and her therapist encouraged her to put the
incident behind her. Thus, perhaps Kate, like Megan, has become so adept at trying to ignore her
feelings that she had trouble expressing herself to me.

2. **Implications**

While it is difficult to draw definite and widely applicable conclusions from this
investigation, it does have important implications for adults with CP, for family members,
psychologists, service providers and clinicians, and also for Disability Studies scholars. First, the
complexity of participants’ lived experience points to the need for more rigorous and
comprehensive investigations into the social and psychological experiences of adults with CP.
An extensive literature search yielded hundreds of articles on various medical, educational,
therapeutic, and social interventions for children with CP, but very little information about adults
with CP. Internet groups like the CP Network and the CP Group allow users to exchange
information with one another, but participants express frustration with the lack of information or
support services from providers, such as doctors, therapists, counselors, etc. Moreover, both the
literature and participants’ narratives indicate that service providers frequently adopt a purely
medical model perspective and fail to understand the social and attitudinal barriers with which individuals with CP must contend on a daily basis.

These findings can be beneficial to adults with CP themselves as they demonstrate that social devaluation is a very real phenomenon that can have harmful psychological effects. Hopefully these findings can help others with CP who seek validation of their feelings of devaluation. Contrary to messages they may have received from family members and therapists, to openly discuss feelings of devaluation is not to lack personal strength or to blame CP for other psychological problems. Rather, it is to acknowledge the very real, and often very difficult, consequences of living in a disabling society. Discussing these issues may not only improve psychological health, but may also help individuals to develop a disability identity and a desire to integrate into the disability community.

Psychotherapists, in particular, need to attend to the social oppression which their disabled clients encounter, and to work with clients to negotiate this oppression. Reeve (2000) recommends that therapists be required to undergo Disability Equality Training “to raise awareness of how their own attitudes can disable people” (p. 673). For therapists to recognize, and help their clients recognize, disability as a marginalized status could help to alleviate some of the social pressures and self-blame that disabled individuals frequently encounter. Reeve also argues that “disability counseling can offer a way of facilitating [the development of disability identity] and as a result empower the disabled client by opening up the possibility of changing one’s world” (p. 674)

These findings also have important implications for other service providers and for family members, particularly parents, of individuals with CP. The normalizing pressure that some parents seem to place on their children to successfully integrate into the mainstream and to
ignore negative feelings of devaluation is emblematic of the medical model approach to disability. Therapists, doctors, and educators are highly complicit in this normalizing pressure and help to indoctrinate family members from the time that disabled children are very young (Olkin, 2003). First families, and then disabled individuals themselves are made to feel like disability is a tragic fate that they must overcome through strength and perseverance. This study points to the need to educate doctors and other service providers in alternative approaches to understanding disability, which they can then transmit to family members and ultimately to disabled individuals themselves. This is not to suggest that individuals with CP should not receive therapy or other medical treatment in order to improve their function as much as possible. However, even providers need to acknowledge that the experience of disability is about much more than impairment, and that an important way of providing support is also to help individuals negotiate the effects of living in a disabling society.

This study also points to the more general importance of connecting individuals and family members to the organized disability community, and service providers can help to strengthen these connections. For several participants in this study, developing supportive peer relationships and coming to understand disability as a form of social oppression has been crucial in buffering them from depression. Although exposure to the community sometimes heightened participants’ awareness of their own social devaluation, it also instilled a sense of belonging and a commitment to combat oppression. A couple of participants who did not join the disability community until later in life commented that they wished they had become involved sooner, and one participant praised her mother for encouraging her get involved as a teenager. Connecting families with children with CP to the disability community may help to alleviate the pressure of normalcy that was so apparent in some participants’ narratives.
Finally, this project suggests the need to strengthen ties between disability studies and psychology so that we may better understand the everyday lived social and psychological experiences not only of individuals with CP but of people with disabilities in general. Scholarship by Carol Thomas (1999), Dan Goodley and Rebecca Lawthom (2006), Carol Gill (1997, 2001) and Donna Reeve (2008), to name just a few, has helped to bridge the space between disability studies and psychology in order to develop more realistic and nuanced understandings of the disability experience that move beyond individual pathology and take into account larger structures that create and sustain disability as a marginalized status. These scholars have similarly called for a greater focus on how these structures directly impact the behaviors and emotional well being of disabled individuals; however, we need to continue and even strengthen this commitment, as it can have significant consequences for improving the lives of people with disabilities.

