What are the differences between individuals with disabilities who flourish and those who never really adjust after a trauma? How do those born with a disability differ from individuals who acquire one later in life? Fully updated and revised, this second edition of a unique rehabilitation counseling text reflects growing disparities among “haves” and “have-nots” as they bear on the psychosocial aspects of disability. New content focuses on returning veterans afflicted with physical and mental health problems, persons with disabilities living in poverty, and the need for increased family and community-based engagement. The book provides updated information about assisted suicide, genetic testing, new legislation, and much more.

Using a minority model perspective, the text provides students and practitioners of rehabilitation and mental health counseling with vivid insight into the experience of living with a disability. It features first-person narratives from people living with a variety of disabling conditions, which are integrated with sociological and societal perspectives toward disability, and strategies for counseling such individuals. The text encompasses a historical perspective, psychological and sociological research, cultural variants regarding disability, myths and misconceptions, the attitudes of special interest and occupational groups, the use of positive psychology, and adjustments to disability by the individual and family. A wealth of counseling guidelines and useful strategies is geared to individuals with specific disabilities. Designed for a 15-week semester, the book also includes thought-provoking discussion questions and exercises.

New to the Second Edition:
• Reflects the growing disparities between “haves” and “have-nots” as they impact people with disabilities
• Includes new content on veterans with physical and mental disabilities
• Describes the experience of impoverished individuals with disabilities
• Examines the need for increased family and community-based engagement
• Discusses strengths and weaknesses of the Americans With Disabilities Act
• Covers assisted suicide, genetic testing, and recent legislation
• Includes expanded coverage of sexual identity
• Provides an Instructor’s Manual and PowerPoints as supplemental downloads

Key Features:
• Provides 16 personal narratives demonstrating the “normalcy” of individuals with different types of disabling conditions
• Includes stories of people living with blindness, hearing impairments, spinal cord injuries, muscular dystrophy, mental illness, and other disabilities
• Delivers counseling strategies geared toward specific disabilities, with “do’s” and “don’ts”
• Discusses ongoing treatment issues and ethical dilemmas for rehabilitation counselors
PSYCHOSOCIAL ASPECTS of Disability
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I would like to thank my family who continue to think I can fly long after I could no longer walk. To my students past, present, and future, and that metaphorical ONE student who started my heart and keeps my passion burning and continues to give me a purpose to get out of bed in the morning. To the insiders and newly found friends who normalized their lived experience with a disability and exemplify that we are like everyone else. And to my wife Darlene, who is always behind the curtain, but the one for whom I continue to have great gratitude and love, seeing the potential to thrive in me that I thought I had lost.

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What a marvelous and amazing textbook! Drs. Marini, Graf, and Millington have done a remarkable job in the design of this highly unique book, which comprehensively and very thoughtfully addresses the psychosocial aspects of the disability experience. These highly respected scholars have produced a major work that will be a central text in rehabilitation education for years to come and be particularly helpful and instructive for students learning about the impact of disability on individuals and families. In this second edition, the authors have taken great care to update and add content to this exceptional text.

This book has many innovative features that I believe are noteworthy. Probably the most unique aspect of the book is that every chapter is followed by a personal story and perspective of an individual with a disability that relates to the chapter content. These pointed and well-written personal stories, from an “insider perspective,” will greatly assist students in hearing and understanding the material at a different level and applying it to real people, rather than simply reading text content. The book is also distinguished from others through the sociological perspective taken in the historical account of how people with disabilities have been treated and perceived over time. Typically this content is found in other foundational texts and it is very helpful to have this type of review in this book, as it sets the stage and establishes the context for the content that follows.

In relation to the substantive content of the book, the authors have done a very thorough job of exploring societal attitudes, cultural perspectives, sexuality, and in reviewing the seven most commonly discussed theories of adjustment, adaptation, and coping with disability and applying these conceptual frameworks to both congenital and adventitious disability experiences.

The book also provides information on how other professional disciplines perceive and are trained to view disability, in order to provide students with a better understanding of the total rehabilitation process and interdisciplinary approaches. The authors also uniquely discuss the medical and psychosocial aspects of caregiving in this country and highlight some of the most difficult decisions individuals and families may have to make in this process. A review of positive psychology is also included, where questions about why some people with disabilities thrive and adapt after injury or chronic illness, while others do not, and is explored in some depth. In another unique and innovative aspect of this book, the authors provide a discussion of counseling strategies and interventions directed at assisting individuals with disabilities and their families to cope and adapt, including a discussion of the ethical issues and responsibilities for counselors in this critical process.

In this second edition, each of the chapters was updated and some significant new material was added for the reader. For example, in the area of social justice, oppression and disability, new material was added to provide a more comprehensive review and discussion of the complex issues associated with the social and economic inequities people with disabilities face each day. In another chapter on positive psychology, more
emphasis was provided to deal with posttraumatic issues and the increase in depression and anxiety in our society related to the state of the economy and poverty. The psychosocial experience of injured workers has also been substantially updated and expanded, as well as the chapter addressing attitudes of special interest groups, the ethics of using online counseling approaches, and the need to design and develop appropriate disaster response plans for people with disabilities who are confronted with natural disasters in our environment. Finally, in the chapter on family adaptation and culture, the authors added a section on visitors from other countries that explores cultural differences that need to be understood in relation to the impact on disability and the disability experience itself.

I believe this text has clearly addressed some of the limitations found in other books that cover similar content, and with this second edition even improved the value of the original text. I wholeheartedly endorse this exceptional work by these scholars and hope that students preparing for helping roles in the area of disability and rehabilitation, including rehabilitation counselors and other related disciplines, have the opportunity to use this book in their advanced studies.

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Like many people without disabilities, I went through the first 23 years of my life with somewhat ambivalent feelings about those with disabilities. Basically, I did not have an opinion of them as a whole because I had never really been exposed to anyone with a disability and was too self-absorbed. What little knowledge (or lack of it) that I did possess, I realize now, was stereotypical, prejudicial, and fraught with misconceptions. When I did see someone with a disability, I often felt compelled to offer help or money. As an able-bodied person, I felt good about periodically doing things like giving money to Jerry's Kids in the Labor Day Muscular Dystrophy Telethon, opening doors for people in wheelchairs, and pretending not to be anxious in "their" presence. Yes, I thought I was pitching in and doing my part for this group of disenfranchised people, all the while unknowingly disempowering them. Then one day, without warning, I became "one of those people."

At age 23, during the second period of a Lakehead University varsity hockey game in which I was playing in Thunder Bay, Ontario, Canada, I was tripped up into the end boards, slamming headfirst with no real time to react. In an instant, I catapulted away from the boards and lay on my back with my helmet cutting into my nose. My neck was immediately broken and I lay there paralyzed from the chest down, somehow knowing it right at that moment, yet somehow fully believing that I would be all right in a few weeks. The other team's physician was heard to have later said he thought I would not make it through the night. With the excruciating pain I felt running through my neck and the immense fear that was beginning to overwhelm me, I was not really sure I wanted to live. My subsequent 11 months of hospitalization and rehabilitation that followed were initially riddled with setbacks. Three weeks after the accident, I was transferred to Toronto for surgery and rehabilitation. My girlfriend Darlene (now my wife) quit her job to be with me. My sister Darlene also came for 3 weeks, but had to return home with no news of improvement. After a neck fusion to replace my shattered vertebrae, my lung collapsed a few days following surgery, putting me into respiratory arrest. After being revived, I was placed on a respirator for a month. During that time, I lay in bed with a halo vest (circular plate screwed into my forehead and attached with bars to a hard plastic vest, which wears like hockey shoulder pads), most times too fatigued to try to breathe on my own. Two friends bussed the thousand miles to see me and one remained to coach and pester me off the respirator. One of the first lessons I learned as someone with a disability was that the love and support of friends, family, and significant others are immeasurable.

Nevertheless, I continued with complications of pneumonia and bladder infections. I was in intensive care for more than 2 months and, once moved to a regular room, finally had the opportunity to sit up in a wheelchair for the first time. Having looked at nothing but the ceiling for so long and wearing a halo vest that did not allow me to gaze downward, I wanted to see my image in the mirror. As I was wheeled in front of it, I gazed in disbelief and then began sobbing uncontrollably. I was devastated at how much weight I had lost. Having been a bodybuilder since the age of 12 and an athlete playing all sports
practically since I left my mother’s womb, I could not believe that I had lost 45 pounds of muscle mass on my arms, chest, and legs. More than a decade of hard work was gone in a couple of short months. I grieved the loss of who I once was, feared the thought of what was to be, and wanted to die. At the same time, there was still some part of me that denied the severity of my injury and still believed I would walk again.

Darlene’s stability, dedication, and faith in me kept me going, as did the daily calls and periodic visits from family and friends 1,000 miles away. When I finally was released to Lyndhurst Rehabilitation Hospital in Toronto after 4 months of bedrest, I began to relearn daily living activities we typically master by the age of 4, such as eating, brushing, and dressing. Daily muscle-strengthening exercises as well as occupational therapy helped to alleviate some of my dysthymia; however, things were not happening quickly enough. The local and national media took great interest in sensationalizing my and Darlene’s dedicated love story about a hockey player who would have committed suicide had it not been for the love of his former-model girlfriend. But none of the notoriety mattered. I was still in a wheelchair.

After almost 11 months of institutionalization, I had gained back about as much mobility as I ever physically would. I had an incomplete C5–C6 tetraplegia, essentially paralyzed from my chest down, having shoulder, bicep, and wrist extension functioning still remaining. In my last media interview, which I gave shortly before returning to Thunder Bay with Darlene in December, the last question I was asked was if there was anything else I wanted to say about my ordeal that no one else had yet queried me. I thought about it for a long moment, then slowly responded by saying that despite all the hard work and recovery I had made over the past 11 months, I would not be “walking” out of the hospital. I otherwise felt healthy, but I was paralyzed for life. In my mind, it seemed like I had failed. I knew that things would never be the same. In the rehabilitation hospital, I was with many people my age who were also now in wheelchairs. It was a sanctuary from the outside world because we were all in the same situation; nobody stared at you, nobody judged you, and nobody discriminated against you. I also realized that I was afraid to go home. I was afraid of what people would think, and how they would react to me in a wheelchair. Although I was still the same person I was before, I realized that many people would not see it that way. I was plagued with other worries as well. Would I be able to have sex and father a child? Would I be able to work or was I to collect disability for the rest of my life and be accountable to quarterly social worker visits? How would others relate to me? How often would I be sick and rehospitalized? Would I have to live in a nursing home? Who would take care of me? How could I replace my interest and love of playing sports? What was I going to do now that I was no longer physically able to do anything? I was terrified at what lay ahead and pictured that life as I knew it was over. There was not going to be a happy ending to my story.

What I have learned in the past 35 years as a former athlete turned wheelchair-user and now scholar in the field of rehabilitation counseling psychology for the past 26 years composes this second edition. Many of my earlier concerns have been, and continue to be, answered. Now, however, as a researcher and professor, I have other questions about the psychosocial aspects of disability. What are the dynamic differences between those people with disabilities who appear to do well or succeed versus those who never really adjust following a trauma? What are the differences between people born with a disability versus those who acquire one later in life? Why are some
people with disabilities plagued by secondary complications, whereas others with similar disabilities are not? What are the cultural differences regarding disability, and how do families respond to a loved one with a disability? How do the attitudes of others without disabilities impact how we perceive ourselves? What are the psychological and mental health implications of social and economic inequities, oppression, and poverty on people with disabilities? These and other related topics are explored in this edition.

What sets this psychosocial text about disability apart from the numerous others we have read is that this is the first to truly allow counselors and other related health professionals to *walk a mile in our shoes* and to learn from the writings of 16 people with disabilities across North America. As such, parts of the book are devoted to the compiled short stories of people with various disabilities regarding their experiences as to what life is like living with each of their conditions. These enriched stories from people who are deaf or blind, or have albinism, mental illness, tetraplegia, paraplegia, poliomyelitis, head injury, spinal muscular dystrophy, multiple sclerosis, and other disabilities are shared along with counseling guidelines for working with people with similar disabilities. What readers will quickly realize is that these are people first and foremost who have lives, and whose disability happens to be but one of many traits or qualities possessed by them and not the salient feature defining them. The remainder of this book deals with a number of issues and strategies for counseling people with disabilities. Having taught, researched, and read extensively on this topic for more than two decades, I think this text covers what my colleagues—Noreen Graf and Michael Millington—and I believe are the pertinent and current topics in the field.

Part I explores disability from a sociological perspective or those factors external to the person. Topics here include: Chapter 1—the history of how people with disabilities have been viewed and treated in society throughout the centuries to the current day and into the foreseeable future; Chapter 2—attitude formation, societal attitudes, and myths about disabilities and improving our social consciousness; Chapter 3—culturally different issues and attitudes toward disability; and Chapter 4—attitudes toward disability by specific special interest and occupational groups.

Part II focuses on the psychology of disability surrounding the individual and his or her family. Specific chapters address: Chapter 5—theories of adjustment to disability by the individual; Chapter 6—family adaptation across cultures toward a loved one who is disabled; Chapter 7—sexuality issues and disability; and Chapter 8—the psychosocial world of the injured worker.

Part III addresses a mixture of pertinent topics concerning psychosocial issues of disability. These chapters include: Chapter 9—quality of life across the life span for persons with disabilities; Chapter 10—implications of social support and caregiving of loved ones with a disability; and Chapter 11—thriving versus succumbing to disability: psychosocial factors and positive psychology.

Part IV addresses counseling strategies and insights for working with persons with disabilities. Chapter 12—which counseling theories and techniques work best with different disability populations and why; Chapter 13—social justice, oppression, and disability: counseling those most in need; Chapter 14—counseling families in the community; Chapter 15—ethical responsibilities in working with persons with disabilities and our duty to educate; and Chapter 16—basic dos and don’ts in counseling persons with disabilities.
As noted earlier, interwoven at the end of each chapter are “Insider Perspective” short stories from people with various types of disabilities across North America. Contributors were solicited through advertisements and word of mouth, requesting that they focus their experiences to address the following six areas:

1. Basic demographic information about themselves and their disability, how/when it happened, education, age, marital and living arrangement status, employment or history;

2. How they perceive they have been treated by society (in public places, hospitals, social occasions, etc.) overall as well as specific instances that may occur every now and then;

3. What ways they have used to adapt or respond to their disability, which could include aspects of one’s personality, family support, and finances;

4. If and when they felt as though their situation (which may/may not have had anything to do with their disability) became difficult to deal with at times, and if so, what generally triggered these feelings;

5. What they believe to be the greatest assets and the greatest barriers in their lives; and

6. What key message/advice they would want to convey to soon-to-be counselors or health professionals regarding working with people with disabilities.

Viewing the world from their eyes and in their own words is perhaps the most profound aspect of this or any other psychosocial textbook to date. Readers will be struck by the fact that these are ordinary people generally leading otherwise “normal” lives with bumps in the road along the way. Some stories are longer than others, as each accounts for different life experiences and focuses on different dynamics occurring in their lives. Although we have included only 16 of the more intimate of these personal accounts, there were more than 40 submissions in the original call for stories. This book is dedicated to getting their word out to anyone interested in this topic.

Finally, disability is discussed as a social construct throughout this text, which addresses disability from a minority model perspective. The perceived shortcomings of people with disabilities to adequately function in society are viewed more as a failure of our society to fully accept and integrate them. Historically, people with disabilities have been marginalized and dehumanized, and thus not considered equally worthy of the status afforded to its non-disabled majority members. As with other minority groups, these sentiments take time to change people’s perceptions. Where ignorance or misinformation has guided people’s thinking, education and contact with people with disabilities have generally produced a positive attitudal change. However, where blatant discrimination, prejudice, and ethnocentricity exist, attitudal change then becomes questionable. This book is dedicated to those students, practitioners, academics, and interested others who may be uneducated or misinformed.

Irmo Marini, PhD, CRC, CLCP

As an aid in using this book as a course text, a PowerPoint deck and Instructor’s Manual are available for download. To access these materials, send an e-mail to textbook@springerpub.com.
Projects of this magnitude are never done without a great deal of assistance. As such, I would like to thank a former PhD student Dr. Amber Feist and current PhD research assistant Chia Vang for scouring through over 1,100 topics of all the available literature regarding the psychosocial aspects of disability past and current for my chapters alone. A special thank you goes to my wife Darlene Marini who inputted over half of the references, a tedious selfless effort. To Sheri Sussman who has been there for six of my seven books, thank you. To all the staff who copyedited and oversaw the project, including Ashita Shah, Pamela Lankas, Roxanne Klaas, Michael O’Connor, Joanne Jay, and Chris for their flawless eyes on catching all the errors.

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Share

Psychosocial Aspects of Disability: Insider Perspectives and Strategies for Counselors, Second Edition
CHAPTER 5

Theories of Adjustment and Adaptation to Disability

Irmo Marini

OVERVIEW

This chapter explores perhaps the most profound and important empirical question researchers have regarding the psychological and sociological impact of the disability. How do people with disabilities react to their situations, and why do some actually excel, whereas others become indefinitely incapacitated both mentally and physically? To begin with, there is some debate regarding appropriate terminology. Some experts, such as Olkin (1999), do not agree with the term adjustment to disability. Olkin argues that the concept of adjusting is a pathological term presuming something is wrong and implies people with disabilities must successfully negotiate or transition through a series of stages to finally accept their situations (Olkin, 1999, p. 45). He is not a proponent of the stage model of disability, but rather believes that individuals “respond” to their disabilities throughout their lives, and that final adjustment or acceptance does not exist. Other experts, such as Livneh (1991), do support a stage-like model and believe people with later onset or adventitious disabilities often do transition through stages and do reach a level of final adjustment or acceptance; however, they may experience setbacks. Still, other experts, such as Vash and Crewe (2004), describe how some people with disabilities may actually “transcend” beyond their disabilities once they acknowledge or come to terms with their situations, accept the implications, and embrace the experience.

In this chapter, the terms adjustment, adaptation, reaction, and response are used interchangeably despite the fact they may be different concepts but have overlapping definitions. When used, they essentially refer to individuals with disabilities in their attempts to come to terms with their disabilities. The terms adjustment and adaptation also have a temporal or time component to them (Livneh & Antonak, 1997). In other words, one would typically need to be adapting before reaching the final adjustment. Livneh and Antonak describe psychosocial adaptation as:

An evolving, dynamic, general process through which the individual gradually approaches an optimal state of person-environment congruence manifested by; (1) active participation in social, vocational, and avocational pursuits;
(2) successful negotiation of the physical environment; and (3) awareness of remaining strengths and assets as well as existing functional limitations. (Livneh & Antonak, 1997, p. 8)

The concept of adjustment, however, is defined as:

A particular phase (e.g., set of experiences and reactions) of the psychosocial adaptation process. As such, adjustment is the clinically and phenomenologically hypothesized final phase—elusive as it may be—of the unfolding process of adaptation to crisis situations, including the onset of chronic illness and disability. It is alternatively expressed by terms such as (1) reaching and maintaining psychosocial equilibrium; (2) achieving a state of reintegration; (3) positively striving to reach life goals; (4) demonstrating positive self-esteem, self-concept, self-regard, and the like; and, (5) experiencing positive attitudes toward one’s self, others, and the disability. (Livneh & Antonak, 1997, p. 8)

In addition, as discussed in Chapter 2, each day we experience thoughts, emotions, and behaviors that may or may not be in congruence with each other (e.g., we can be emotionally upset about something, but behaviorally smile and pretend nothing is wrong). Each of the earlier concepts involves an emotional, cognitive, and behavioral response. When Olkin (1999) states that individuals respond to their disabilities, they feel and think something while they are responding. Likewise, when individuals accept their circumstances, this again involves certain cognitions, behaviors, and emotions that accompany successful adaptation. Therefore, people who are believed to have genuinely adapted to their disabilities should otherwise experience congruent feelings of contentment, thoughts of self-confidence with their disability identities, and some type of overt accompanying measurable behaviors, such as socializing more, assertiveness, being employed, volunteering, or attending school, and should have the desire and confidence to date if relevant.

Overall, seven common theories of adaptation to a traumatic physical disability are explored in addition to other adaptation concepts. Some proposed theories have stronger evidence-based empirical support, whereas others are more qualitative and case study accounts as well as clinical observations. This chapter first explores people born with a congenital disability, and questions whether such individuals experience any adjustment process as they have no preinjury, nondisabled experience with which to compare their situations. Olkin (1999) shares her life experience as an individual born with polio and prefers to describe her experience as “in response” to life circumstances she interfaces within her external environment. Yet, others born with a disability report different developmental experiences. As this phenomenon of adaptation to a congenital disability is less understood or written about in the literature, we lead off with this investigation. The remainder of the chapter explores the following seven theories of adjustment: stage models (Livneh, 1991), somatopsychology (Lewin, 1935; Trieschmann, 1988; Wright, 1983), the disability centrality model (Bishop, 2005), ecological models (Livneh & Antonak, 1997; Trieschmann, 1988; Vash & Crewe, 2004), recurrent or integrated model (Kendall & Buys, 1998), transactional
model of coping (Lazarus & Folkman, 1984b), and chaos theory (Parker, Schaller, & Hansmann, 2003).

RESPONSE TO DISABILITY FOR PEOPLE WITH CONGENITAL DISABILITIES

Although there is a multitude of conceptual and empirical literature regarding the adjustment or adaptation to an acquired disability, far less attention has been directed toward the psychosocial impact of a congenital disability, or those disabilities people have at birth (Bogart, 2014; Varni, Rubenfeld, Talbot, & Setoguchi, 1989). Some researchers anecdotally believe that because individuals born with a disability have no predisability background to compare with or loss of function to grieve, they do not have any apparent difficulties adjusting (Olkin, 1999). Bogart (2014) assessed 226 individuals with congenital versus acquired disabilities measuring life satisfaction, self-esteem, disability identity, disability self-efficacy, and relevant demographic factors. She found the empirical support that individuals born with a disability were more satisfied with life and reported a higher disability self-concept than those who acquired their disability. This congenital group also scored higher in disability identity and self-efficacy about life satisfaction. In other words, those born with a disability had positive affirmations about being identified as disabled, and this in turn protected their well-being. Bogart also found, however, that despite scoring higher in life satisfaction, disability identity, and self-concept, participants with congenital disabilities did not score high in self-esteem. Dunn and Burcaw (2013) suggest that affirming disability pride/identity is still a relatively new concept. Other researchers indicate the findings regarding congenital versus acquired disability adaptation are mixed. (Cadman, Boyle, Szatmari, & Offord, 1987; Olkin, 1999; Trask et al., 2003; Varni et al., 1989; Wallander, Varni, Babani, Banis, & Wilcox, 1988; Witt, Riley, & Cairo, 2003).

From a psychosocial development standpoint, we theoretically all pass through some critical life cycle stages of development (Erikson, Erikson, & Kivnick, 1986). Erikson et al. unfortunately did not account for when a disability occurs, and as a former student of psychodynamics would likely view the individual as experiencing some pathology at various stages. Statistically, data from the 1994 to 1995 National Health Interview Surveys, Disability Supplement population study (Witt et al., 2003) indicate that psychological maladjustment was 10% to 15% higher among children with CID as opposed to otherwise healthy children in the early 1970s (Pless, Roghmann, & Haggerty, 1972). As previously indicated, however, the level of severity of disability has little impact on the response (Wallander & Varni, 1998). In the 1994 to 1995 national health survey of biological mothers, the psychosocial status of 3,362 disabled and nondisabled children and adolescents aged 6 years to 17 years were assessed. Children with psychiatric disabilities were excluded. Poor maternal health or mental health, child-perceived family burden (scored by answering yes to one or more of three questions asking whether family disruptions in work status, sleep patterns, or financial problems occurred), and living in poverty were all positively associated with reported maladjustment of the children. Mothers of children with disabilities were more likely to be divorced, separated, or never married, as well as in poorer health and depressed, as opposed to mothers with a nondisabled
child. In addition, children with communication or learning limitations also were positively associated with poor adjustment. Conversely, Varni et al. (1989) found that family cohesion, organization, and moral-religious emphasis were all predictors of positive psychological and social adaptation in 42 children with congenital or acquired limb disabilities. Researchers also found that increased parental distress, such as wishful thinking and self-blame, were associated with increased distress among children and adolescents with cancer. It appears that environmental or external influences, such as emotionally stable family support and cohesion, are key factors that predict child adaptation.

Olkin (1999) notes that even among well-meaning or well-intended parents, children with disabilities can still run into adjustment problems. Specifically, Olkin discusses the “conspiracy of silence,” where well-meaning parents intentionally withhold information or ignore discussing important topics with their child regarding his or her prognosis, sexuality, and so on, because the parents perceive it upset their child. Similarly, some parents overprotect them by not allowing opportunities for their child to compete, or attempt new experiences for fear of him or her failing. This undermines the child’s ability to handle stress and be exposed to new experiences, ultimately hurting the child as he or she becomes an adult (Hogansen, Powers, Geenen, Gil-Kashiwabara, & Powers, 2008). By being sheltered, some children with disabilities are often less physically independent, having had everything done for them, and as a result may experience low self-esteem and greater social anxiety and immaturity (Holmbeck et al., 2002; Levy, 1966; Thomsagard, 1998). Seligman (1975) describes the concept “learned helplessness” to describe instances where individuals repeatedly have things done for them over time, essentially learning to be helpless and unable to perform tasks or activities they could otherwise be capable of performing had they been taught or empowered to learn.

In referring to the Erikson et al. (1986) theory of psychosocial development, some children with congenital disabilities might otherwise experience psychosocial difficulties with shame or self-doubt (Erikson’s autonomy versus shame) at an early age as a result of not being allowed, or physically able, to explore their environment (Kivnick, 1991). This can carry over during school-age years (Erikson’s industry versus inferiority stage), where children with severe disabilities are unable to master their environment and, at times, come under ridicule from fellow students (Connors & Stalker, 2007; Kivnick, 1991). Adolescents with disabilities can experience a particularly awkward and difficult time (Erikson’s identity versus identity confusion). Generally believed to be a time when they develop a sense of identity, Kivnick (1991) notes how adolescents’ general acceptance of their disabilities and mastery over their environment dictates the strength of their identities. If adolescents have been unable to master and/or explore their environment, they may theoretically succumb to societal expectations about disabilities. Other potentially problematic areas during the teenage years include body changes because of puberty, body image, peer relations, sexuality, and rejection (Davis, Anderson, Linkowski, Berger, & Feinstein, 1991; Gordon, Tschopp, & Feldman, 2004; Hofman, 1975; Rousso, 1996). Livneh and Antonak (2007) cite the importance of body image on self-esteem and note how persons with disabilities may be particularly vulnerable to poor body image perceptions. Not being viewed as “different” becomes critically important to the psychosocial well-being of adolescents; the alternative, rejection and ridicule, can be devastating to their self-esteem (Bramble, 1995; Connors & Stalker, 2007; Davis et al., 1991; Gordon et al., 2004; Howland & Rintala, 2001; Rousso, 1996).
Despite what appears to be a number of societal attitude barriers for people growing up with an acquired or congenital disability, overall reports of happiness, contentment, and life satisfaction are mixed, but generally positive (Albrecht & Devlieger, 1999; Allman, 1990; Bogart, 2014; Cohen & Napolitano, 2007; Connors & Stalker, 2007; Freedman, 1978; Lucas, 2007; Marinic & Brkljacic, 2008). Connors and Stalker (2007), for example, in interviewing 26 children aged 7 to 15 years, found that despite the children citing public reactions of sometimes being stared at, condescended, harassed, and being pitied, they otherwise reported seeing themselves in a positive way and similar to nondisabled children. As Thomasgard (1998) and others have found, however, parental perceptions and projections of their child’s psychosocial well-being are frequently viewed much more negatively than the child views his or her circumstances (Holmbeck et al., 2002; Trask et al., 2003), sometimes leading to parental guilt.

Marinic and Brkljacic (2008) surveyed 397 persons with varying types of disabilities compared with 913 nondisabled Croatians regarding levels of happiness and well-being. Of the group with disabilities, approximately 22% were either born with their disabilities or acquired them before the age of 7 years. The authors correlated happiness among both the groups with life satisfaction by measuring Happiness with the Fordyce scale (1988) and subjective well-being (SWB) using the Personal Wellbeing Index (Cummins, 2006), which measures satisfaction with life domains. Results indicated both groups showed positive happiness and satisfaction with the majority of life domains; however, happiness levels of persons with disabilities were lower than the control group in several areas. Less than 15% of people with disabilities rated themselves as “extremely happy” compared with 40% of the nondisabled control group, scoring only slightly lower in mean scores than their able-bodied counterparts. In contrast, Myers and Diener (1996) conducted a meta-analysis of 916 research projects from 45 countries with over one million participants, finding that people on average are moderately happy and scored a mean of 6.75/10 on the same scale. Participants in the Marinic and Brkljacic (2008) study also scored moderately satisfied regardless of disability. The disabled group, however, scored significantly different in the areas of happiness and physical safety and community acceptance. The authors opine that safety of the physical environment and positive or negative societal attitudes had an impact on their happiness, whereas this is not a consideration for people without disabilities.

Overall, people born with a disability are statistically at a greater risk for substance abuse problems, twice as likely to drop out of school, and more likely to be living in poverty than children without disabilities (Helwig & Holicky, 1994; Olkin, 1999). Research indicates that family and community support are critical in the positive psychosocial development of children and adolescents. When family cohesion, stability, and nurturing are dysfunctional, the likelihood increases for children to grow up with greater levels of adjustment problems. In addition, the person–environment interaction has time and again in numerous studies proved to be critical regarding individual self-concept and adaptation to disability. There is, however, what Freedman (1978) describes as the “disability paradox,” whereby people with disabilities who otherwise perceive themselves as having successfully coped with environmental and societal barriers, and believe they have emerged even stronger than others, report a very high quality of life and level of happiness (Weinberg, 1988).
THEORIES OF ADJUSTMENT AND ADAPTATION TO ACQUIRED DISABILITIES

A Brief History of Adjustment Theories

This section addresses seven various models of adjustment, adaptation, or reaction to an acquired disability that occurs some time later in life. Again, some models have stronger evidence-based empirical support, whereas others are supported by clinical observation or qualitative self-report methods. As this line of academic study has evolved, some of the earliest theories on adjustment to disability were postulated by Dembo, Leviton, and Wright (1956), and later expanded upon by Wright (1960, 1983). Successful versus unsuccessful adjustment was initially conceptualized within a “coping” versus “succeeding” framework. Essentially, Dembo et al. (1956) theorized that successful coping involved assisting clients to recognize what they functionally could do as opposed to dwelling on what they could no longer do, emphasize personal accomplishments, take direct control of one’s life, successfully negotiate physical and social access barriers, enjoy and expand on social activities, and appropriately deal with negative life experiences. Conversely, the poor adjustment was described as succumbing to one’s disability by dwelling on the past, focusing on one’s limitations rather than assets, and passively accepting the disabled role as defined by the society (e.g., helpless, pitied, incapable).

Wright (1983) refined her earlier theory by equating adjustment or acceptance to disability by emphasizing the values and beliefs individuals ascribe of their conditions. Wright distinguished between successfully reevaluating one’s disabling circumstances as opposed to devaluing or denigrating oneself with the onset of a physical disability. She proposed four reevaluation changes that must occur for successful adaptation. Specifically, (a) subordination of physique or placing less self-worth emphasis on one’s physical appearance, (b) containing or minimizing the “spread” effect of the disability to other nonaffected functions and activities, (c) enlarging one’s scope of values and interests consistent with one’s abilities, and (d) transformation from comparative to asset values. In other words, instead of comparing oneself to those without disabilities, focus more on the remaining abilities and qualities one can engage in rather than the functions one can no longer engage in. Wright’s thinking on adjustment to disability went through a transformation as well. In her 1983 classic, Physical Disability: A Psychosocial Approach, she affirms the significance of the social environment and interpersonal relationships on adjustment; whereas, in her 1960 book titled Physical Disability: A Psychological Approach, she focused mostly on the psychodynamics of adjustment and the individual. Although psychologists have been criticized for ignoring the impact of environmental barriers and negative societal attitudes on an individual’s adjustment, Wright and others began to acknowledge this relationship early on (Forshaw, 2007).

Stage Models

Livneh (1986, 1991) provides a succinct summary and synthesis of more than 40 explicit and implicit stage models of adjustment, described as a reaction to a sudden and unexpected permanent physically disabling condition. The variations of this model range in
theory from three to 10 stages, but most commonly four to six stages. Livneh cites several authors regarding some shared assumptions or rules of thumb applicable to these models. Several of the more pertinent assumptions are: (a) Adjustment is not a static, but rather a dynamic, ongoing process, despite the concept that adaptation is considered to be the outcome (Kahana, Fairchild, & Kahana, 1982); (b) the initial insult causes a psychological disequilibrium that typically destabilizes over time; (c) most individuals sequentially transition through time-limited stages by coming to terms psychologically with whatever trauma has occurred to them; (d) although most individuals experience most stages, others may not; (e) not everyone transitions through all stages sequentially; some individuals skip stages, some regress backwards to a previous stage, some can get stuck in a stage for long periods, whereas others may never reach the final adjustment stage (Gunther, 1969, 1971); (f) experiencing different stages separately and sequentially does not always occur, as some individuals may be observed to be in overlapping stages (Dunn, 1975) without any particular timeline, and often fluctuate based on individual circumstances and coping mechanisms; (g) observations at each stage can be correlated with certain cognitions, emotions, and behaviors; and (h) although stages are self-triggered, appropriate behavioral, psychosocial, and environmental interventions (counseling) can positively affect coping strategies to successfully transition toward adaptation (Livneh, 1991, pp. 113–114).

The five stages of adjustment to a sudden-onset physical disability postulated by Livneh (1991) are formulated as follows.

**Initial Impact**

This first stage involves the individual and the family reaction during the initial hours and days following a sudden and severe bodily trauma, such as a spinal cord injury, limb amputation, heart attack, or sudden onset of a life-threatening disease. Two substages are commonly identified: shock and anxiety. Shock is characterized as surreal with a described numbing-like effect (Gunther, 1971). Thought processes are disorganized, disoriented, and confused, and many individuals have difficulty concentrating and are unable to make simple decisions (Livneh & Antonak, 1997; Shands, 1955). Anxiety is described as overwhelming and can trigger a panic attack or hysteria-like behavior in extreme reaction cases. Some empirical support for these two reactions exists in the cross-sectional study by Livneh and Antonak (1991) with 214 rehabilitation facility inpatient and outpatient participants with various conditions, including spinal cord injury, cerebrovascular accidents, and multiple sclerosis. Participants were able to distinguish between the past and present reaction to their disabilities, indicating that the earlier adaptation phases were significantly more frequent in the past than present, including shock, anxiety, depression, internalized anger, and externalized hostility.

**Defense Mobilization**

This stage is characterized by two substages as well: bargaining and denial. Bargaining is described as a religious or spiritual attempt to negotiate with God or a higher power to be cured with the expectation of full recovery. In essence, the individual (and often
the family) pray for survival and/or recovery with a promise to pay penance for any past wrongdoing (Livneh, 1991). In addition, in return for a cure or recovery, individuals may promise to donate to the church, do charitable work, and so on. Livneh describes bargaining as being short term in nature, whereas denial is seen as lasting longer. Although bargaining and denial are seen as overlapping, denial is viewed as a more “extensive level of suppression or negation of the disability and its ramifications to maintain self-integrity” (Livneh, 1991, p. 119). Related to this is the extensively studied and debated coping dimensions of problem-versus emotion-focused coping (Carver, Scheier, & Weintraub, 1989; Folkman & Moskowitz, 2004).

Problem-focused coping is described as a more task-oriented, constructive, and positive way of dealing with stressful events, whereby an individual recognizes the problem, thinks of strategies to solve it, weighs the pros and cons of the decision, decides, and implements the chosen strategy (Cheng, Kuan, Li, & Ken, 2010; Endler & Parker, 1990). Emotion-focused coping is described as a coping strategy to minimize or reduce the negative emotions associated with the stressor by denying, avoiding, or engaging in distracting activities (Folkman & Lazarus, 1980, 1985). The debate has centered around which coping strategy is more appropriate for alleviating an individual’s distress. Typically, problem-focused coping has received greater support; however, emotion-focused coping appears best in instances where an individual experiences some emotionally overwhelming and extreme trauma that he or she has little control over, and the problem cannot be solved. More recently, researchers suggest that the coping domains cannot be distinguished from one another and may overlap and represent variations of each other (Endler & Parker, 1990; Folkman & Moskowitz, 2004).

Cheng et al. (2010), in their study of 180 undergraduate students regarding problem- and emotion-focused coping strategies, found that “certainty emotions” (such as anger, disgust, happiness, and contentment) elicited problem-focused coping because the students perceived being in control of the situation. “Uncertainty emotions” (hope, surprise, worry, fear, and sadness) most often elicited emotion-focused coping when the event was perceived as uncontrollable. These findings were originally supported by Folkman and Lazarus (1980) and have since been affirmed by Nabi (2003) and Smith and Ellsworth (1985).