3. **Future Directions**

As this was an initial exploratory investigation, it raised more questions than answers and there are many exciting potential directions for future inquiry. As indicated above, while I tried to recruit as diverse a range of individuals as possible, given a limited timeline and the fact that this was a study for a graduate school dissertation, the ultimate sample was relatively homogenous, particularly in terms of racial composition, sexual identity, perceived socioeconomic status, and education level. Future research could focus on obtaining a sample that is more representative of the population of adults with CP as a whole in order to better determine how and to what extent these individuals experience stigma. Also, as this study ultimately became a more general inquiry into the social and psychological experiences of adults
with CP, it was very broadly focused. A number of more specific questions could be derived from the overall findings that emerged.

First, future studies could more thoroughly investigate how family life influences the experiences of individuals with CP. Clearly, parents are very influential in the development and even in the adult lives of participants, and most participants indicate that their families are highly supportive. However, families also seem to exert pressure on their children to control their bodies as well as their thoughts and feelings in order to successfully integrate into the mainstream. This pressure, in turn, seems to affect how participants viewed themselves and their experiences, even as adults. A future study could specifically examine how these dynamics operate by speaking to multiple family members about their experiences with and understandings of disability.

Second, there is a need to focus upon the experience of depression in adults with CP, including the factors that contribute to and help to alleviate depressive symptoms. Many of the participants in the present study appear to have first experienced depression at similar points in their lives – in their early twenties, when making the transition to independence. Future research could explore the relationship between transitioning to independence, pressure to adhere to mainstream roles and values, and depression.

Third, it is important to thoroughly and systematically examine the relationship between involvement in the disability community and overall social and psychological well-being, not only for individuals with CP but for other impairment groups as well. This study suggests that involvement in the disability community helps to buffer participants against depression even as it makes them more aware of their marginalized status. Future research should explore the specific factors that might contribute to improved well-being: for example, is it simply having an
alternate reference group after feeling isolated so long, the value of acceptance that the community espouses, and/or the struggle for social justice. Of course, these factors are deeply intertwined and difficult to tease out, but doing so will help to build a more sustainable community that can better support each of its members.

Finally, this study demonstrates the possibility and points to the importance within disability studies of focusing on impairment-specific experience. Recently, more scholars in disability studies have begun to acknowledge the importance of examining the experiences of particular impairment groups; however they have focused primarily upon individuals with intellectual impairments/autism. Nonetheless, even under the umbrella of physical and motor impairments, there is an array of impairment manifestations that can affect how individuals think and feel about their disability experience, and that can also influence everyday interactions and relationships with others. Individuals with CP have been cited as one of the least socially accepted impairment groups (Yuker, 1988), and in this study I wanted to see how this translated into people’s actual lived experiences.

Although individuals did not specifically discuss stigma as much as I believed that they might, it is evident from many of their narratives that certain aspects of impairment contribute to strained social interactions, isolation, and even depression. Additionally, heightened experiences of marginality from the mainstream also lead some participants to the disability community where they have found acceptance and camaraderie. This investigation demonstrates the importance of developing theory grounded in the concrete, everyday experiences of people with disabilities. Future disability studies research should acknowledge that impairment can affect multiple aspects of disabled people’s lived experience, and that conducting impairment specific
research does not pose a threat to disability community or to the pursuit of disability justice. On the contrary, it builds community by acknowledging and celebrating diversity.