Denial is the other major substage cited during this period (Livneh, 1991; Livneh & Antonak, 1997). Denial is a defense mechanism to protect the self from overwhelming fear and sadness by optimistically hoping things will get better and temporarily escaping the immense emotional sadness and fear of the unknown. Smart notes that denial can take three forms: denying the presence of the disability, denying the implications of the disability, or denying the permanency of the disability (Smart, 2009, p. 393). Livneh (1991) cites additional cognitions, behaviors, and emotions during this stage, including distorting facts and selective attention to good news, repressing unacceptable realities, constantly seeking information, setting unrealistic goals, having unrealistic expectations, refusing to modify the home or talk to people with similar disabilities, and evading future planning with the belief that it will not be necessary (Dunn, 1975; Falek & Britton, 1974; Gunther, 1971; Naugle, 1991). Ironically, people in denial have been observed with a range of emotions, including cheerfulness and happiness at one end as they unrealistically hope for recovery (Parker, 1979), to despair and anger during moments of realizing the permanency of their disabilities (Weller & Miller, 1977).
Meyerowitz (1980), however, noted that denial could be adaptive as well, protecting the individual from the overwhelming life-altering news. As Livneh and Antonak (1997) cite, denial continues to be debated by researchers regarding its relative value or hindrance in adjusting to a disability. Specifically, Livneh and Antonak (1997) cite denial in the literature as either a stage or phase of adaptation in dealing with traumatic loss, or a defense mechanism that protects our ego to minimize or escape overwhelming anxiety. In this latter instance, denial is part of emotion-focused response, which has arguably been viewed as temporarily helpful soon after injury, especially where the circumstances cannot be controlled (Meyerowitz, 1980). Theoretically, and for practical application purposes, should counselors confront patients and their families regarding the seriousness and/or grim permanency of the disability, or should these individuals be allowed to “hope?” This is debatable. The practical application may indeed be to assist individuals by never taking their hope away but to encourage them to continue with their rehabilitation programs, therapy programs, and so on, in the event their disability may be with them for a while. This tangible compromise could then be viewed as “healthy denial,” where the individuals and their families continue to move forward, while not being denied their hope that a miracle or medical advances may exist in the near or distant future (I. Marini, personal communication, September 14, 2009).

Initial Realization

The third stage is also characterized by two major substages: mourning and depression and internalized anger. Mourning or grief is typical of shorter duration where the individual grieves the loss of body function and past way of life. Depression is longer and future oriented, where cognitions involve fear of an often uncertain and perceived grim future. Suicidal ideation is sometimes present during this stage as well as asking “why me” of God or a higher power (Kubler-Ross, 1981). The theory of mourning and depression has encountered some debate among the researchers as to whether or not all individuals go through a diagnosable clinical depression, and whether going through depression is mandatory to move on to acceptance (Trieschmann, 1988). Wortman and Silver (1989) reviewed the existing empirical evidence regarding bereavement following a physical disability and found that not all individuals report experiencing depression. Recently, Maciejewski, Zhang, Block, and Prigerson’s (2007) brief study with 233 individuals who had suffered the death of a loved one from natural causes found participants mourned the loss of a loved one more so than they reported becoming depressed. The temporal sequence reported by grieving loved ones included disbelief, which peaked at 1 month, yearning at 4 months, anger at 5 months, and a depression plateau at about 6 months post-loss. Acceptance of the loss was observed to gradually occur as time went on over a 24-month observation period. Livneh (1991) and Livneh & Antonak (1997) cite common reactive depression observations during this stage as including feelings of hopelessness, despair, anxiety, intense sadness, withdrawal, and despondency as well.

Alternatively, Worden’s task of mourning concept identifies four tasks that mourners can actively work through to adapt to their loss (Worden, 2009, p. 38). The first task involves accepting the reality that the loved one has died and will not return. Some mourners see their loved one in a crowd, deny he or she is dead, keep their possessions
ready for them to return, and so on. The second task Worden identifies is the process of experiencing the emotional and behavioral pain. Some mourners repress painful emotions and do not allow themselves to feel the pain. Burying or avoiding such emotions can eventually lead to clinical depression. The third task involves adjusting to the world without the loved one. External adjustments include taking on the activities (e.g., paying bills, shopping, house chores) the loved one performed, while internal adjustments involve being an independent person from your loved one concerning self-esteem, self-identity, and the like. Spiritual adjustments during this task involve making sense of the world and testing one’s faith and beliefs as to why this happened. The final task is that of maintaining an enduring, healthy connection with the deceased loved one while moving on with a new life. Worden indicates that these tasks are not fixed stages and can be experienced and worked on simultaneously because grieving is a fluid and not a static process.

Smart (2009) differentiated between how the individual mourns and/or possibly becomes depressed following a disabling injury, and the societal expectation “requirement to mourn” as hypothesized by Wright (1983). It is expected that people with disabilities should feel bad and constantly grieve their losses indefinitely because it is the presumed normal response to their misfortune. This societal belief that an individual must mourn and continually grieve a loss is a common misconception, but a projected value judgment by others nonetheless regarding how they think they would feel if they became disabled. Despite studies showing that most persons with a traumatic onset disability gradually adjust to their situations over time, the societal requirement to mourn continues to be perpetuated (Livneh & Antonak, 1991; Marini, Rogers, Slate, & Vines, 1995; Silver, 1982; Wright, 1983).

Internalized anger essentially involves self-blame, guilt, and shame. The individual blames himself or herself and often views the disability as punishment from God for some alleged wrongdoing (Hohmann, 1975; Marini & Graf, 2011). This self-blame can be amplified if the individual was indeed the cause of his or her injuries (e.g., drunk driving), which can make the adjustment much more difficult (Livneh & Antonak, 1997). Suicidal ideation, risk-taking, and self-injurious behavior can occur at this stage as well. Janoff-Bulman (1979) differentiated between behavioral and characterological self-blame attributions and their perceived impact on adjustment. Behavioral self-blame refers to individuals who believe their behavior caused their injuries; in such cases, individuals can adjust more readily knowing that they were, and are, in control of the events. Conversely, characterological self-blame refers to individuals who attribute blame to flaws in their characters or personalities, and hence, believe their fate was unavoidable and deserving. Overall, research is mixed regarding self-blame attributions of disability, with some finding a positive relationship between coping and self-blame attributions (Janoff-Bulman, 1979) and others finding a negative relationship where individuals with spinal cord injury were perceived as coping less well (Bordieri, Comninel, & Drehmer, 1989; Westbrook & Nordholm, 1986). Bordieri and Kilbury (1991) surveyed 84 rehabilitation counseling graduates using observer simulation regarding self-blame attributions. They found that characterological self-blamers were rated as coping less well, more depressed, and having perceived less control of future life events than individuals who attributed blame to behavior.
Retaliation

In Livneh’s (1991) conceptualization of the five-stage model of adjustment, retaliation is the fourth stand-alone stage with no substages. In their 1997 description of this concept, Livneh and Antonak refer to retaliation as externalized hostility. This stage essentially involves “rebelling against a perceived dependency fate...anger is now projected onto the external world in the form of hostility toward other people, objects, or environmental conditions” (Livneh, 1991, p. 124). During this stage, individuals may blame and lash out at perceived incompetent medical professionals for not doing enough, and/or significant others for no apparent reason, because of frustration and anger. Behaviorally, individuals may become noncompliant with hospital rules, use profanity, make accusations, attempt to manipulate hospital staff and significant others, or physically strike others (Krueger, 1981–1982; Livneh & Antonak, 1997). Smart (2009) notes how some individuals may initially be angry with God about being unfairly punished. Marini and Graf (2011) surveyed 157 persons with spinal cord injury regarding their spiritual or religious beliefs and practices and found that, whereas some respondents were initially angry with God postinjury, this tended to subside over time in the majority, but not all, cases.

Final Adjustment or Reintegration

This final stage delineates a cognitive, affective, and behavioral component. Livneh and Antonak note how acknowledgment is a cognitive reconciliation or acceptance of the disability and its permanency. A new disability self-concept is formed, and individuals seek to master their environment by problem solving. Persons who reach this stage can “accept him or herself as a person with a disability, gain a new sense of self-concept, reappraise life values, and seek new meanings and goals” (Livneh & Antonak, 1997, p. 22). Emotionally, individuals are “okay” with their disabilities, and can talk about it without becoming upset. Behaviorally, persons in this stage begin to pursue social, academic, and/or vocational goals actively, and learn to navigate physical and social environmental barriers successfully. Livneh and Antonak (1991) found correlational support for acceptance among 214 rehabilitation patients during the temporal later phase of disability onset. Similarly, Marini et al. (1995) surveyed 63 people with spinal cord injury during their first, second, or fifth year postinjury, finding that self-esteem increased over time as respondents became more comfortable and confident with their disability status.

Despite all the caveats to the stage model of adjustment, some criticisms have been cited (Kendall & Buys, 1998; Olkin, 1999; Parker et al., 2003). Some concerns relate to the dangers of counselors expecting and anticipating persons with sudden onset physical disabilities to go through specific stages (Kendall & Buys, 1998). Others cite the complexity of human behavior and the attempt to fit everyone through these stages when there are so many complex individual differences regarding people’s coping mechanisms, environmental factors, and extenuating circumstances (Parker et al., 2003). Related, some researchers argue that there exists little empirical support for the stage model of adjustment (Chan, Da Silva Cardoso, & Chronister, 2009; Olkin, 1999).

Although many injured people have been found to progress from initially experiencing higher to lower levels of distress over time, others do not show any signs of intense distress, and some remain in a heightened level of distress for longer periods (Wortman...
& Silver, 1989). As discussed later with the recurrent model, some researchers argue that people with physical disabilities do grieve the loss of bodily function and preinjury lifestyle, and that the permanency of the loss leads to recurrent and unpredictable periods of chronic sorrow (Burke, Hainsworth, Eakes, & Lindgren, 1992; Davis, 1987; Kendall & Buys, 1998; Teel, 1991).

Somatopsychology

As briefly introduced in Chapter 4, field theory postulated by Kurt Lewin (1935, 1936) centers around the belief that our self-concept or self-worth can be, and is, affected by the feedback we perceive from interacting with others in our environment, referred to as our “life space.” Although Lewin’s original theory did not include the impact a disability has on this reciprocal interaction, researchers since then have refined the hypothesis to include the impact of disability (Barker, Wright, Meyerson, & Gonick, 1953; Dembo et al., 1956; Trieschmann, 1988; Wright, 1960, 1983). The revised theory has been encompassed as Behavior (B) is a function (f) of Psychosocial variables, such as self-esteem and coping skills (P); Organic factors related to the disability, such as paralysis or blindness (O); and Environmental or physical access and attitudinal factors (E), comprising the formula $B = f(P \times O \times E)$ summarized by Trieschmann (1988). Lewin’s somatopsychology theory was the first to take a more social psychological view of human behavior as opposed to focusing exclusively on individual behavior in isolation.

Specific to this theory, then, is the central question: “How do people with disabilities perceive themselves in Western society’s mirror?” A synopsis of historical attitudes, in general, would suggest many people with disabilities have been stigmatized, discriminated against, persecuted, devalued, dehumanized, and essentially treated as minorities (Chubon, 1994; Olkin, 1999; Mackelprang & Salsgiver, 2009; Smart, 2009). Arguably, for individuals who possess a more internal locus of control, many of these negative experiences would potentially not have as demoralizing an emotional effect as for persons who have a more external locus of control (Elfstrom & Kreuter, 2006; Frank & Elliott, 1989). Past research indicates that the link between locus of control and emotional well-being is mediated by coping strategies (Elfstrom & Kreuter, 2006; Frank & Elliott, 1989). These authors found that people with spinal cord injuries who perceived that they were more in control of their life circumstances (internal locus) possessed greater levels of acceptance and emotional well-being than the group who believed their destinies were not in their hands (external locus). As Maltby, Day, and Macaskill (2007) note regarding clinical depression and various illnesses and disabilities, people who are internally located tend to attribute their self-worth to their own efforts and internal evaluation, whereas people who are externally located are more likely to evaluate their self-worth based on how others respond to them and believe their circumstances are controlled more by environmental influences and not themselves. Wright (1983) would otherwise view those externally located individuals who regularly experience discriminating and demoralizing attitudes of others as more susceptible to “succumbing” to the societal limitations imposed by society, thereby adjusting less well.

Some of the empirical support for this theory centers around assessing the attitudes of people with disabilities about their lived experiences in the community. As earlier noted, Li and Moore’s (1998) survey of 1,266 adults with disabilities found acceptance
of disability about their experiences in the community. Aside from friends and family's emotional support playing a significant role in adjustment, perceived societal discrimination had a negative impact on accepting one's disability. DiTomasso and Spinner (1997) additionally found that their respondents with disabilities reported greater levels of loneliness when confronted by the negative attitudes of others. Similarly, Hopps, Pepin, Arseneau, Frechette, and Begin's (2001) sample of 39 adults with physical disabilities showed a high correlation between feelings of loneliness, social anxiety, and poorer social skills they attributed to poor physical access in their communities. Finally, in Graf, Marini, and Blankenship's (2009) qualitative survey of 78 people with spinal cord dysfunction to compose in 100 words or less what experience(s) best exemplified their living with disabilities, most frequently reported anger and frustration from encountering physical access barriers in the community. Repeated negative experiences with others in society can, over time, impact how well someone adjusts to his or her disabilities.

Disability Centrality Model

The most recent adaptation model regarding chronic illness and disability (CID) has been shown to have great promise theoretically, empirically, and with tangible clinical implications (Bishop, 2005). Drawing upon Devins’ illness intrusiveness approach (Devins, 1994; Devins et al., 1983), Livneh's (2001) conceptual framework, and the value change concepts of Dembo et al. (1956; Wright, 1960, 1983), Bishop proposes the disability centrality model (DCM). Bishop (2005) describes six tenets as the theoretical underpinnings for DCM that factor in subjective and objective quality-of-life (QOL) satisfaction, and control over one's medical and environmental circumstances. These are summarized as follows: (a) The impact of a CID can be measured by a multidimensional subjective QOL measure; (b) QOL is an individual's overall perceived subjective satisfaction of life domains that are disproportional because of individual differences regarding which domains are more important (central) to us; (c) the onset of a CID results in an initial reduction in overall QOL and centrally important satisfying activities as well as feelings of personal control; (d) the degree of QOL reduced is dependent on how many central domains are affected; (e) individuals seek to maintain and maximize overall QOL by minimizing gaps (distress) caused by the CID; and (f) people strive to close these gaps by either changing their values and interests commensurate with their disabled abilities, employ strategies to increase perceived control over their health and environment, or alternatively do nothing to improve control or change their values (Bishop & Feist-Price, 2002; Devins et al., 1983).

Bishop (2005) incorporates the concept of domain satisfaction and importance described by Devins et al. (1983) and others (Frisch, 1999; Pavot & Diener, 1993) regarding the relative significance various QOL domains may have for each. For example, a construction worker with a grade 9 education who sustains a tetraplegia and has derived great satisfaction from work and playing sports preinjury will likely experience a poorer adjustment if he or she can no longer engage in either domain. In contrast, a professor with the same injury will likely be able to retain employment and try to compensate (develop new interests) for being unable to play sports. In both instances, the former individual would likely experience a greater reduction in satisfaction and perceived control than the professor, and hence a greater reduction in overall QOL (Frisch, 1999).
Although Bishop (2005) concedes there will never be a universal agreement on what all the QOL life domains should include, there has been an increased agreement over the years on certain domains, including physical and mental health, social support, employment or a satisfying or avocational activity, and economic or material well-being (Bishop & Allen, 2003; Jalowiec, 1990). Cummins (2002) differentiated between objective and subjective QOL domains. Objective indicators include more tangible domains, such as employment, wage earnings, marital status, and so on, whereas a more subjective assessment of one’s QOL, which Roessler (1990) describes, is an individual’s private assessment or feeling about his or her life situation. As Cummins (2005) has noted, however, there is a weak relationship between objective and subjective measures of QOL. In other words, people can have what others may think is a great job, income, marriage, and so on, and yet those that seem to have it all score poorly on life satisfaction, subjective well-being, and happiness (Dijkers, 1997; Myers & Diener, 1995).

In addition, Devins’s illness intrusiveness model (Devins et al., 1983; Devins & Shnek, 2000) proposes that when individuals sustain a CID, the impact compromises psychological well-being by temporarily or permanently reducing positive or meaningful activities, as well as reducing real or perceived control to regain the positive activities or outcomes and avoid negative ones. The central question then becomes whether or not individuals can compensate for lost interests that once brought them enjoyment but they no longer can engage in. With Bishop’s DCM, the counselor must be able to assess what are the “central” or most important life satisfaction domains for clients, and how these can be compensated for or replaced (Groot & Van Den Brink, 2000; Misajon, 2002). This concept is similar to Wright’s (1960, 1983) “value change” theory, whereby individuals who perceive a loss in one area of their lives attempt to develop new interests within their capabilities (i.e., transitioning from enjoying jogging to reading for persons with a mobility impairment). This has also been termed preference drift (Groot & Van Den Brink, 2000) and response shift by Schwartz and Sprangers (2000).

Empirical support for DCM is building. Bishop (2005) assessed 72 college students with disabilities using the Delighted-Terrible Scale (Andrews & Withey, 1976), the Ladder of Adjustment Scale (Crewe & Krause, 1990), and what Bishop (2005) describes as the Domain Scale, which assessed 10 domains regarding QOL. Overall, results indicated a positive correlation between QOL and psychosocial adaptation to CID. A second correlation was found between satisfaction and perceived control about the impact of CID and QOL. Bishop describes counseling interventions that empower clients to assert more control over their circumstances, develop new interests or response shift, and work through the loss of satisfying activities no longer accessible.

Bishop, Shepard, and Stenhoff (2007) conducted a follow-up DCM study with 98 persons with multiple sclerosis. In this study, Bishop et al. discuss the subjective quality of life (SQOL) or subjective well-being relating to the previously described QOL domains (Johnson, Amtmann, Yorkston, Klasner, & Kuehn, 2004) and psychosocial adaptation. The assessments used were the Delighted-Terrible Scale, Ladder of Adjustment Scale, and the Disability Centrality Scale (DCS, Bishop & Allen, 2003), the last of which measures 10 life domains, including physical health, mental health (emotional well-being, happiness, enjoyment), work/studies, leisure activities, financial situation, relationship with significant other, family relations, other social relations, autonomy/independence, and religious or spiritual expression (Bishop & Allen, 2003, p. 7). Results indicated a positive
correlation between scores on the self-management scale and both perceived control and QOL. The second positive correlation was found between scores on the Ladder of Adjustment Scale and overall QOL satisfaction across domains. Bishop et al. (2007) again cite similar tangible counselor intervention strategies involving assisting clients in developing new interests and asserting more control over their situations. Livneh and Antonak (1997) view the DCM as an ecological model; however, it is treated separately here because of its emphasis on perceived control and satisfaction of life domains.

**Ecological Models**

Chan et al. (2009) observed that even within the ecological models of adjustment to disability, there is an overlap representing the stage or phase theory of adjustment including early reactions of shock, anxiety, and denial; intermediate reactions of depression, internalized anger, and externalized anger; and later reactions involving acknowledgment, acceptance, and adjustment (Chan et al., 2009, p. 58). As we conclude later, all of these proposed theories have overlapping and similar concepts.

Two theorists who arguably summarize the complexity of ecological models best are Trieschmann (1988) and Vash and Crewe (2004). These models involve a foundation of three major determining factors that consider: (a) nature of the disability, (b) characteristics of the person, and (c) environmental influences. Within each of these determining factors are subsets that require exploration by the counselor to assess what, if any, bearing each of these factors has on psychosocial adjustment. It is important to note that none of these factors may negatively influence poor adjustment; or conversely, any one of these factors in and of itself if deemed important by the individual may delay or prolong adjustment. A summary of each is provided.

**Nature of the Disability**

This factor explores aspects of the disability itself and the implications of each. The first subfactor considers the *time of onset* regarding whether an individual was born with a disability or acquires it sometime later in life. Vash and Crewe (2004) discuss some potential implications for someone who is born with a disability, including being treated as an infinite child, isolated and overprotected, unable to engage in many childhood activities, and as Olkin (1999) describes, sometimes subjected to a "conspiracy of silence" where parents do not discuss their child's prognosis or treatment with him or her at the risk of upsetting their child. Conversely, as we explore in detail regarding the psychosocial aspects of an acquired disability, one can succumb to a whole host of other adjustment issues (Kendall & Buys, 1998; Livneh, 1991). The next subfactor, *type of onset*, concerns whether or not the disability had a sudden impact (spinal cord injury from a car accident) versus a prolonged onset (more gradual, such as multiple sclerosis) and the implications of each. In the case of sudden onset, perceived attribution of blame becomes a factor that influences adjustment. Specifically, research is mixed regarding the implications of self-induced versus other-induced attribution of blame on adjustment. Although, on the one hand, findings indicate those who accept the responsibility of their injuries may possess a more internal locus of control and therefore may adjust better, they also may be more self-critical and angry at the fact that they could have possibly
prevented their accidents (Athelstan & Crewe, 1979; Bulman & Wortman, 1977; Reidy & Caplan, 1994). *Functions impaired* addresses the relative importance each of us places on our functional abilities. For example, some individuals are most terrified to lose their sight, whereas others fear becoming paralyzed or losing their hearing the most. Related to this factor is the significance these abilities play in our lives. An academic whose livelihood and intrinsic interests revolve around reading may be devastated by vision loss. Wright (1983), however, reminds us of the “insider” perspective, whereby those persons who have lived and adapted to their disabilities emphatically disagree that it is the worst thing (bodily function) they could lose. Unfortunately, many in the lay public perceive any disability as a tragedy, and one that they are not certain they could live with (Olkin, 1999). *Severity of the disability* essentially considers how severe the disability is, with the once assumed belief that those with more severe disabilities were likely more maladjusted (Livneh & Antonak, 1991). Although some literature finds that this may indeed be the case, it is more commonly believed now that the severity of a disability has little or no impact on how someone adjusts (Livneh & Antonak, 1997; Shontz, 1991; Wallander & Varni, 1998). *Visibility of the disability* considers the reactions individuals with visible disabilities sometimes experience (wheelchair users), such as discrimination, devaluation, and being ignored (Graf et al., 2009; Marini, Bhakta, & Graf, 2009). Conversely, consider the plight of those with invisible disabilities unknown to the public (low back injuries) who may be thought of as lazy or unmotivated if unable to participate in certain activities, such as not wanting to find a job because of an ongoing chronic pain. *Stability of the disability* addresses whether the disability is stable and will not become worse (spinal cord injury) versus those that have an uncertain prognosis, but become progressively worse over time (Parkinson's disease; Cheng et al., 2010; Elfstrom & Kreuter, 2006; Folkman & Lazarus, 1980; Frank & Elliott, 1989). The uncertainty of waking up each morning not knowing whether one is still able to walk or see not only leaves an individual with no control over his or her situation but also compromises making any future plans. Finally, the concept of *pain* deserves a category unto itself in addressing psychosocial adjustment. As Vash and Crewe (2004) emphasize, unlike many of the other disabilities, chronic pain is a primary or secondary debilitating condition that can have a significant negative impact on an individual’s thoughts, emotions, and behaviors. Cognitively, individuals can exhibit poor concentration and attention, suicidal ideation, and reduced problem-solving abilities. Emotions often include depression, feelings of hopelessness and helplessness, and despair (Banks & Kerns, 1996; Fishbain, Cutler, Rosomoff, & Rosomoff, 1997). Behaviors have been defined as social isolation, withdrawal from activities, and, in worst case scenarios, addiction to pain prescription medications and other substances and drug abuse (Lewinsohn, Clarke, & Hops, 1990; Waters, Campbell, Keefe, & Carson, 2004).

**Personal Characteristics**

These determining factors involve individualized traits or characteristics. *Gender* largely considers gender differences in coping with a disability as well as societal expectations of males and females (Hwang, 1997; Livneh, 1991; Marini, 2007; Tepper, 1997). There are mixed findings regarding which gender adjusts to a disability better; however, Western societal expectations of each gender are quite clear (Charmaz, 1995a, 1995b; Hwang,
1997). Men are supposed to be rugged, independent, breadwinners, stoic, athletic, dominant, and tough (Charmaz, 1995a, 1995b; Marini, 2007; Zilbergeld, 1992), whereas women are expected to be beautiful in physical appearance, passive, homemakers, and good nurturers (Hwang, 1997). Males and females with severe disabilities may not be able to live up to some or any of these expectations and may have difficulty adjusting if they rely on external cues (societal expectations) for affirmation of their self-concept/self-esteem (Charmaz, 1995a, 1995b; Marini, 2007; Nosek & Hughes, 2007). 

Activities affected relate to the significance individuals place on their activities. A hockey player who becomes paralyzed and is no longer able to play sports may experience greater difficulty adjusting than a professor who has the same injury but still can perform academic activities. Similarly, interests/values/goals pertain to the differing passions people have in their lives. Those who proverbially “put all their eggs in one basket” or have few if any interests, and lose the ability to engage in them, likely find adjustment more stressful than those people who have multiple interests and are still able to return to some of them (Massimini & Delle Fave, 2000; Schafer, 1996). Lewinsohn et al. (1990) indicate that when people experience a loss and withdraw from engaging in what once were pleasurable activities, there is a greater likelihood of lengthening or exacerbating a reactive depression. Remaining resources are described by Vash and Crewe (2004) as the abilities and traits an individual retains regardless of disability. These include intelligence, motivation, sense of humor, extroversion, social poise, resilience, emotional stability, and coping strategies, all of which have been implicated in positive adjustment (see Livneh, 1991). Finally, spiritual and philosophical base refers to one’s spiritual or religious beliefs, particularly as to whether some people believe their disabilities are punishment from God or a higher power, with the assumption that those who believe they are being punished have a more difficult time adjusting (Byrd, 1990; Gallagher, 1995; Graf, Marini, Baker, & Buck, 2007). Conversely, individuals who believe their disability to be divine intervention or calling for them to serve a higher purpose for God experience lesser adjustment difficulties (Eareckson, 2001; Graf et al., 2007).

**Environmental Influences**

As extensively detailed earlier, environmental influences may have a significant impact on adaptation to disability (DiTomasso & Spinner, 1997; Graf et al., 2009; Hopps et al., 2001; Lewin, 1936; Li & Moore, 1998; Wright, 1983). In this determining factor, Vash and Crewe (2004), as well as Trieschmann (1988), describe several contributing factors. Family acceptance and support becomes significant in that if a disabled loved one is viewed as a contributing family member and not devalued, this correlates with a more positive adjustment to the disability (Li & Moore, 1998). In addition, those families that have been shown to possess positive coping strategies and support one another typically adapt well to the disability (Trask et al., 2003). Income plays an important role not so much in overall happiness, but rather overall QOL (Diener & Seligman, 2004; Inglehart, 1990; Lykken, 1999). Once people have their basic needs met, there is relatively little difference in happiness ratings between those who are extremely wealthy versus those of more modest means (Diener & Seligman, 2004); however, a higher income and adequate health care positively impacts the ability to remain healthy as well as purchase necessary accommodations and equipment/devices (modified van, accessible home) for...
a better QOL. *Available community resources* refer to support from local agencies, which could include Centers for Independent Living (CILs), Veterans Affairs services, Client Assistance Programs (CAPs), access to modernized hospitals, and so on. Individuals with severe disabilities who live in rural settings with no resources may not only have to travel long distances for appointments but also be required to be away from home and family at times, having to remain in the city for several days (Smith, Thorngren, & Christopher, 2009). *Social support* is also critical for positive adjustment and fostering self-esteem in most, but not all, instances (Buunk & Verhoeven, 1991; Li & Moore, 1998). Schwarzer and Leppin (1992) define functional support by differentiating between the instrumental support (offering financial aid), informational support (giving information and advice), and emotional support (caring, empathy, and reassurance). Functional support is further delineated by individuals’ perceptions of the support they received (retrospective evaluation) and the perception of available support if needed (anticipation of getting the support; Lakey & Cassady, 1990; Symister & Friend, 2003). Much like Yuker’s (1988) extensive review of the impact of contact regarding positive and negative attitudes toward disability, empirical findings are somewhat mixed regarding the benefits of social support (Barrera, 1981; Cohen, 2004; Heller & Rook, 2001; Hupcey, 1998; Lazarus & Folkman, 1984b; Li & Moore, 1998). On the positive side, social support is believed to be a buffer against stress, an appropriate coping strategy, and a regulator of negative emotions (Cohen, Gottlieb, & Underwood, 2000). For example, people who sustain a severe disability may have friends who give or lend them money, help them in finding community resources, and provide emotional support by empathizing and genuinely listening to their concerns. Conversely, having a social support system who are themselves dysfunctional, have promised to help but always have excuses, or in the worst-case scenario take advantage of the person with the disability by neglecting, abusing, or stealing from him or her are all clear examples of a potentially poorer adjustment process for the disabled individual. Finally, *institutionalization* becomes a concern for those people with severe disabilities who are unable to physically take care of themselves, do not have the funding to hire an attendant, or have no family or friends who can perform a caregiving function. In such cases, individuals are faced with temporarily or permanently having to reside in a nursing home. Aside from most Americans not wanting to live in a nursing home, the U.S. General Accounting Office (2002) published a study indicating an approximate 25% abuse rate that either resulted in death or serious injury of nursing home residents nationwide. Forms of abuse include neglect, physical abuse, sexual abuse, and malnourishment. Clearly, individuals who have no choice but to live in a nursing home may, in the worst-case scenario, be subjected to such abuse or minimally deprived of the freedom to control their environment and thus experience a resulting reduction in QOL (Bishop, 2005). In a best-case scenario of well-run nursing homes, persons with severe disabilities may be medically well cared for, as well as having a support network that residents would not otherwise have living alone.

**Recurrent or Integrated Model of Adjustment**

The recurrent or integrated model of adjustment following an acquired disability was essentially hypothesized because of perceived shortcomings of the stage or linear model of disability (Davis, 1987; Wikler, Wasow, & Hatfield, 1981; Wortman & Silver, 1989).
One of the several criticisms of the stage model was its theoretical emphasis likening the stages of grief over a deceased loved one (Kubler-Ross, 1981) to that of acquiring a disability. The main argument is that people with acquired disabilities continue to live with their disabilities. Every day, therefore, although the emotional upheaval subsides over time, those with acquired disabilities continue to periodically experience chronic sorrow throughout their lives. In this sense, there is never a final adjustment or adaptation stage where the disability no longer affects the individual (Davis, 1987; Kendall & Buys, 1998; Wortman & Silver, 1989).

Pertinent to this model are several key concepts. Beck’s (1967) cognitive theory defines cognitive schema as our ingrained beliefs and assumptions regarding ourselves, others, and how the environment works (Beck & Weishaar, 1989). When a sudden and traumatic disability occurs, many individuals attempt to cling on to comfortable, old schemas because of the overwhelming anxiety and uncertainty the disability brings. Wright (1983) refers to this as “as if” behavior, whereby individuals attempt to minimize anxiety by denying or distorting reality and pretending as if nothing (the disability) has happened. As the old schema no longer adequately works and the individual begins to realize the implications of the disability, depression may set in (Kendall & Buys, 1998). Yoshida (1993) uses the analogy of a wildly swinging pendulum to describe the initial injury phase of anxiety, fear, and grief. Over time, however, the pendulum gradually slows to a middle set-point where individuals either develop new positive or negative schema of life with a disability (Yoshida, 1993). Positive new schema are formed when individuals with traumatic disabilities can: (a) search and find meaning in the disability and in postdisability life; (b) learn to master or control their environment, their disabilities, and their futures; and (c) protect and enhance the self by incorporating the new disability identity (Barnard, 1990; Kendall & Buys, 1998, p. 17). Conversely, the negative schema can also be formed about the disability, allowing stereotypical societal expectations about the disability (helpless, incapable) to influence one’s self-worth (Charmaz, 1983; Stewart, 1996). Wright (1983) would describe those who develop negative schema as otherwise having succumbed to their disabilities.

Undoubtedly, individuals with acquired disabilities who develop a more negative schema postinjury in all likelihood are more susceptible to self-pity, low self-esteem, and likely more frequent episodes of chronic sorrow. Regardless, according to the theory of recurrent periods of sadness, even individuals who have developed positive schema and have otherwise been successful in their lives still experience the sorrow or sadness from time to time (Kendall & Buys, 1998). As some research has shown, it is quite likely that these periods of sorrow may be facilitated by environmental influences, such as a relationship rejection, job rejection, or discrimination perceived by the individual because of his or her disability (Graf et al., 2009; Li & Moore, 1998; Marini et al., 2009). Overall, response to the disability varies for everyone, depending on one’s coping mechanisms (Lazarus, 1993; Lazarus & Folkman, 1984b).

Transactional Model of Coping

The most frequently cited and empirically supported theory of coping with stressful events is that of Lazarus and Folkman’s transactional theory (1984a, 1984b). The authors define coping as “constantly changing cognitive and behavioral alternatives to manage
specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984a, p. 141). These appraisal efforts are constantly changing as the individual interacts with his or her environment back and forth, like watching a tennis match. Central to the transactional theory are two major components of a sequential appraisal process salient to when people encounter a stress-inducing event. The first component, referred to as primary appraisal, is an individual’s assessment as to whether a situation is stressful or not. The key to this appraisal is the motivational strength attributed to various personal goals (goal relevance) the stressor may pose, otherwise called goal congruence or incongruence. Individuals assess whether the stressful event is deemed beneficial or harmful/threatening to the goal. Specifically, in the case of disability, the goal of maintaining optimal health is compromised by the stressful event. If not, no coping mechanisms are required, and the individual returns to a state of emotional equilibrium. If, however, the situation is deemed as harmful or threatening, the individual moves into the secondary appraisal component. At this level, individuals assess their options for coping and expectations about what will happen (Lazarus, 1993). Three subcomponents are involved: blame, or who the event is attributable to; coping potential as to whether the individual has any control to change the circumstances of the event and whether they can influence the person–environment relationship; and future expectations regarding perceptions as to how the situation plays out. At both levels of appraisal, Lazarus and Folkman (1984b) discuss the problem-focused versus emotion-focused coping strategies defined earlier. The authors suggest that emotion-focused coping is more likely when individuals perceive they have no control over the situation and that the stressful event (e.g., disability) is indeed harmful or threatening to achieve or block one’s goals. Positive-focused coping has previously been shown to be more effective in the long run as far as adaptive coping strategies, particularly in situations where individuals can insert some control over their situations to minimize or eliminate the stressor (Carver et al., 1989; Cheng et al., 2010; Folkman & Lazarus, 1991; Folkman & Moskowitz, 2004; Groomes & Leahy, 2002; Nilsson, 2002; Provencher, 2007).

Overall, the transactional model of coping has excellent application in understanding how persons with CID react and cope with a catastrophic injury resulting in significant functional loss and reduction in critical QOL domains (Bishop, 2005). In many such injuries, most individuals indeed do not have control over the situation, have initially little or no control over their health status, and in the case of permanently disabling injuries, such as a spinal cord injury or traumatic brain injury, are unable to perceive a positive future. Similarly, in cases where parents learn that their child is born with cerebral palsy, muscular dystrophy, or some other disabling condition, they too are likely to experience very similar emotions, cognitions, and behaviors as those with the disability (e.g., shock, anxiety, denial, anger, and acceptance; Livneh & Antonak, 2005).

Chaos Theory of Adjustment

Chaos and complexity theory (CCT) of adjustment is essentially the human application response of a phenomenon originally hypothesized from the disciplines of mathematics, meteorology, engineering, physics, biology, geography, astronomy, and chemistry (Livneh & Parker, 2005, p. 19). Its origination appears to lie with the mathematician
and meteorologist Edward Lorenz back in the 1960s, when he famously coined the term *butterfly effect*, essentially explaining how a butterfly flapping its wings in Brazil could ultimately end up causing a tornado in Texas a month later (Gleick, 1987). This theory, in addition to Rene Thom’s (1975) multidimensional and nonlinear catastrophe theory, forms the basis for its eventual application to human behavior.