Not only does this study demonstrate that specific manifestations of impairment affect experiences, but also that impairment can affect the experiences of non-disabled interaction partners. Alex suggests that non-disabled people fear individuals with CP more than they do individuals from other impairment groups, and Drew believes that people with CP are treated like “the lowest life form on earth.” It is likely that non-disabled individuals have such negative attitudes towards people with CP because CP, even more than other impairments, challenges mainstream perceptions that we all have control over our bodies. Unlike other impairments such as blindness, deafness, or paraplegia, CP frequently affects numerous regions of the body, so different aspects of individuals’ with CP impairment experiences are more difficult for others to ignore. On the contrary, they may force non-disabled individuals to confront their fears of not having bodily control. Thus, more closely examining the social experiences of individuals with CP in particular can likely provide greater insight into non-disabled people’s beliefs about disability in general as well as how they regard specific impairments.
IX. CONCLUSION

This study was a descriptive, phenomenological investigation into the everyday social and psychological experiences of individuals with cerebral palsy. It sought to answer two main questions: (a) “How do adults with cerebral palsy experience their disabilities on a social and psychological level?” and (b) “How, and to what extent, are they able to effectively integrate these experiences in order to formulate lives that they characterize, through their narratives, as rich and meaningful?” Participants have worked in a variety of ways to achieve social acceptance and inclusion; their narratives are often highlighted by a struggle to establish control, not only over their bodies but also over their broader lived experience and the manner in which they are perceived by others. Nonetheless, most have also managed to find meaning in their lives and have developed various support systems where they feel accepted and valued for who they are. In particular, immersion into the disability community, while sometimes heightening awareness of their devaluation, helped to bolster participants’ confidence and sense of self. This investigation, though broad and exploratory, will hopefully contribute to our knowledge regarding the lived experiences of adults with cerebral palsy while also helping to further bridge the gap between disability studies and social psychology.
CITED LITERATURE


Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don’t see myself as disabled. *Disability & Society*, 17, 509-527.


APPENDICES

APPENDIX A - INTERVIEW I GUIDE

I’m interested in knowing about what it’s like for you when you interact with strangers or people who you don’t know very well during the course of your everyday life in your community. I am interested in knowing what it’s like for you to interact with others in very routine and even mundane situations like grocery shopping or riding a bus.

- Can you tell me about how people generally respond to you and to your disability? I’m interested in knowing about both the good and bad experiences you have had when interacting with others.
  - PROBE: Can you talk about some situations where people act strangely, or dumbly, or treat you differently because you have a disability?

- During the course of your everyday life, can you tell me about certain types of situations in which you are treated differently because you have CP?
  - What are these situations like for you?
  - Who are the people generally involved; how do they respond/behave towards you?
  - How does their behavior make you feel?
  - How do you respond to their behavior?

Now, please think about a specific time when you felt that you were being treated differently because of your CP? It can be a recent experience or something that happened a long time ago.

- Can you tell me the story of that encounter and how you felt about it?
  - What happened?
  - Where and when did the experience occur?
  - Who was involved?
  - How did the experience make you feel?
  - How did you respond to being treated differently?

Next, please think about whether there have been specific times where you have felt devalued because of your CP, or as though you were being viewed or treated as less of a person because of your disability?

- What helps you to make sense of these situations?
- How do you explain them to yourself?
- How do these situations affect the way you see and feel about yourself as a person?
- What helps you to move on and to get past them?
- Are there particular people in your life with whom you share these situation
APPENDIX A (continued)

- Do you feel like these individuals understand how you feel and that you receive support from them?
- What kinds of things do they say or do to support you?

How do you believe that people with disabilities are treated in general, and do you believe that people with CP are treated differently than people with other disabilities are treated? How and why do you think that this is the case?

In my research, I am specifically questioning if and how people with CP experience stigma. I am defining stigma as the personal experience of feeling different and socially devalued based upon a particular characteristic, in this case CP. I am wondering to what extent you have ever thought about aspects of your own life in terms of stigma, and to what extent you think that the concept of stigma is relevant to the overall experience of people with CP?

Finally, I would like for my research to help support people with CP in terms of their everyday social experience. Can you think of anything else I haven’t covered or anything else you would like to discuss in this regard?