An intriguing major concept about CCT is that, despite its complexity and initial perceptions of random, nonorganized sets of behavior, there is indeed an ordered and deterministic set of rules (Chamberlain, 1998). Several concepts must first be understood and are briefly defined here. *Nonlinearity* is often referred to as “sensitive dependence on initial conditions” (Butz, 1997, p. 36). Nonlinear behavior is described as a nonrepetitive, unpredictable, aperiodic, and unstable phase that experiences critical junctions of instability called *bifurcation points* (Capra, 1996). These bifurcation points might otherwise be analogous to watching ice crack on a lake. Specifically, there is no order to when the ice cease in one direction and fork off to another. Bifurcation of behavior after an acute injury is representative of the anxiety, fear and shock, and individual experiences during the crisis; however, with each critical bifurcation point (fork), it allows for growth, stability, and new behavior to result (Chamberlain, 1998). *Fixed point attractors* are stable and predictable set points that Livneh and Parker (2005, p. 20) describe as synonymous with watching water approaching a drain. *Limited cycle or periodic attractors* are predictable open and closed loops, with donut-shaped trajectories where the system approaches two separate points periodically but is unable to escape the cycle (Livneh & Parker, 2005, p. 20). *Strange attractors* are indicative of the unpredictable and unstable chaotic trajectories that demonstrate the sensitive dependence on initial conditions and bifurcates over time (Capra, 1996). The fixed point attractors, limited cycle attractors, and strange attractors all constitute the first-, second-, and third-order changes, respectively.

*Dynamic systems* are neither random nor determined systems interconnected with one another that depend on the system itself (the individual), the environment, and the interaction between the two (similar to somatopsychology). Complex systems are open systems in that they exchange and lose energy, information, and material interacting with their environment (Cambel, 1993). To survive, the system must reduce internal disorder or entropy (decay) while drawing energy from the environment. The level of entropy (minimal versus extreme) represents the degree of chaos occurring within the system or individual in human application. There are, however, also closed systems where the entropy cannot be dissipated, and new energy cannot enter from the environment. In closed systems that are isolated from renewable environmental energy, maximum entropy continues (Kossmann & Bullrich, 1997). This may otherwise be a representation of what Livneh (1991) describes as “getting stuck” in a certain stage of psychosocial adjustment. *Self-organization* is defined by Livneh and Parker (2005) as open systems with nonlinear trajectories that experience dramatic changes following a stressor (injury), spontaneously develop new structures and behaviors (schema), and experience internal feedback loops that ultimately self-organize, stabilize, and develop new ways of adaptation (Capra, 1996; Livneh & Parker, 2005, p. 21). *Self-similarity* involves similar patterns within chaotic systems, such as the fact that no two snowflakes are alike; however, they all have six sides. Self-similar patterns are called “fractals,” which are determined patterns essentially fixed inside of the chaos (Mandelbrot, 1977).
In aligning the hard science of chaos theory with human behavior, Livneh and Parker (2005) indicate that under everyday conditions, most persons without disabilities essentially function under a state of cognitive and behavioral equilibrium. When a crisis occurs, however, we react in a more complex and unpredictable manner. Chaos is described as an indication of this overwhelming anxiety, capable of facilitating emotions such as depression and anger (Butz, 1997). As a result of these distressing emotions, adaptation involves a series of bifurcation points that are unpredictable and may be observed with varying degrees of maladjustment in different people (Francis, 1995). There are, however, some “self-similar” observations (e.g., shock, anxiety, denial, anger) that can be observed in most individuals. As time goes on, the individual reorganizes his or her cognitions, emotions, and behaviors to restore preinjury equilibrium. Interactions with the environment (others) can have a positive or negative effect on the individual’s adjustment that may either slow, stall, or facilitate adaptation. Livneh and Parker suggest that counselors can assist people with acquired CID to shift their focus and energy from the past and present thinking to the future, with a goal-directed and community-oriented participation. Clients can be encouraged to look past their health and survival mentality, and begin thinking about social, vocational, and environmental mastery activities. Finally, knowing that many individuals instinctively retrench (withdraw, succumb) following a traumatic injury, counselors can encourage clients to recognize their spontaneity and creativeness and begin taking risks again (Livneh & Parker, 2005, p. 24).

Additional Adjustment Concepts

Value Change System

Although indirectly addressed previously, there are several additional concepts and/or theories regarding acceptance of loss and disability worthy of noting. The first stems from Dembo et al. (1956) and later Wright's (1960) theory of value system changes that are necessary regarding acceptance of loss. In her later conceptualization, Wright (1983) cites four value changes that may or may not occur in any particular order for the individual. The first is enlargement of the scope of values. This pertains to individuals needing to refocus or let go of preinjury activities or values they are no longer able to perform, and instead expanding activities and interests to match their new abilities (e.g., an athlete who enjoyed playing sports becomes paralyzed and expands his or her values consistent with the limitations from his or her disabilities to enjoy reading). The second value change is the subordination of physique, essentially cognitively reframing the significance of what is beautiful about oneself. Individuals who place great importance on their physical appearance and abilities must be able to redefine their remaining attributes (e.g., intelligence, personality) as becoming most important. The third value change, containment of disability effects, pertains to people with disabilities not allowing the disabilities to “spread” to other parts of their beings and assertively correcting those without disabilities who assume this to be so. For example, someone with a physical disability may be presumed as also being mentally retarded. Numerous personal reports exist regarding a waitress asking a nondisabled companion what his or her wheelchair-using partner would like to eat, based on the assumption that the individual is incapable of ordering for him- or herself. The fourth value change needing to occur
for successful adjustment is a transformation from comparative to asset values, involving cognitive reframing as well. Asset values are more intrinsic and personal regarding what the individual finds to be valuable and needs to change in his or her life to sustain asset values. Comparative values, however, are evaluations we make on comparing what we have with what is supposedly normal and about what others have. Therefore, refocusing on one's assets without comparing them to what other nondisabled persons perceived as normal or standard needs to occur. Dembo et al. (1956) hypothesized in their coping with disability framework that for persons with disabilities to successfully adapt and not ultimately succumb to the disability, they must be able to focus on the things they can do, take control of shaping their lives, recognize personal accomplishments, manage negative life experiences, minimize physical and social barriers, and participate in activities that are pleasurable.

**Dual Process Model of Self-Regulation**

The dual process model was originally hypothesized by Brandstadter and Renner (1990) to describe assimilating and accommodating striving for one's goals over a lifetime. Recent studies have adapted the hypothesis to incorporate barriers to goal attainment for persons with disability. Specifically, value changes about the concepts of tenacious goal pursuit (TGP) versus flexible goal adjustment (FGA) determine an individual's adaptation (Boerner & Wang, 2012; Coffey, Gallagher, Desmond, & Ryall, 2014). TGP pertains to modifying one's situation (learning new skills, lifestyle changes, compensating for deficits) to fit one's goals. If these modified changes are still ineffective in obtaining one's goals, the individual with a disability must then accommodate for it by being more flexible and consider modifying or changing goals, relinquishing blocked goals, and pursuing goals that are more feasible considering one's functional deficits. Researchers have shown that people with disabilities experience more positive emotions and subjective well-being when they are more flexible in relation to reduced depression, greater life satisfaction, optimism, and QOL (Boerner, 2004; Brandstadter, 2009; Brandstadter & Renner, 1990; Coffey et al., 2014).

**Good Fortune Comparison**

This concept refers to some sense of relief persons with CID experience when they meet and/or perceive other persons with severe disabilities are much worse off than they. This is referred to as the “downward comparison,” whereby one's perceived good fortune is the belief that he or she could have sustained a more severe disability (Shotton, Simpson, & Smith, 2007). In the Shotton et al. (2007) study of psychosocial adjustment, appraisal, and coping strategies of nine persons with traumatic brain injuries (TBI), one of the significant findings was the comfort participants expressed in knowing their injuries could have been much worse. Psychologically, this realization allowed these individuals to enjoy what abilities they had remaining as opposed to what abilities they had lost.

**Coping Flexibility**

This concept refers to persons being able to adapt to an ever-changing environment in relation to their degree of coping flexibility versus being rigid or not possessing relevant coping skills to make necessary changes in their lives to adapt (Bonanno, Pat-Horenczyk, & Noll, 2011; Cheng, Lau, & Chan, 2014). Bonanno and Mancini (2008)
note an individual's ability to flexibly adapt to posttraumatic events by using multiple coping strategies as needed experience greater positive adjustment. Conversely, people who do not possess these skills or are inflexible to life circumstance changes psychologically adjust to their disability and their environment less successfully. Cheng et al. (2014) describe the various concepts of coping flexibility in detail, which incorporates the dual process theory of coping (Brandtstädter, 2009). Empirical findings indicate that elderly people who can deploy relevant coping strategies regarding the deterioration in health and bereavement of lost loved ones adapt better than those who are inflexible to accepting such changes (Stone, Schwartz, Broderick, & Deaton, 2010).

Conceptualized Synthesis of the Seven Theories of Adjustment to an Acquired Disability

Having explored both the old and contemporary theories and concepts of psychosocial adjustment (adaptation, response, or reaction) to disability, what then are the major overlapping areas that appear to be consistently supported empirically? In other words, what cognitions, behaviors, and emotions do most people who acquire a CID go through immediately following, then long after, a disability? We attempt to synthesize the areas of agreement various authors have conceptualized in essentially explaining the same process. The references for these conclusions are found within this chapter, and therefore not all are repeated here.

First, following a traumatic, acquired injury with permanent long-term functional implications, all humans experience some reaction. They may or may not experience Livneh's (1991) five stages of adjustment in the exact sequential order initially proposed; however, the caveats Livneh noted with the stage theory make these cognitions, behaviors, and emotions more probable as he indicated that some people skip stages, regress back to a previous stage, overlap stages, and can become stuck in a stage. In analyzing this initial period following an injury, most people are overwhelmed with shock and anxiety, synonymous with the Parker et al. (2003) chaos theory in describing bifurcation points. This also overlaps with Yoshida's (1993) analogy of a wildly swinging pendulum initially following trauma to explain the response to overwhelming anxiety and shock as part of the recurrent model (Kendall & Buys, 1998). This type of response lasts differing lengths of time for different people, based on personality traits and strengths of coping strategies, family stability and support, and type of interactions with the environment or community.

Second, as Lazarus and Folkman (1984b) have hypothesized, in appraising whether an event (injury) is considered harmful or a threat, unquestionably in such instances it is. The disabling injury is largely not under an individual's direct control, and as Cheng et al. (2010) found, we tend to gravitate toward using emotion-focused coping, because this is a situation we are unable to problem solve our way out of by self-repairing our bodily injuries. We, therefore, must rely on our physicians, and sometimes pray or bargain with God in the meantime, for a full recovery with or without medical intervention. Interestingly, Levin's (2001) analysis of over 200 epidemiological studies regarding religion/spirituality and its impact on mental and physical health found positive relationships between religious participation and beliefs about dealing with CID more positively.
Third is whether or not some or most individuals experience a clinical reactive depression of a mild, moderate, or severe nature from the loss of perceived and/or real preinjury functioning and QOL. Unquestionably, the majority of people grieve the loss of bodily function and previous way of life; however, whether or not these same people fall under the clinical diagnosis of depression varies from person to person. Again, synonymous with the Parker et al. (2003) bifurcation points (which way do the cracks in the ice go), how one adjusts depends on the personality traits and strengths in coping, family stability and support, and types of interactions with the environment. The person–environment interaction is essentially the theoretical framework for somatopsychology as well as the “dynamic systems” concept of Parker et al.’s explanation of chaos theory. The ecological model is a more complex model, but essentially similar to somatopsychology, noting the interplay between aspects of the disability involving the person, personal characteristics, and resources to cope, and the interplay of environmental forces (Trieschmann, 1988; Vash & Crewe, 2004). Then, whatever is considered a normal grief response (generally 3 to 6 months), anything occurring beyond that may otherwise be classified as noteworthy to address in counseling (Livneh & Antonak, 1991; Silver, 1982). Suicidal ideation and suicide completion are statistically higher for people with disabilities, so although not everyone becomes depressed, some disability groups are more likely to think about suicide as an option compared with the general public (e.g., spinal cord injury vs. deafness).

Fourth is the occurrence of anger, be it internal or external. Do most people with acquired disabilities, at some point after their injuries, become angry? Olkin (1999) discusses the contradictory societal perception of persons with disabilities as expected to be happy and grateful for the charitable crumbs thrown their way but, conversely, are also required to mourn their losses as well indefinitely. She further asserts that society does not tolerate, accept, or understand the anger from people with disabilities, but that whatever negative emotion is displayed, it is somehow always thought to be related or salient to the disability. Clinical observation and empirical studies suggest anger is a response, whether a short-term transitional occurrence or long-term periodic state (Graf et al., 2009; Livneh & Antonak, 1991; Marini et al., 2009). Livneh (1991) initially described self-blame and anger at God or a higher power for causing the injury or not being able to prevent it. When the higher entity or medical profession is unable to cure impairments of the disability, the anger is redirected outwardly toward medical staff, family, and God or the higher power (Graf et al., 2007; Marini & Graf, 2011). What few researchers have addressed, however, is not so much anger, but the combination of sheer boredom and frustration people with acquired disabilities feel during their first weeks and months of recovery, and later when they encounter environmental barriers and negative societal attitudes (Graf et al., 2009; Marini et al., 2009). Initially, the boredom and frustration faced by people with an acute injury experience waiting for the few minutes every day to see the doctor can be aggravating. Once out in the community, people with disabilities periodically become angry and frustrated in their interactions with others in the community regarding wheelchair parking violators, inaccessible washrooms, rude or condescending medical staff, long waiting times to see a doctor, and so on (Graf et al., 2009; Marini et al., 2009).

Fifth, and perhaps the most controversial, is whether persons with acquired or congenital disability eventually experience some final adjustment, adaptation, or transcendence.
to their disabilities (Livneh, 1991; Vash & Crewe, 2004). In defense of stage theory, Livneh (1991) noted the caveat that some individuals can regress back to an earlier stage. This is otherwise understood to mean that periodic setbacks can occur. Indeed, this is essentially very similar to the concept of periodic “chronic sorrow” that Kendall and Buys (1998) maintain in the recurrent model of adjustment. It is also synonymous with Parker and colleagues’ (2003) chaos theory concept of “self-organization,” where individuals encounter bad events and adapt or change what is necessary and within their control to adjust to the situations. The larger question becomes, what causes these periodic instances of chronic sorrow? Only two answers are plausible: (a) The individual experiences additional or recurrent health problems (e.g., loss of sight with diabetes, severe pressure sore requiring surgery for spinal cord injury); or (b) someone or something in the person’s “life space,” interacting with the environment, upsets the individual. In the first instance, this potential health setback and subsequent sadness is an otherwise normal reaction. If these setbacks do not occur, it has already been demonstrated in various empirical studies that persons with disabilities revert to preinjury levels of emotions after roughly 2 months (Brickman & Campbell, 1971; Silver, 1982). The second instance regards a negative experience with others or from encountering an environmental barrier; these causes are both socially constructed. A prejudicial or discriminatory attitude reminds the person with a disability that he or she not only has a disability but also is devalued by some people because of it (Li & Moore, 1998). Such interactions may well hurt the individual and can cause temporary sadness and/or anger as well. Similarly, when individuals with disabilities encounter an inaccessible restaurant or public place, it reminds them of their disability and the environmental barriers imposed on them that deny their civil rights (Graf et al., 2009; Marini et al., 2009). Regardless, many people without disabilities in society automatically assume that when someone with a disability appears upset, it is somehow salient to the disability, and this may indirectly be so (e.g., the requirement of mourning) (Wright, 1983).

Finally, how do people with disabilities reach any successful adjustment, adaptation, response, or reaction to their disability? For stage theory proponents, it is by successfully transitioning through the various stages over time and coming to terms with the disability. As with the grieving process, time heals. For somatopsychology proponents, it is that critical person–environment interaction where the individual possesses the personal characteristics and coping skills to succeed and learns to control and master his or her environment. Disability centrality proponents also postulate mastering one’s environment and substituting new and interesting activities that are central to sustaining satisfaction and QOL in place of those once pleasurable activities no longer accessible because of the limitations imposed by the disability. Ecological models are more complex, but again similar to somatopsychology in that psychosocial adjustment depends on the interplay of an individual’s characteristics and coping abilities, aspects of the disability itself, and environmental influences, including family and community support.

Overall, all models arguably converge into one at some point, or certainly overlap enough to provide counselors with some good insights as to what persons with disabilities may experience. For those with congenital disabilities, there does not appear to be a transitional stage of adjustment. It is more likely that this population experiences periodic sorrow if they allow themselves sometimes to wish they could do all the activities someone without a disability supposedly can do. Such cognitions, however, from the
literature appear to be rare (Connors & Stalker, 2007). In addition, it appears emotional upsets may otherwise have an external cause, such as being ridiculed or reminded of one's minority status. Again, this would hopefully be a rare occurrence, and the literature suggests that persons with congenital disabilities are otherwise generally happy and satisfied with their QOL. For those with acquired disabilities, there is, for the time being, an emotional instability in grieving the loss of bodily function and preinjury lifestyle. This does appear to stabilize in most cases over time, and it does so when individuals can cognitively reframe (adapt new cognitive schema) about their situations and what is important in life. This is accomplished by letting go of, and not dwelling on, what one used to be able to do, but instead focusing on new interests, values, and goals commensurate with remaining disability assets. The perception of being in control and mastering one's environment is central to reestablishing self-esteem. And, as discussed in the “disability paradox” theory (Freedman, 1978) and later in this text on positive psychology, people who have not only survived their disabilities but also become very successful in spite of them perceive themselves as stronger than most nondisabled persons. It, therefore, seems appropriate to end this chapter with Nietzsche's (1888) classic quote, “What does not kill me, makes me stronger,” otherwise experienced as posttraumatic growth.

REFERENCES


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U.S. General Accounting Office. (2002). Nursing homes: More can be done to protect residents from abuse. GAO/HEHS02–312, Washington, DC.


INSIDER PERSPECTIVE

The Story of Michael Hoenig

“We are getting home just in time for my reader,” I said to my friend Hugh as we pulled into the driveway of my home in Davenport, Iowa. “Medicaid pays for her time, right?” he responded. The statement puzzled me. Hugh was a fellow Center for Independent Living board member, who should know better than to assume that all persons with disabilities receive public assistance.

Blind since birth, I was raised in a family with a very strong work ethic. Although my parents were not immune to preconceived notions about blindness, college and a full-time job were a part of my life plan since my earliest memory. Having attained my BA in psychology from Central College, Pella, Iowa, in 1984, I entered the University of Iowa’s graduate program in rehabilitation counseling during the fall semester of that year. My 1985 internship at the Iowa Department for the Blind led to a position as a rehabilitation teacher, and since then I have enjoyed full-time employment. After much prodding from a rehabilitation counseling professor turned colleague, I completed my MA in 1987.

Take away the blindness, and this sounds like a pretty normal scenario. One prone to generalities would assume that someone in my situation would own my home and have a busy, active life. As a blind person, though, I frequently hear an astonished “You own your home?” from new acquaintances. In the United States, one often hears of the dominance of the White male in our culture. I find it ironic, then, when a 70-something, well-intentioned woman runs in front of me to open the door, warning me: “It’s heavy!”