THANK YOU!
APPENDIX B - INTERVIEW II GUIDE

1. How would you describe, on a social level, what it’s like to have CP?

2. How would you describe, on a psychological level, what it’s like to have CP?

3. Tell me more about how you think your family experiences have influenced your feelings about having CP?

4. Tell me more about how you think your experience in school and with other children has influenced your feelings about having CP?

5. Tell me more about how you think your experience with friends has influenced your feelings about having CP?

6. Tell me more about how you think your experience with work has influenced your feelings about having CP?

7. Tell me more about how your experience with romantic relationships has influenced your feelings about having CP?

8. What do you think that your life would be like if you did not have CP?

9. How would you describe yourself to somebody who didn’t know you very well?

10. What, if anything, do you think you have in common with people who have other disabilities instead of CP?

11. How do you think that your gender and/or your race affect your experience with CP?

12. If there was a cure for CP, would you take it? Why or why not?
QUESTION 1

a. Please imagine that you were asked by a child with CP and/or her parents to describe what it’s like to live with CP as an adult. What would you say? Why? What advice would you give? Why?

b. Please discuss in a paragraph or two how your thoughts and feelings about having CP have changed over the course of your lifetime?

   PROBE: For example, was there a specific event or period in your life that changed how you think and feel about having a disability, or have your thoughts and feelings simply evolved with time, or have they remained relatively stable?

c. Please address what factors contributed to this change? How do you believe that these factors played a role?

d. Do you ever think about what your life would be like if you had never had CP? If so, what do you think it would be like?

QUESTION 2

a. Reflecting upon your life as a whole, please describe in a paragraph or two who or what has contributed the most to how you think and feel about your CP? You may discuss multiple people or things in your answer.

   PROBE: What do you believe this person or thing has contributed to your understanding/view of your CP?

b. How do you think your thoughts and feelings about your CP would be different without these persons or things?
APPENDIX C (continued)

QUESTION 3

This study focuses on the social and psychological experiences of individuals with CP. However, during the interviews and in your diaries, many of you also commented on your physical experiences with CP (i.e., your experiences with your bodies).

a. Please discuss in a paragraph or two how you believe that your physical experiences with CP affects your social and psychological experiences?

   PROBE: For example, how might pain, paralysis, drooling, or incontinence and other physical experiences affect your social interactions or feelings about yourself?

b. Please discuss how you believe that these physical challenges have changed as you have gotten older?

c. Please discuss what steps you have taken to address these challenges. Have they been successful?

QUESTION 4

When I began this project, I wanted to focus on how individuals with CP experience stigma and social marginalization? But since I have gotten to know each of you and have been privileged with hearing your life stories, I’m beginning to think about the experience of having CP as one of resilience and finding and/or creating new meanings.

a. Please discuss in a paragraph or two how you agree or disagree with my assessment (and by all means, feel free to disagree).

b. How has having CP contributed to your resilience and ability to find meaning in life?
APPENDIX D - CONSENT FORM

CONSENT FORM
University of Illinois at Chicago
Consent for Participation in Research
“Social experiences of individuals with cerebral palsy”

What am I being asked?

You are being asked to be a participant in a research study about the social and psychological experiences among individuals with cerebral palsy conducted by Kelly M. Munger at the University of Illinois at Chicago. I (Kelly Munger) am conducting this research in partial fulfillment of required work toward a Doctoral degree under the direction of my academic advisor, Carol J. Gill, Ph.D. You have been asked to take part in the research because you have responded to my request for participants and may be eligible to participate. I ask that you read this form and ask me any questions you may have before agreeing to be in the research.

Your participation in this research is voluntary. There are no consequences should you elect not to participate. Should you agree to participate, you may withdraw from the research at any time, for any reason, with no consequences. Procedures to ensure confidentiality and anonymity are detailed below.

Summary

The primary goal of this research is to learn about social and psychological experiences among individuals with cerebral palsy and how they negotiate everyday social interactions. It will also explore the way in which these experiences and social interactions affect a person’s sense of self. The project involves participating in two one-on-one interviews and keeping a diary. In addition, you will also have the opportunity to interact with other participants through an online discussion board. There is no anticipated risk associated with this research except for the possibility that you may experience emotional discomfort from discussing personal information. You will receive monetary compensation in exchange for participation, even if you are unable or unwilling to complete the project. You may also benefit from the opportunity to discuss your life experiences with others, and to express your feelings and ideas. The information you share may also ultimately help other individuals with cerebral palsy, as well as doctors, therapists, and other

The purpose of this research is to study the experiences of people with cerebral palsy and to learn how these experiences affect these individuals’ social interactions and how they see themselves.
APPENDIX D (continued)

What procedures are involved?

As your part in this research, you will be asked to participate in two interviews lasting approximately two hours each, during which I will be asking you about your social and psychological experiences with cerebral palsy.

Additionally, for one month after the first interview, you will be asked to keep a diary in which you record and describe your experiences and social encounters in your everyday life. You may choose how you would like to convey this information to me (e.g., via telephone, via e-mail, via postal mail). During this period, I will be contacting you weekly to discuss this activity. These conversations may occur via email or telephone, depending upon your preference. They may be arranged at your convenience, and are not expected to last longer than one half hour per week.

You will also be invited to participate in an online discussion board with other individuals with cerebral palsy which will be conducted over the Internet. Each week for one month, I will post a question to the board, and you will be asked to type your responses to these questions so that other participants may read and react to them. You will be able to create a false name and will not be asked to reveal any other information that can be linked to your identity. Questions posted to the discussion board will be similar to the questions asked in the interviews.

What are the potential risks and discomforts?

There are few, if any, potential risks and discomforts in this study. It is possible that some participants who take part may feel uncomfortable about talking about their personal experiences and interactions with others. Your participation in this research is voluntary, and in all activities in the study you can decide what to discuss or what not to discuss. You may choose not to answer any question you do not want to answer, either in the individual interviews, or in the online discussion board, and still remain in the study. You may also choose to withdraw from the study at any time.

Are there benefits to taking part in the research?

There are no direct benefits to taking part in the research beyond the opportunity to discuss your life experiences and to express your feelings and ideas, both with the researcher and with other individuals who take part in the online discussion board.

What about privacy and confidentiality?

The only people who will know that you are a research subject are my school advisor, myself, and the individual transcribing the interviews from audiotape into a written format.
APPENDIX D (continued)

In the case that you send your diary via email, entries will also be kept in a locked filing cabinet, or, in the case that they are emailed, will be downloaded and kept in a password protected file (after which the original email will be deleted). During the online discussion board, you will be able to create a pseudonym and will not be asked by the researcher to reveal any information that can be linked to your identity.

For your part, you will be asked to keep confidential all information shared within the group from outside parties. However, while the researcher will stress to all participants the importance of protecting the information shared within the group, she personally cannot guarantee compliance.

The researcher will not, without your written permission, disclose to others any information about you, or provided by you during the research, except:

- if necessary to protect your rights or welfare (for example, when the UIC Institutional Review Board monitors the research or consent process); or

- if required by law.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. Any information that is collected in connection with the interview portion of this study that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

Tapes and printed response records will be kept in a locked area that is accessible only to the investigator and to her advisor. Tapes will be disposed of upon completion of the project. All response records from the diary study and discussion board will be removed from e-mail/the Internet upon completion of those activities.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

You will receive up to 100 dollars as compensation for your participation in this study. You will receive 25 dollars upon the conclusion of each of the individual interviews, and will be mailed 25 dollars upon the conclusion of the diary study and then an additional 25 dollars upon the conclusion of the discussion board.

Can I withdraw or be removed from the study?

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without negative consequences of any kind. You may also choose not to answer any questions you don’t want to answer and still remain in the study. The
researcher may withdraw you from this research if anything happens to prevent you from completing the interview. You will also be withdrawn in the case that you must leave an interview early, that you fail to perform the research activities, or that there is a recording equipment failure. You will receive payment for each interview that you begin, even if you are unwilling or unable to complete it. You will also be paid for any portion of the diary study that you complete. Should you choose to participate, you will also be paid for your participation in the virtual focus group, even if you are unwilling or unable to complete it.