As I pass through middle age, I find myself evaluating my life more and more frequently. By and large, this is a very pleasant exercise. My career has been very successful, and I am quite content with my present position at the University of Iowa as a manager of projects that serve individuals with disabilities. I am well-established financially, owning my home and having enough money left over to take frequent trips, which have included 11 Caribbean cruises and jaunts to England, Mexico, the former Soviet Union, New Zealand, and Costa Rica. I can enjoy my passion for sports, music, dancing, and the theater, having realized a lifelong dream by attending a 2006 World Series game in St. Louis. I have been blessed with an eclectic mix of friends, and very rarely have to spend time alone when I choose not to do so.

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I am a realist, however. Blindness has imposed some additional challenges. I have not, for instance, found a marriage partner. I am a very outgoing person by nature, but find situations that have the potential to lead to relationships awkward and sometimes intimidating. I have convinced myself that because I miss out on body language and need to rely on my potential partner for transportation, I may always experience great difficulty in finding a partner. I do not experience the same freedom that sighted persons enjoy in traveling. I cannot decide to jump in the car for a spur of the moment weekend trip. When flying, I am often asked to board a flight early or to wait until everyone has deplaned before I do so. When I walk into a new social setting, I am keenly aware that others notice my blindness. A quick scan of the local newspaper is not possible in a conventional manner. Recreation presents some challenges as well. With no adapted sports, such as beep baseball, goal ball, or a blind bowling league in our community, I have found participation in group sports to be almost impossible.

Do these barriers keep me from enjoying life? Absolutely not! I have come to realize that, should I meet a suitable marriage partner, blindness will not keep us apart. I use several modes of transportation, including buses, cabs, paid drivers, walking, and, most importantly, friends. By introducing myself in new social situations and striking up a conversation, I address the hesitancy so typical of someone who has just met his or her first real live person with a disability. By making computers and the Internet accessible to blind persons, assistive technology has opened the information superhighway, making that scan of the morning paper possible. To compensate for the lack of physical recreation opportunities, I have taken up dancing, which in turn has opened up an entirely new social network. My theater-going and cruise experiences are enhanced by friends who share my interests and have convinced me that my blindness is not a burden to them.

Ultimately, the key to my success and adaptability is an inner satisfaction. For me, that stems from faith in an omnipresent God who governs every aspect of my life. I find that I am most challenged when I choose to abandon the belief that if God is for me, who can be against me? Although I turn to the Creator for inward strength, I turn outward to find joy in cultivating friendships. I truly believe that my blindness has resulted in friendships that otherwise would not have occurred. Take, for instance, the woman who observed my putting sour cream on a baked potato in a restaurant. She turned to her husband and said, “Just look at him. Isn’t that wonderful?!” I could not resist pointing out to her that I had lots of practice, and we soon fell into a casual conversation that led to an extremely meaningful friendship. Then there is the middle school teacher who annually taught a disability awareness unit to her students. Appreciative of her work, I stopped by her school to say thanks, never dreaming that, several years later, I would count her among my closest friends. Yes, I must challenge stereotypes on an almost daily basis, but I find that doing so pays huge dividends.

My sense of humor has carried me through many situations that might have otherwise become stressful or embarrassing. I frequently slip in a pun during my daily 2-hour commute, putting new vanpool passengers at ease. I am the first to repeat the newest “blind joke,” flying in the face of what many consider political correctness. If we cannot laugh about our everyday experiences and share some of that humor with others, life gets boring rather quickly.
In the leadership training curriculum that one of our projects developed during the early portion of this decade, our consultant wrote: “We do not believe that a disability-free world is better.” This statement has caused me to do a great deal of thinking. By now, it should be evident that I do not view blindness as a tragedy. I would not wish it on my child. I have to live with it, at least for now, and am going to do the very best I can. Why would you want someone else to face the attitudinal and physical barriers that so frequently confront individuals with disabilities?

You are about to enter an extremely important profession. Unemployment among people with severe disabilities is estimated at near 70%. You will have the opportunity to do something about that. If I impress nothing else on you, I implore you to see the individuals you serve first as persons, not as clients. Yes, you do have to maintain a professional relationship, and yes, you need to do assessments, but please do not form your opinions based on a test score. Your client has dreams, feelings, and aspirations, just as you do. Listen to them, and work with him or her to achieve them. I can tell you from personal experience that rehabilitation professionals who are not willing to see their clients as capable human beings are doing them a disservice. My counselor did many good things for me, but the one thing that I best remember is a conversation during which he tried to persuade me to pursue a career in computer programming. I had told him frequently that this field held no interest for me whatsoever. Although I now have very positive feelings and a great deal of respect for my lead professor in graduate school, I did not feel that way when he tried to exempt me from having to do a work sample as part of a class assignment.

As you reflect back on your life and career 15 years from now, perhaps you will remember reading a small chapter written by a blind guy who knew how to put sour cream on his baked potato. Remember that this guy was once a rehabilitation client and that he chose his career with the assistance of his counselor. As you do so, commit yourself once again to honoring the capabilities of each of your clients, and do the very best that you can to guide them as they exercise their right to chart their life course.

DISCUSSION QUESTIONS

1. Are there any real meaningful differences in the terms adjustment, reaction, adaptation, and response? How might they be the same or different?

2. Of the seven proposed adaptation theories of adjustment to disability, which one(s) appear to have the greatest face validity and why?

3. Is the author correct in claiming that the theories are essentially describing the same phenomena?

4. Which functional abilities (e.g., sight, mobility, cognition, auditory) would be the most difficult to lose, and what abilities and subsequent enjoyable activities would you have left?

5. Which might be more difficult to experience: being born with a disability, or sustaining one later in life?
EXERCISES

A. Have students list what their top five most enjoyable activities are, then develop a list of five other potential substitute activities if they were no longer functionally able to enjoy the top five anymore because of a disability.

B. Ask students to outline what they perceive would be the single most difficult aspect of adjusting to any disability.
CHAPTER 7

Sexuality and Disability

Noreen M. Graf

OVERVIEW

Sexuality and disability is a topic that has been neglected for a long time by professionals. In their review of the literature, Kazukauskas and Lam (2010) identified the reasons for this neglect: inadequate supports, time constraints, no guiding policies in facilities, lack of training, negative attitudes, and discomfort on the part of counselors. Additionally, they noted recent studies that reported counselors’ limited knowledge and discomfort in addressing body and sexual functioning topics such as bowel and bladder functions, body image, sexual acts and behaviors, sexual preference, and reproductive function and choice (Booth, Kendall, Fronek, Miller, & Geraghty, 2003; Haboubi & Lincoln, 2003). Kazukauskas and Lam (2010) contend that rehabilitation counselors may be the only professionals who remain with the consumers throughout the process of rehabilitation and are ethically committed to addressing the full range of needs for people with disabilities so that consumers can become as fully integrated and independent as possible. To accomplish this, they must be competent and knowledgeable about issues of sexuality:

The sheer nature of some sexuality issues (e.g., dysinhibition, sexually inappropriate behavior, social skills issues) necessitates that all rehabilitation professionals regardless of specialization, be able to handle sexuality-related situations that may arise. (Kazukauskas & Lam, 2010, p. 16)

Based on their study of 199 certified rehabilitation counselors related to knowledge, attitude, and comfort in addressing the sexuality and disability issues of consumers, the authors recommended enhancing training and education. This chapter focuses on (a) sexuality and related components; (b) disability and intimate relationships; (c) disability type and related sexual issues; (d) sexual orientation, sexual functioning, procreation, and parenting; (e) sex education, sex therapy, and sexual surrogates; and (f) sexual abuse.
SEXUALITY AND RELATED COMPONENTS

Defining Sexuality

Defining sexuality is complex because it involves all the factors that affect how individuals view themselves and behave about their gender. Their upbringing influences them, the culture they associate themselves with, and the society at large. The World Health Organization states, “The definition of sexuality is complex: it includes gender roles and sexual orientation and is influenced by the interaction of biological, psychological, cognitive, social, political, cultural, ethical, legal, historical, religious and spiritual factors” (World Health Organization, 2010a, p. 4). Daily (1984) views sexuality from a psychological, emotional, and functional perspective and describes sexuality as having five components: identity, intimacy, sensuality, sexualization, and reproductive aspects. Identity is the continual process of discovery of who we are in relation to our sexuality, intimacy refers to the emotional closeness with others, sensuality is the experience of our body through our five senses, sexualization is the use of the body for the benefits of control, manipulation, and influencing others, and finally, reproductive aspects involve the functions of conceiving and child-rearing.

It is important to understand that these components are integrally connected and influenced by society and culture and by the rules set up to govern sexual behaviors, including the selection of a socially acceptable mate. Although society seems to be allowing for greater flexibility regarding sexuality, it is more aptly described as increased tolerance for those who deviate from the expected norm. In 2015, the U.S. Supreme Court ruled same-sex marriages to be legal in all states citing the 14th Amendment of the Constitution which addresses citizens rights and equal protection of the laws (U.S. Supreme Court, 2015). As well, hard-fought legal sanctions against discrimination based on race or ethnicity have created tolerance for marriages among people of differing cultures. However, tolerance for marriages of sexual relationships and sexual expression for people with disabilities is yet to be achieved.

Sexual Stigmatization

Vash and Crewe (2004) discussed the historical sexual stigmatization of people with disabilities as originating from biological and social sanctions that attempted to eliminate what was viewed as a “defective gene pool” because survival was based on physical abilities. As the society has progressed, survival is no longer contingent on physical ability. Vash and Crewe (2004, p. 85) pointed to a lessening of “the rejection of disabled mates.” This is a far cry from “acceptance,” which is apparent to those people with disabilities seeking mates and may profoundly affect their self-esteem as finding a mate is often regarded as symbolic of one's desirability and worth.

Olkin (1999) discussed sexual myths about people with disabilities (PWDs), noting that much of society views PWDs as lacking a sex drive, incapable of sexual performance, and lacking both the social skills and appropriate judgment to be sexually appropriate. People without disabilities (PWOD) who partner with PWDs are frequently viewed as either deviant or desperate. Moreover, a number of myths related to the sexuality of women with disabilities (WWDs) may negatively affect the behavior of individuals in society and the willingness to engage in romantic and intimate
relationships with PWDs. Morris (1993) describes some of these from an insider perspective:

That we are naive and lead sheltered lives
That we are asexual or at best sexually inadequate
That we cannot ovulate, menstruate, conceive or give birth, or have orgasms
That if we are not married or in a long-term relationship it is because no one wants us and not through our personal choice to remain single or live alone
That our only true scale of merit and success is to judge ourselves by the standard of their world
That we are sweet, deprived little souls who need to be compensated with treats, presents, and praise (Morris, 1993, p. 16)

The impact of rigid social role expectations on PWDs has been profound. As early as the 1980s the rehabilitation literature has discussed the psychosocial issues related to the stigmatization of WWDs as asexual and dependent. When women are viewed as unable to meet their obligations to have children or nurture children, and when they are viewed as unable to be employed, society views them as both roleless and sexless (Danek, 1992; Thurer, 1991).

Social Construction of Gender Identity and Body Image
Clearly, PWDs are deprived of sexual equality despite social advances. To further understand this disparity, it is necessary to examine the social construction of gender identity and body image. Although gender usually refers to the biological makeup of a person, there is also a strong social component that contributes to how we define sex differences. Our gender expectations, roles, and interactions are also determined by the social distribution of sex-based power and resources (Gentile, 1993).

Gender-based roles influence how individuals think and feel about themselves and others as males and females. For example, in a traditional North American household, women are expected to have greater responsibility tending to the household and the children, and men are expected to take on greater responsibility in providing financial support for the family. These roles reinforce the woman as a psychological/emotional caretaker and the man as a physical/financial caretaker. If a woman is physically, psychologically, sensually, or developmentally impaired, how will she clean the house? How will she bathe the children? Will she be able to engage in sexual activity with her husband? If a man is impaired, how will he make money to pay the bills? How will he be able to manage house repairs?

Although these questions are still relevant today, it is clear that the lines that define the traditional role distribution have become increasingly blurred. It is frequently necessary for both partners to have full-time jobs to support the family, parenting roles and responsibilities are shifting, and there is an increase in single-parent households. Even so, traditional roles and attitudes appear resistant to change because they are deeply ingrained in today’s social structure. Questions about being able to meet traditional roles and responsibilities continue to contribute to the reluctance to consider PWDs as intimate and sexual partners and to recognize and normalize the sexual needs and desires of PWDs.
Sedikides, Oliver, and Campbell (1994) examined gender differences about romantic relationships. In a study of the costs and benefits of romantic relationships, the authors noted that for both males and females, the most important benefits were described as companionship, feeling loved and loving, and happiness. However, females viewed intimacy, self-growth and understanding, and an increased self-esteem as more beneficial, and males viewed sexual gratification as more beneficial. Females viewed a loss of identity and innocence as a greater cost and males viewed the monetary loss as more consequential. In other words, females continued to believe they would be emotional caretakers at the risk of losing their identity and males continued to believe that they were less intimate and more responsible financially.

Impact of Gender-Based Values and Social Roles on PWDs

In our society, even our values tend to have either a masculine or feminine orientation. For example, assertiveness is associated with males and compassion with females. Interestingly, many of the values that guide rehabilitation professionals are masculine-based rather than feminine-based. For example, Burns (1993) noted that independence is a masculine-oriented goal, whereas interdependence and the importance of relationships tend to be a feminine orientation. Most rehabilitation counselors are quick to vocalize the importance of the greatest amount of independence possible as the outcome goal. This lack of taking gender into account can pose difficulties for consumers who have a strong female orientation. Although interdependence is still not a focus of rehabilitation, some agencies have begun to write a policy that reflects as much independence as desired by the consumer. In New York, the Vocational and Educational Services with Disabilities (VESID) website lists: “One major goal of the vocational rehabilitation process is to foster the greatest degree of independence and responsibility, as desired by an individual” (VESID, 2017, para. 3). Although still not an acknowledgment of the feminine perspective as equally viable, it leaves open the possibility of accommodating potential gender differences.

Burns (1993) noted that regarding sexuality, treatment discrepancies are apparent. For example, when male consumers exhibit inappropriate behaviors, they are more likely to be viewed as behaving “badly.” Similar inappropriate behaviors from female consumers are considered as “psychological problems.” Similarly, Scotti, Evans, Meyer, and Walker (1991) noted that women are more likely to be punished or medicated for equivalent sexual behaviors that may be ignored or rationalized when exhibited by male clients. Much needs to be done to create equality in treatment that gives consideration to issues of gender regarding values, expectations, and desires of consumers.

Self-Esteem and Body Image

The effect of social messages about sexual roles and expectations is profound. Messages from society, treatment professionals, caretakers, and the portrayal of sexuality by the media have had a great impact on how PWDs feel about their bodies and themselves. The fact that beauty is socially dictated is historically evident. From the paintings of Rubin, when larger sizes were an indication of beauty and prosperity, to the fashion photography of the present, where there have been recent bans against using severely
underweight models in advertisements, there is always a clear message from society regarding physical beauty and sexual desirability.

Today the average person in the United States is exposed to 5,000 advertisements a day (Aufreiter, Elzinga, & Gordon, 2003). Billions of dollars are spent on making the body fit into whatever socially constructed image of beauty is currently accepted. People subject themselves to endless diets. They have surgeries to alter their face; to add and subtract from their breasts, hips, and stomach size and shape; and recently surgeries have been performed to increase height that involve cutting and lengthening one's leg bones. People receive injections to reduce lines on their face, have hair transplants, and spend billions of dollars on products that claim to make them appear younger. All this is for the sake of conforming to socially imposed standards that people hope will render them attractive to others, and therefore more desirable and ultimately more lovable. What is the message in all this to people with physical deformities, with losses of limbs or other body parts, and for those who need mobility aids?

In a study of sexual identity, body image, and life satisfaction among 134 women with and without physical disabilities, Moin, Duvdevany, and Mazor (2009) noted similar sexual desires and needs, but differences in lower levels of body image, sexual self-esteem, and sexual and life satisfaction for WWDs when compared with women without disabilities (WWODs). These differences were even more apparent in younger women. The study also found that about one-third of the WWDs did report sexual satisfaction, and that sexual satisfaction was also found to be strongly correlated to life satisfaction.

When physical appearance is altered as a result of disability, the body falls further away from the expectations of society and body image, and the attitude one has toward the physical self may decline and affect self-esteem. A low self-esteem affects a person’s willingness and confidence to engage in social activities and to engage in relationships with others. Lack of socialization can further contribute to a person’s isolation, lower quality of life, and lack of self-confidence to the point that the possibility of rejection appears so great that it may no longer seem worth the risk. People with physical anomalies may fear that others will laugh at them, reject them, or come to think of them as deviant. Even more than the body, the face plays an important role in a person’s self-image and self-identity and is distinctly different from that of the rest of the body.

Callahan theorized that each body part holds a symbolic meaning as well as functional use; arms symbolize strength, hands symbolize creativity and the ability to provide, legs represent speed and vitality, and reproductive organs indicate pleasure, intimacy, and procreation. In her examination of facial disfigurement (one’s self-presentation to others) in people with head and neck cancer, Callahan described the “profound psychological trauma” (Callahan, 2004, p. 73) that can occur regarding one’s bodily integrity and sense of self. Similarly, 60 years ago, in reviewing psychosocial problems associated with facial deformities, MacGregor concluded that, coupled with the adjustment problems of the person and societal negative attitudes, prejudice, and discrimination:

Wherever plastic surgery can correct or improve the facial injury or congenital malformation, it should be undertaken as early as possible in order to avoid not only the obvious disadvantages but to prevent deep psychological wounds which may be incurred but not so easily eliminated. (MacGregor, 1951, p. 638)
In brief, accepting and loving one's body as it is in a society that does not endorse or support such a notion is challenging. A number of practices can assist in increasing body image, but much of it relies more on changing one's thinking than one's body, refusing to accept the media-portrayed image of the beautiful man or woman, and giving up the practice of comparing oneself with those photo-altered images of often emaciated women or muscle-bound men. Yuen and Hanson (2002) concluded that physical activity could increase body image for people with acquired mobility impairments. In their study, people who were physically active evaluated both their physical appearance and their health as more positive; they showed more concern about their physical fitness and were more satisfied with their bodies than those with a mobility impairment who were not active.