Who should I contact if I have questions?
The researcher conducting this study is Kelly Munger. If you have questions now, please ask her at this time. If you have questions later, you may telephone the researcher at: 312 955 0440 or email her at: kmmunger@gmail.com

Or you may contact Carol J. Gill, Ph.D., academic advisor at the University of Illinois at Chicago by e-mailing her at cg16@uic.edu, calling (312) 355-0550, or writing to

Carol J. Gill, Ph.D.
University of Illinois at Chicago (MC 626)
1640 W. Roosevelt Road
Chicago, IL 60608
USA

What are my rights as a research subject?

If you have any questions about your rights as a research subject, you may call the University of Illinois Office for Protection of Research Subjects at 312-996-1711.

Remember: Your participation in this research is voluntary. This means that you can choose to participate or not to participate. If you decide to participate, you are free to withdraw at any time without consequences. You will be given a copy of this form for your information and to keep for your records.

Signature of Subject

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I have been given a copy of this form.
APPENDIX D (continued)

Signature

Date

Printed Name

Signature of Researcher

Date (must be same as subject’s)
APPENDIX E- IRB APPROVAL

Approval Notice
Initial Review (Response To Modifications)

December 17, 2008
Kelly Munger, BA, MS
Disability and Human Development
400 North McClurg Apt 2211
Chicago, IL 60611
Phone: (312) 955-0440 / Fax: (312) 996-0885

RE: Protocol # 2008-0898
“Exploring the Lived Experiences of Stigma among Individuals with Cerebral Palsy”

Dear Ms. Munger:

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited review process on December 8, 2008. You may now begin your research.

Please note the following information about your approved research protocol:

Protocol Approval Period: December 8, 2008 - December 7, 2009
Approved Subject Enrollment #: 10
Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.
Performance Sites: UIC
Sponsor: None
Research Protocol(s):
   a) Exploring the Lived Experiences of Stigma among Individuals with Cerebral Palsy
Recruitment Material(s):
   a) Flyer: Experiences of Individuals with cerebral palsy; Version 1; 10/02/2008
APPENDIX E (continued)

b) Listserv/Website Announcement: Experiences of individuals with cerebral palsy; Version 1; 10/02/2008

c) Recruitment Script: Experiences of Individuals with cerebral palsy; Version 1; 11/12/2008

Informed Consent(s):

a) Consent Form: Experiences of Individuals with cerebral palsy; Version 3; 11/26/2008

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category:
(7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

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<th>Submission Type</th>
<th>Review Process</th>
<th>Review Date</th>
<th>Review Action</th>
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<td>Initial Review</td>
<td>Expedited</td>
<td>10/11/2008</td>
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<td>Expedited</td>
<td>12/08/2008</td>
<td>Approved</td>
</tr>
</tbody>
</table>

Please remember to:

➔ Use your research protocol number (2008-0898) on any documents or correspondence with the IRB concerning your research protocol.

➔ Review and comply with all requirements on the enclosure, "UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.
APPENDIX E (continued)

Sincerely,

Marissa Benni-Weis, M.S.
IRB Coordinator, IRB # 2
Office for the Protection of Research

Enclosure(s):

1. UIC Investigator Responsibilities, Protection of Human Research Subjects
2. Informed Consent Document(s):
   a) Consent Form: Experiences of Individuals with cerebral palsy; Version 3; 11/26/2008
3. Recruiting Material(s):
   a) Flyer: Experiences of Individuals with cerebral palsy; Version 1; 10/02/2008
   b) Listserv/Website Announcement: Experiences of individuals with cerebral palsy; Version 1; 10/02/2008
   c) Recruitment Script: Experiences of Individuals with cerebral palsy; Version 1; 11/12/2008

cc: Tamar Heller, Disability and Human Development, M/C 626
    Carol J. Gill, Disability and Human Development, M/C6
CURRICULUM VITAE