Some studies also suggest that attention to making oneself as attractive as possible has positive effects on self-image and physical appearance for PWDs (Kammerer-Quayle, 2002). Elks noted that physical attractiveness had been shown to affect:

Heterosexual dating, peer acceptance, teacher behavior, attitude change, employment interviews, and jury decisions, and that attractive people are less likely to be judged to be mentally ill, are liked and helped more, and judged to have higher social skills and greater opportunities for social interaction than unattractive people. (Elks, 1990, p. 36)

A recent controversy over cosmetic surgery for children with Down syndrome (DS) brought to light the ethical dilemmas involved in such a practice when in 2008 the parents of a child with DS subjected the 5-year-old to a number of surgeries on the tongue, eyes, and ears to correct the facial indicators of DS. As parents, they sought to eliminate the future stigmatization their child would face, but some bioethicists argued that it was an unnecessary and elective surgery that should have waited for the child to reach the age of consent (Fox News, 2008). Adult protective services have also expressed concerns related to a growing increase in cosmetic surgery for people with intellectual disabilities (Cambridge, 2002), and a number of cases have come before hospital ethics boards weighing the value of enhancement and restorative procedures in adults and children (Opel & Wilfond, 2009). The National Down Syndrome Society (NDSS, 2011) acknowledges cosmetic surgery for children with DS as a personal choice of parents but does not encourage cosmetic surgery, stating that:

The goal of inclusion and acceptance is mutual respect based on who we are as individuals, not how we look. Altering a child’s appearance as a means of encouraging acceptance does not change the reality of the disability. In fact, some education experts believe that the physical characteristics of Down syndrome may offer visual cues to people about an individual’s disability and thus foster an easier acceptance and understanding of that disability. Many families believe that to alter their child’s facial features would be to disrespect his or her individuality and that an important part of that individuality is the condition of Down syndrome. (NDSS, para. 3)

For rehabilitation counselors, simply ignoring the importance of physical appearance or waiting for an adjustment to occur is not appropriate, because appearance is clearly
tied to how people feel about themselves and interact with others. Kleve, Rumsey, Wyn-Williams, and White (2002) demonstrated the importance of social supports and interactions in a positive adjustment to disfigurement. However, the interaction may depend on self-esteem, and self-esteem may be tied to body image. Thus, attention to physical appearance may need to move beyond basic hygiene concerns to the application of cosmetics and, in some cases, cosmetic surgery. These considerations have historically been extended to PWDs only on a limited basis, such as for those with facial burns. However, a person's level of adjustment to having an apparent physical difference also needs to be taken into consideration because those with poor adjustment may demonstrate feelings of depression, social avoidance and anxiety, fear of being evaluated negatively by others, and shame. Demographic variables, including age and sex, can also influence adjustment to physical differences. Overall, women reported more difficulty than men with visible physical differences, and late adolescents and young adults also typically have greater concern for visible differences. Even hidden physical differences can interfere with adjustment because if the physical differences are typically concealed, distress may also be high because of the fear of others finding out, suggesting that the secrecy and anticipated discovery by others can also increase distress (Moss & Rosser, 2008).

DISABILITY AND INTIMATE RELATIONSHIPS

Partnering Desires and People With Disabilities
In 1943, Abraham Maslow identified basic human needs like love, affection, and belonging that encompass both the need to love and the need to feel loved to overcome loneliness and feelings of alienation. Although recognizing the need for love, Vash and Crewe (2004) discussed pairing as a part of a preprogrammed biological drive that is reinforced, if not required, by society. The state of being without a partner is viewed by society as an indication of one's inferior status, bringing humiliation and disgrace to the individual. The proof of one's worth often comes with the acquisition of a partner. Much of today's values are embedded in past survival needs that are no longer relevant; a time when lack of medical sophistication led to numerous infant deaths and death of mothers during childbirth. As successful procreation was far more contingent on physical makeup, people with disabilities were excluded from consideration as life partners and dismissed as sexually responsive or desirable. Changes in survival rates and medical advances appear to have little effect on some attitudes as persons who do become partners of PWDs are frequently seen as being less intelligent, and less sociable, than partners of PWODs (Goldstein & Johnson, 1997).

PWDs are not excluded from experiencing partnering desires or, unfortunately, from the messages imposed by society. They look to attract partners for reasons of love, intimacy, and security, yet it is difficult to see role models with disabilities represented as sexually and physically attractive. For some PWDs, values of physical beauty become less meaningful to the fulfillment of their lives, yet the importance of relationships and pairing do not necessarily diminish (Wright, 1960). Vash and Crewe (2004) note that like PWODs, not all PWDs are interested in pairing or having children, but for most people partnering is a strong urge. Not only do they need to deal with the
devices that indicate a disability, such as wheelchairs, canes, and so on, which may cause people to reject them, but they also need to overcome the negative or dismissive attitudes of others.

**Attitudes of PWODs**

Perhaps the greatest barrier to partnering is the attitudes of PWODs. A few studies have looked at how attractive PWODs find PWDs (Man, Rojahn, Chrosniak, & Sanford, 2006; Marini, Feist, Chen, Torres-Flores, & Del Castillo, 2011; Miller, Chen, Glover-Graf, & Kranz, 2009). Rojahn, Komelasky, and Man (2008) found that college students reported similar romantic attractiveness to people with and without disabilities but noted a clear preference shown for physical health, suggesting a disconnection between the explicit ratings and implicit attitudes. Some researchers have also investigated attitudes toward having relationships with PWDs (Howland & Rintala, 2001; Kreuter, 2000; Snead & Davis, 2002; Wada et al., 2004). Wong, Chan, Da Silva Cardoso, Lam, and Miller (2004) concluded that the type and severity of the disability are major determinants in the choice to become involved with a PWD. Miller et al. (2009) found that college students were willing to have friendships and acquaintanceships with PWDs, and also willing to date PWDs; however, they were least willing to marry or have a partnership with PWDs, especially with those having severe disability. Additionally, PWODs were more willing to become involved with persons with physical disabilities and least willing to engage with persons with psychological disabilities.

**The Impact of Type of Disability**

Antonak (1981) noted a hierarchy of stigma attached to disability; those with physical disabilities receive the least social stigma, and those with psychiatric disabilities receive the greatest stigma. Gordon, Chariboga-Tantillo, Feldman, and Perrone (2004) assessed attitudes regarding friendship and marital relationships with PWDs and concluded that the majority of students were more willing to be friends with persons with medical, physical, and sensory impairments, but were less inclined to want friendships with persons with mental retardation and psychiatric illness; only 13% stated that they would marry someone with a psychiatric illness and 4% with mental retardation. In their study, Miller et al. (2009) found that college students were the least willing to marry or have a partnership with persons with cognitive or psychiatric disabilities.

**The Impact of Severity of Disability**

Taleporos and McCabe (2003) found that people who reported greater severity of disabilities as measured by the level of independent functioning were less likely to have partners or to be married than those with less severe disabilities. Individuals with the most severe disabilities were also less likely to have partners and were less likely to be married than those with less severe or no disabilities. Similarly, Miller et al. (2009) determined that the more severe the disability, the less willing PWODs were to engage in a relationship. While this finding is expected and distressing, they also found that the personal attributes of intelligence, kindness, and humor in PWDs were the most
likely factors to overcome intimacy reluctance on the part of PWODs by increasing their reported willingness to enter into more intimate relationships with PWDs.

Although not often seen in the rehabilitation literature, Vash and Crewe (2004, p. 97) noted that some people are sexually attracted to amputees. While they term this as “unwholesome turns,” they also note that there is some discussion regarding if such an attraction “empowers or exploits people with disabilities” (Vash & Crewe, 2004, p. 98). The notion of rejecting society’s repulsion of a stump is powerful. Terming such an attraction as “sick” plays into the ever-present insistence that society regulates beauty. If, however, there is coercion, manipulation, or force used in the satisfaction of one person’s desires, the health of the fantasy is a moot point because abuse is in place. In a 1998 documentary titled My One-Legged Dream Lover, Kath Duncan explores amputee fetishism (Duncan & Goggin, 2002) as having a limited number of researchers (Dixon, 1983; Kafer, 2000). The website ASCOT-World (www.ascotworld.com) is a disability and amputee support group and social club that contains an online matchmaking service welcoming devotees (the term used for nondisabled persons who are attracted to persons with amputations).

The Impact of Types of Relationships

For a number of reasons, PWDs often have more difficulty forming friendships and finding partners for romantic relationships than PWODs (De Loach, 1994; Goldstein & Johnson, 1997; Howland & Rintala, 2001; Rintala et al., 1997). One reason revolves around the process of obtaining a mate, which progresses from an acquaintance relationship to friendship, courtship, romance, and finally to a long-term commitment. Although most people seem willing to acknowledge and interact with people with disabilities on an acquaintance level, some studies have shown that many people are less willing to progress to dating and marriage.

A few studies have examined the attitudes of PWODs about engaging in intimate relationships with PWDs. These studies have concluded that PWDs may have difficulty making friends, forming romantic relationships, and finding partners. For the most part, these are discouraging in that PWODs express a willingness to have casual relationships but are less willing to date or marry PWDs (Miller et al., 2009).

In a survey of 1,013 students, Hergenrather and Rhodes (2007) found that females held more positive attitudes toward dating and marrying PWDs than did males. Measuring attitudes is important; however, attitudes do not necessarily translate into action. Despite more reported positive attitudes among females without disabilities, males with disabilities reported that WWODs were only interested in friendships. Likewise, WWDs believed that men made judgments not to date them based on devices such as wheelchairs and prosthetic devices.

Fear and discomfort may also play a role in a person’s decisions related to intimacy with PWDs. Milligan and Neufeldt (1998) found that women were more willing to date men with a spinal cord injury (SCI) if they had previously been in relationships with PWDs, suggesting that initial discomfort may be overcome with exposure. Another important factor in this study was the level of independence and adjustment of the male as being relevant to female willingness to consider partnering; those perceived as more adjusted were more desirable partners. Thus, not only does the PWOD need to work...
through discomfort and uncertainty, but the PWD is more desirable if viewed as adjusted and more self-sufficient. In this study, other concerns of females about dating persons with SCI were reported as caregiving, health concerns, restriction of activities and physical limitations, financial issues, and sexuality/conception issues.

Similarly, in a study examining the attitudes of 395 college students, Marini et al. (2011) found that 66% of students surveyed indicated that they would not have a problem dating someone in a wheelchair after having seen a photograph and reading a brief bio of the individual. Of the 33% who indicated that they would not be willing to become intimately involved with people in wheelchairs, the top-rated reasons included the perception of caretaking as being too much work, feeling awkward in not knowing what to say or how to treat them, believing they would be sick too often, and believing that the PWDs could not be sexually satisfying. Those students who had had a previous close relationship with someone with a disability, however, were more likely to be open to having a more intimate relationship. The authors concluded that students with a past close disability relationship could separate societal myth and misconceptions regarding wheelchair users.

For many people, a committed and loving marriage is the ultimate goal. The ability of a relationship to withstand challenges depends on the particular strengths of the couple both individually and as a pair. Couples who enter a relationship where disability is already a factor do so with at least some anticipation of the potential challenges they face. However, when disability occurs after the establishment of a relationship, greater difficulties have statistically been supported, and divorce is more likely to occur (DeVivo & Richards, 1996).

Kreuter (2000) examined the relationships of 49 persons with SCI and concluded that those who were injured before the marriage had more stable marriages than those injured after marriage. Similarly, sexual satisfaction was reported as greater among couples where the marriage was postdisability (Crewe & Krause, 1988). In predisability marriage, when one partner became the caregiver of the other, there was a negative impact on the relationship; and, when the partner with the disability was female, there was a greater likelihood of divorce. Overall, divorce statistics for people with disabilities are high, and there is a lower rate of marriage among this population (DeVivo, Hawkins, Richards, & Go, 1995; Urey & Henggeler, 1987). DeVivo et al. (1995) examined over 600 recorded marriages among people with SCI and found almost twice as many divorces as would be expected among nondisabled persons of the same age and gender.

**DISABILITY TYPE AND SEXUAL ISSUES AND CONCERNS**

**Sexuality and Physical Disabilities**

In a study to examine sexuality and quality of life, McCabe, Cummins, and Deeks (2000) reported that people with congenital physical disabilities had a low level of sexual experience and knowledge and had negative feelings related to sexuality, but they had high sexual needs and desired to increase their sexual knowledge. In terms of sexual experiences, 12% had never romantically kissed or hugged anyone, nearly 30% had never held someone while naked, almost 40% had never engaged in sexual intercourse, and 60% were not currently having intercourse in a relationship. Their study determined that although sexuality
was associated with quality of life, it was not associated with life satisfaction, making the point that, at least for their sample, sexuality and sexual experiences add an important and desired dimension to life but are not necessary for achieving satisfaction in life.

Shakespeare (2000) noted the social and financial difficulties related to establishing a sexual relationship as follows:

> It also helps to have someone to have sex with. Most people meet potential partners at college, at work, or in social spaces. Unfortunately, disabled people often don’t get to go to college, or to work, or achieve access to public spaces because of physical and social barriers. Being sexual costs money. You need to buy clothes, to feel good about, and go places to feel good in. If you are poor, as 50% of disabled Americans are, then it is correspondingly harder to be sexual. More than money, being sexual demands self-esteem. It demands confidence, and the ability to communicate. (Shakespeare, 2000, p. 161)

Taleporos, Dip, and McCabe (2002) point to the positive connection between sexuality variables and psychological well-being. In a study of 748 PWDs and 448 PWODs, they found that people with higher self-esteem were more likely to be sexually satisfied and feel good about their bodies and their sexuality. However, because WWDs are frequently viewed as asexual (Di Giulio, 2003), little attention has been paid to their sexual functioning, creating barriers to sexual fulfillment faced by women. Stinson, Christian, and Dotson (2002) found that because of negative stereotypes, women with developmental disabilities (DD) lacked access to gynecological health care, were given limited choices regarding reproductive issues, and had a lack of sex education. In addition, several social, psychological, and physical barriers prevent women from sexual expression and functioning (Christian, Stinson, & Dotson, 2001; Westgren & Levi, 1999). In a qualitative study of adults with physical disabilities, Kattari (2014) found that there was a lack of confidence among participants to bring up disability in sexual negotiations. Participants’ previous attempts to discuss needs associated with their disability had resulted in their partners shutting down, being unsupportive, or exhibiting behaviors that hurt their feelings. Even participants who described their partners as open and validating around sexual topics struggled with self-esteem, and lacked confidence to ask for their wants and needs to be met.

Vash and Crewe (2004) point to a number of physical issues related to sexual activity, including the effects of paralysis, pain, amputations, neurological impairments, and bowel and bladder dysfunction, on the ability to experience erotic sensation. In a study of 504 WWDs and 442 WWODs, to compare sexual experiences, Nosek, Howland, Rintala, Young, and Chanpong (1997) reported that WWDs did not differ from WWOD in sexual desire but they did find significantly lower levels of sexual activity, satisfaction, and response. The level of sexual activity among WWDs was predicted by living with a significantly positive attitude. Women who had a more positive self-image and viewed themselves as approachable reported higher sexual activity. Interestingly, the severity of their disability was not a factor in the level of sexual activity. Factors related to positive sexual response included having a positive attitude toward using assistive devices, higher income level, and less stereotypical concern. Greater sexual satisfaction was predicted by sexual activity and a more positive attitude about assistive devices.
Problems related to sexual functioning after SCI are reported as arousal, frequency of sexual activity, initiation, and enjoyment (Klebine, 2007; Kreuter, Sullivan, & Siosteen, 1994). Two interesting qualitative studies conducted by Whipple, Richards, Tepper, and Komisaruk (1996) and Richards, Tepper, Whipple, and Komisaruk (1997) reported that women with SCI initially dissociate themselves from their sexuality, believing that they can no longer experience sexual pleasure. Over time they may become ready to reintegrate sexuality into their lives. Men with SCI are more likely to report limited opportunity for sexual expression and are often unsatisfied with their sexual lives.

In a study to examine issues that negatively impact sexuality for men with SCI, Sakellarious (2006) identified the topics of dependency, spread, body beautiful, social disapproval, personal assistance, and impairment as barriers. Participants revealed that the frustration that comes from societal views of independence is more closely related to body performance rather than self-direction. Participants stated that others were more likely to see the wheelchair than the person in it. Like women, participants believed that they were being held to a standard of the socially prescribed beautiful body, which they could not attain, leading to “aesthetic anxiety.” Practically, the need for a personal assistant was also noted as a barrier to sexual expression because privacy was limited in that attendants needed to undress, empty the bladder, and position the individual for them to participate in sexual activity. Physical impairment of bodily sensation also was noted as a barrier for some as were financial resources and environmental barriers that limited accessibility.

Sexual Concerns and Learning Disability
Concerns related to the sexual function of people with DD differ greatly from those related to people with physical challenges and are frequently based on the capacity of the person to understand sexual functioning in terms of consequences and the rights of others. Szollos and McCabe (1995) noted that people with intellectual disabilities frequently have misinformation related to sexual functioning. Staff members who care for persons with learning disabilities frequently experience discomfort with the sexual expression of such individuals. Double standards are commonplace in the beliefs related to sexuality and people with learning disabilities. One study, for example, found that even people opposed to abortion on moral grounds believe that it should be made available if the woman has a learning disability. Staff members were also found to frequently rely on personal judgments rather than facility policies when they felt a need to address sexual behaviors by residents. Many times this led to the cessation of normal sexual expression and interaction. At other times, staff members tolerated inappropriate behaviors or sexual harassment rather than deal appropriately with these behaviors (Parkes, 2006).

There are also concerns related to the sexual abuse of others that appears to occur with greater frequency among this population than the general population (Brown & Stein, 1997). In a study of mild and moderate learning disabilities to investigate how women experience their sexual lives, McCarthy (1998) reported that these women commonly find themselves engaged in sexual activity that is not to their liking and not of their choice and point to a lack of preparation of social service providers on how to deal with behaviors and events related to sexual abuse by and to people with developmental impairments (Brown & Turk, 1992; Brown, Hunt, & Stein, 1994).
Men with learning disabilities may present caregivers with a number of challenging behaviors, including the use of pornographic material, cross-dressing, prostitution, and pedophile tendencies. When looking at the sexual encounters of men and women with learning disabilities, it is interesting to note that women without learning disabilities do not engage in sexual contact with learning-disabled men, but men without disabilities do engage in sexual activity with both men and women with learning disabilities. Pornography is often gained through those sexual encounters and intended to create sexual vulnerability. Cross-dressing is problematic when the theft of women’s clothing takes place, when embarrassment or ridicule results, or when it results in abuse of the PWDs. Prostitution also renders men, like WWDs, vulnerable to sexual assault, sexually transmitted diseases, and exploitation. Men with disabilities may be offered goods and money for sex in public parks and toilets. Whereas WWDs tend to be at a greater exploitation risk in treatment facilities, men are at greater risk in public areas. This type of exposure may lead to sadomasochistic sexual activities that can be adopted by the PWDs and then perpetrated on others. Finally, there is concern that men with learning disabilities may have pedophile tendencies. Although this may be an accurate representation of some males with DD, behaviors that indicate sexual interest in children seem to indicate developmental immaturity; identifying and relating to children may be because of the neglect of their sexuality (Cambridge & Mellan, 2000).