KELLY MEREDITH MUNGER
512 NORTH MCCLURG COURT: UNIT 4604
CHICAGO, ILLINOIS 60611
312-527-2395
KMMUNGER@GMAIL.COM

EDUCATION

Ph.D. Candidate in Disability Studies, expected completion December, 2011
Interdisciplinary Doctoral Program in Disability Studies
University of Illinois at Chicago
Dissertation Advisor: Carol J. Gill, PhD

Master of Science in Disability and Human Development, July, 2004
Certificate in Disability Ethics
University of Illinois at Chicago

Bachelor of Arts, Psychology, May, 2000 (magna cum laude, Phi Beta Kappa)
Minor Concentration in Spanish
Randolph-Macon Woman’s College, Lynchburg, Virginia

PROFESSIONAL EXPERIENCE

Research Assistant, Chicago Center for Disability Research
Department of Disability and Human Development, University of Illinois-Chicago
August, 2004 – May, 2009

Graduate Assistant, Department Library
Department of Disability and Human Development, University of Illinois-Chicago
June, 2003 – May, 2004

September, 2000 – May, 2001

TEACHING EXPERIENCE

Instructor, Foundations of Disability and Human Development
Department of Disability and Human Development, University of Illinois-Chicago
August, 2008 – December, 2008

Instructor, Leadership and Excellence in Neurodevelopmental and Related Disabilities
Department of Disability and Human Development, University of Illinois-Chicago
August, 2008 – present

235
Instructor, Special Topics, Essentials of Clinical Medicine
Disability and Chronic Illness in the Medical Encounter, University of Illinois-Chicago March, 2007 – March, 2009

HONORS

Provost Award, University of Illinois at Chicago, 2008

Applied Health Sciences Graduate Student Award, University of Illinois at Chicago, 2004

Harry S. Truman Scholarship for Public Service, 1999

Trustee Scholar, Randolph-Macon Woman’s College, 1996

PUBLICATIONS


CONFERENCE PRESENTATIONS


Congress of Qualitative Inquiry, Urbana-Champaign, IL. May, 2010. *Casting off the mirrors: Phenomenological investigations of “others’” experiences with cerebral palsy.*

Multiple Perspectives on Access, Inclusion, and Disability Annual Conference. Columbus, OH. April, 2009. *Ethical touch: Disability, assistance, and personal space.*


Multiple Perspectives on Access, Inclusion, and Disability Annual Conference, Columbus, OH. April, 2008. *An excess of access: Philosophical and psychological implications of universal design.*


Society for Disability Studies, Seattle, WA. May, 2007. *The personal is political, but the political is also personal: Exploring the lived experience of stigma among individuals with cerebral palsy.*


Virginia Psychological Association, Fairfax, VA. April, 2000: *Effects of gender and other variables upon attitudes towards people with disabilities.*

**UNIVERSITY SERVICE ACTIVITIES**

Chair, Professional Development Committee, Disability Studies Student Council University of Illinois-Chicago 2010 – 2011

President, Disability Studies Student Council, University of Illinois-Chicago 2007 – 2008

President, Disabled Students’ Union, University of Illinois-Chicago 2002 – 2004

Member, Disability Resource Center Emergency Taskforce, University of Illinois-Chicago
2004

Member, Disability Studies Student Council, University of Illinois-Chicago
2004 – present

Member, Chancellor’s Committee for the Status of Persons with Disabilities,
University of Illinois-Chicago
2003 – 2005

COMMUNITY SERVICE ACTIVITIES

Founding Member, Chicago Disability Pride Parade, Chicago, Illinois
2003 – 2004

Member, Youth Advisory Board, Access Living, Chicago, Illinois
2003 – 2005

Classroom Assistant, Laurel Regional Programs, Lynchburg, Virginia
1997 – 2000

Classroom Assistant, Virginia Institute for Autism, Charlottesville, Virginia
1998 – 1999

Classroom Assistant, Cale Elementary School, Charlottesville, Virginia,
1995 – 1996

Classroom Assistant, Clark Elementary School, Charlottesville, Virginia,
1993 – 1994