Sexuality and Cognitive Disabilities

Cognitive impairments, such as those that occur as a result of a cerebral vascular accident (stroke) or a traumatic brain injury (TBI), can include physical impairments but typically include behavioral, emotional, and intellectual problems. According to the Centers for Disease Control and Prevention, there are about 1.5 million TBIs per year, and most occur in young males with 85% occurring before the age of 25 years. Sexual dysfunction following brain injury is common and may include impotence, lack of ability to ejaculate, premature ejaculation, loss of sensation, diminished sexual libido and body image, sexual identity problems, decreased self-esteem, disturbing exhibitionist behaviors, sexual preoccupation, and masturbation (Ducharme, n.d.; Ducharme & Gill, 1990; O’Carroll, Woodrow, & Maroun, 1991).

As the ability to regulate behaviors is diminished in people with head injury, other behaviors may also emerge that are detrimental to satisfying sexual experiences. For example, people with head injuries may be distracted during sexual activity; they may talk incessantly or aimlessly or may experience fatigue and confusion. Emotionally, people with TBI may be lacking in emotional connection or sensitivity toward their partners and may exhibit self-centered behaviors, showing little regard for their partners’ needs or desires. Treatment for sexual and other behavioral problems includes medications and behavioral therapy (Ducharme, n.d.).

Sexual Concerns and Psychiatric Illness

Intimate relationships among persons with serious mental illness (SMI) also differ from people in the general population in that there is less intimacy and less commitment in
these relationships. They tend to have sex sooner, and the relationships are for a shorter term. They are also more likely to have concurrent sexual relationships and report being less sexually satisfied in their sexual encounters (Perry & Wright, 2006). According to a review by Matevosyan (2009), “Women with SMI have more lifetime sex partners, lower contraceptive usage, higher rates of unwanted pregnancies, and are at high risk for sexually transmitted infections” (p. 109). Of all the types of disability, psychiatric disabilities are the most stigmatized, and that contributes, along with lower income and less social opportunities, to these people pairing with others who are also less socially accepted. According to Perry and Wright (2006),

People with serious mental illness are often forced to try to meet their sexual needs or forge a relationship with other “social undesirables.” In short they seem to take what they can get in terms of where, when, and with whom to have sex. This not only results in relationships that are less satisfying, less intimate, and much shorter lived, but also increases HIV risk by concentrating sexual activity within high-risk populations like IV drug users, sex workers, and others with serious mental illness. (Perry & Wright, 2006, p. 180)

In general, people with mental illness do not use safe sex practices, report lack of satisfaction with their sexual and social lives, and lack a sense of intimacy in relationships. Consumers who live in residential care settings also lack privacy. A number of barriers exist to fulfilling sexual activity in residential settings, including policies that require shared rooms, no sexual activity, frequent histories of sexual abuse, social stigmatization and low self-esteem, medications that interfere with desire and function, intrusive symptoms, social skill deficits, and a lack of support and education related to sexual expression and activity (Cook, 2000).

In an overview of sexuality and psychiatric disabilities, Knoepfler discusses differences in sexual functioning, noting that people with depression are likely to show little sexual desire, as opposed to people with manic disorders who may exhibit rapid transitions in desire and rapid escalation. Knoepfler states that people with personality disorders are varied but “tend to act in impulsive ways disregarding consequences” (Knoepfler, 1991, p. 214) and that persons with schizophrenia, who experience an inability to distinguish between fantasy and reality, may imagine or engage in bizarre sexual behaviors (Knoepfler, 1991). As there are different types of schizophrenia, this characterization is likely true for only a small portion of individuals with the disorder; however, one contribution of this work is that it makes clear that it is important to consider the effects of specific diagnoses on sexuality to avoid the trap of stereotyping individuals in terms of sexual needs, desires, and behaviors.

In a study specific to understanding sexuality among persons with schizophrenia, Volman and Landeen (2007) studied five women and five men with schizophrenia. They found that participants did form and maintained intimate relationships. They viewed their sexuality as one of the factors that made them the same as people without mental illness. They considered their sexuality as part of their well-being and essential in their lives. Sexuality was viewed as physical and emotional and more meaningful when sex was within the context of an intimate relationship. However, all the participants felt that the symptoms of their illnesses and effects of the medications had a strong impact on
their sexuality and compromised their view of themselves, sexual functioning, and ability to have intimate relationships. They noted problems with hearing voices, weight gain, difficulty with achieving orgasm, and a decline in libido. Participants also discussed the effects of social stigma that resulted in being judged and rejected, delaying the age of sexual knowledge and experience until much later in life. Finally, strategies that helped participants were identified as using counseling, medical compliance, positive self-talk, and engaging in a healthy lifestyle. However, talking about sex was identified as causing shame and embarrassment, often leading to not bringing up important concerns with clinicians.

Sexual Concerns and Chronic Health Conditions

For people with chronic health conditions, physical limitations and pain as well as the emotional state may affect sexuality. Persons need to be able to communicate changes in sexuality, including interest, a need for different types of sexual stimulation, and altered positioning and activities. Body pain may have a direct influence on sexual activity and persons may need to make adjustments, such as interrupting sexual activity multiple times to deal with pain or wait for it to subside. This may lead to avoidance of sex with a partner and feelings of grief over the loss and fear of impotence. Partners may feel unloved, angry, and resentful. They may also feel guilty for diminished empathy and cause pain to their partners. Pain management, sexual preferences, and alternatives that take into account religious, cultural, and personal beliefs may be assistive, along with couple’s therapy (Claiborne & Rizzo, 2006). In a study to examine the impact of gynecological cancer on marriage and levels of loneliness, Kömürçü, Beydag, and Merih (2015) found that nearly 80% of the patients reported that their sexual lives changed and almost half the patients stated that they felt lonely. Approximately 60% felt that their husbands were less supportive and half believed that they were in need of psychological support.

Other chronic health conditions are HIV and AIDS. For this population, most of the literature focuses on the prevention of infecting others through abstinence or the use of condoms. In a study of over 2,000 men who had sex with men, 40% were found to engage in unprotected anal sex with a person of unknown HIV status (Golden, Brewer, Kurth, Holmes, & Handsfield, 2004). Although much of the sexuality literature for people with other disabilities focuses on assisting them in engaging in healthy sexual behaviors, little is written for persons who are HIV positive. Not only do they need to focus on not infecting others but also they must protect themselves from acquiring new strains of the virus or other sexually transmitted diseases (STDs), placing them at a greater health risk. In addition, persons who are HIV positive have concerns related to telling partners, anger if they believe their partners transmitted the disease to them, and fear or guilt if they have transmitted the disease to their partners (HIV InSite, 2005). For women who are HIV positive and become pregnant, the risk of the child contracting HIV is about 25% if precautions are taken and considerably less with the appropriate use of medication. As vaginal delivery and breastfeeding increase the risk of contraction, these are avoided for HIV-positive women. Couples who wish to have biological children risk infection of one another (if one partner is not seropositive) and the child. The risk may be reduced by minimizing the number of unprotected sexual interactions through only engaging
in unprotected sex at the point of ovulation. Another method is to use intrauterine insemination after washing the sperm free of HIV (Gilling-Smith, 2000).

SEXUAL ORIENTATION, SEXUAL FUNCTIONING, PROCREATION, AND PARENTING

Sexual Orientation and PWD

Kline (1991) referred to sexual orientation as encompassing heterosexual, bisexual, and homosexual relations. In addition, there are people who do not engage in the sexual activity, who are referred to as nonsexual, and persons who have a lack of any sexual orientation, referred to as asexual. Kline also distinguishes sexual orientation from gender identity, which includes a psychological self-connection to a gender, to both genders, or to neither. Transgendered refers to persons who identify with the opposite gender. Transsexuals have received sexual reassignment procedures to physically change their biological identity, and transvestites use clothing and makeup to identify with the opposite gender.

Homosexual and bisexual preference in the general population vary from 2% to 13%, with more males than females reporting homosexuality. Few studies have examined the sexual orientation of PWDs; one study by Axtell (1999) featured interviews with bisexual and lesbian individuals and their partners who had disabilities. Nosek et al. (1997) examined sexual orientation of WWDs and found that 87% of the women with SCI were attracted to men, 4% were attracted to women, 7% to both men and women, and 2% were not attracted to either gender. McCabe, Cummins, and Deeks (2000) found that 16% of their sample of PWDs reported at least one same-sex experience and about 5% reported frequent same-sex activity.

Studies related to the cumulative effect of belonging to more than one stigmatized minority status are scant, but it can be assumed that negotiating living with a combination of racial minority status, disability, and gender identity issues might enhance marginalization. Rembis (2010) examined people who were disabled and identified as lesbian, and noted acceptance resistance from both the lesbian and the disability communities. In their review of the literature related to the challenges of lesbians with disabilities, Vaughn, McEntee, Schoen, and McGrady (2013) noted concealing disability and sexual orientation and controlling who is told about invisible disability and sexual orientation are implemented to manage stigma. “Because of the stigma experienced as a person with a disability and as a lesbian, many women try to hide their sexual identity until they feel safe enough to disclose and if at all possible, they hide their disability identity for as long as possible to avoid being ostracized” (p. 53). These issues become further complicated when racial discrimination is added to the pot. For example, racial discrimination in the gay community might be reflected in statements such as, “I don’t do Asians.”

Sexual Functioning

Overall, sexual functioning is important to PWDs, but sexual dysfunction is far more prevalent. In a study of 681 persons with SCI, return to sexual functioning was listed as
the top personal priority for people with paraplegia. It was the second priority for persons with tetraplegia, with only the desire for recovery of arm or hand function superseding sexual recovery desire (Anderson, 2004). For women with SCI, Jackson and Wadley (1999) found a substantial overall decrease in sexual activity following injury. However, over time, participation increased from 49% 1 year after an injury to 76% after 10 years.

Sexual dysfunction among couples in the general population is about 13% compared with 40% of persons with chronic diseases and 73% of persons with multiple sclerosis (MS; Zorzon et al., 1999). Sexual functioning for most WWDs is not physiologically impaired, but depending on the type and extent of the disability, a number of concerns may need attention. For women with an injury in the spinal cord, sexual dysfunction is most often related to a lack of desire to engage in sexual activity and may be more of an emotional and psychological problem than a physiological one. Initial concerns may be related to sexual satisfaction, exploration, and arousal. Individuals and couples may or may not need to try different methods for achieving sexual pleasures. Sexual arousal is both an emotional and physical response that may occur through any of the senses. Arousal can be achieved through the stimulation of any body part, including not only the clitoris and vagina but also breasts, mouth, ears, and feet. A willingness to explore options and discuss body pleasure and sensations is mutually beneficial.

A number of physiological issues are also of concern for women with SCI, including bladder management, bowel management, autonomic dysreflexia (AD), and spastic hypertonia. Bladder and bowel accidents can be minimized or avoided through the management of food and fluid intake and establishing a consistent routine for emptying the bladder and bowel. For women with catheterization, the bladder can be emptied before the sexual activity. Depending on the type of catheter, the catheter can be removed or partially removed, and the tubing may be fastened down with tape to avoid kinking or accidental removal. AD is a life-threatening condition that may be of concern for individuals with SCI. Although laboratory studies have not shown AD to be induced by sexual activity, an onset of multiple symptoms (rise in blood pressure, irregular heartbeat, fever, face flushing, chills, headaches, blurred vision, nasal congestion, and sweating) would require ceasing sexual activity and seeking medical assistance or advice (Spinal Cord Injury Information Network, 2007).

Males with SCI experience both emotional and physiological changes associated with their sexuality and sexual performance. In the general population, men experience psychogenic erection because of psychological arousal (sexual thoughts or visual or auditory stimuli) and reflex erections because of physical contact. For men with SCI, depending on the level and completeness of injury, impairment may occur to one or both of these functions. Men with low-level injuries may retain psychogenic arousal, but higher level injuries result in impairment of this function. However, most men with SCI can achieve reflex erections (unless the S2–S4 nerve pathways are damaged). Also, erectile dysfunction (ED) is not uncommon among men with SCI in that they may not be able to sustain an erection that is sufficient to meet couples’ desires. ED can be treated through medication or a variety of alternative treatments. Oral medication consists of phosphodiesterase inhibitors, such as Viagra® (sildenafil) or Cialis® (tadalafil), that increase blood flow into the penis. Risks of engaging in sex can include priapism (prolonged erection) that can be very painful because the blood fails to drain from the penis and can lead to permanent damage to the ability
to have erections; any onset of symptoms must be medically attended to immediately. Alternative treatments include injections directly into the side of the penis that produce erections that last several hours, placement of a pellet into the urethra (medicated urethral system erection [MUSE]), and the use of a hand- or battery-operated cylinder vacuum pump that pulls blood into the penis that is then constricted with a band (Spinal Cord Injury Information Network, 2007). A number of sex and masturbation products are available through Disabilities-R-Us (http://disabilities-r-us.com), a support and resource website created by PWDs. Another type of assistive treatment involves surgical implantation of a penile prosthesis of variable firmnesses or inflatable devices.

Similar physiological concerns (altered libido, bladder and bowel dysfunction, and spasticity) are present for persons with MS that have an onset between ages 20 and 40 years; it is twice as common in women as in men (Van den Noort & Holland, 1999). For women, decreased vaginal lubrication, impaired ability to masturbate, genital numbness, fatigue, depression, and decreased self-esteem are also of concern (Foley & Sanders, 1997); physical symptoms may be reduced through the use of vibrators, lubricants, and medication to reduce nerve pain. Christopherson, Moore, Foley, and Warren (2006) reported that educational materials are also beneficial in diminishing sexual difficulties for partners but recommend additional counseling for relaxation and positioning, as well as dealing with pain and depression. For all persons with neurological impairments, body mapping may be a useful technique because it involves discovery and mapping of the body parts that receive sensory pleasure, those that involve discomfort, and those that are neutral. This mapping identifies body areas that experience arousal and those that need to be avoided or protected (Matthews, 2009).

Fertility

Fertility issues for men deal primarily with issues of achieving ejaculation and collecting healthy sperm. As the quality of sperm declines following SCI, the collection of sperm within a week of the injury may prove important for men who wish to father biological children. After that time, sperm quality may not be sufficient for the production of children. Additionally, most men with SCI are unable to reach ejaculation, and the collection of sperm may need to be assisted through the use of penile vibratory stimulation (PVS), which uses a vibrator designed to provoke ejaculation. Semen is collected and processed in a medical setting to reduce the risk of AD. Other methods of collecting semen include electroejaculation, which applies electrical stimulation through the anus and induces the release of semen; prostate massage, which applies pressure and massage to the prostate gland; and surgical removal of sperm, which is both costly and the least effective method of viable sperm collection (Brackett, Lynne, Ibrahim, Ohl, & Sonksen, 2010).

For women with SCI, menstruation may cease at the onset of injury, but for the majority of women, it resumes within 6 months. Becoming pregnant and giving birth are not impaired, and birth control is resumed for women who are sexually active. Jackson and Wadley (1999) found that sexually active women with SCI showed a decrease in the use of birth control pills and an increase in elected sterilization and condom use.
Reproductive Choice

“Reproductive health implies that people are able to have a responsible, satisfying, and safe sex life and that they have the capability to have children and the freedom to decide if, when, and how often to do so” (World Health Organization, 2010b, para. 2). Public controversy over the right of some PWDs to marry stems largely from concerns related to the upbringing of children that may result from that union. Influenced by the Eugenics movement in the early 1900s, tens of thousands of persons with cognitive disabilities were institutionalized and prohibited from sexual relations until, in the 1920s, the cost of segregating and overseeing such large numbers became prohibitive. Sterilization was then implemented as a means of ultimately extracting “feeblemindedness” from society (Block, 2000). To control reproduction among persons with disabilities, nearly 30 U.S. states passed laws that permitted involuntary sterilization of PWDs (Silver, 2004), resulting in the forced and indiscriminate sterilization of approximately 60,000 PWDs, in particular adolescents who reached the age of sexual maturation (Reilly, 1991).

Today, sterilization is far more restrictive and regulated by federal rules and state laws. Consideration is also given to a number of ethical issues and revolves around the rights of the individual to be sexually active, expressive, and to procreate that are weighed against the rights of the unborn child to receive adequate care (American Academy of Pediatrics, 2009). Although sterilization is still used as a parenting deterrent, fewer physicians are willing to conduct sterilization without a court mandate (Block, 2000).

Parenting

Historically, the right to reproduce and become a parent has been violated for PWDs. According to Kirshbaum (2000), parenting is one of the last frontiers for PWDs. In her article, O’Toole (2002) states that although little research has explored parenting and PWDs, many WWDs are successful parents despite societal barriers and a lack of sex education, expectations of celibacy, social views of PWDs as undesirable partners, sterilization, high rates of divorce at disability onset for married women, and removal of child custody from WWDs.

According to Powell (2014), “Parents with disabilities are the only distinct community of Americans who must struggle to retain—or even gain in some situations—custody of their children” (p. 15). The rate of child removal from parents with psychiatric disabilities is as high as 70% to 80%. Removal rates for parents with intellectual disabilities is between 40% and 80% and the removal rate for those parents with physical disabilities is 13%. Parents with disabilities have more difficulty adopting children, gaining access to reproductive health care, and are more likely to lose child custody in the case of a divorce.

Societal concerns for parenting by PWDs are based on physical ability and cognitive capacity concerns. The decision to become a parent for a person who has physical impairment and limitations was examined by McNary (1999). Her interviews revealed that the parenting decision was influenced by a number of concerns related to physical considerations, such as having the stamina and energy to raise children and the emotional and financial effect of their disability on their children. Physically, they wondered about their ability to perform child-care tasks, particularly if they “ended up in a
wheelchair” (McNary, 1999, p. 99). They also worried about the safety of their children and their ability to sufficiently respond when necessary. Despite these concerns, participants revealed significant determination and belief in their ability to manage; as one participant stated, “I can conquer it. . . . I’m not going to let it stop me from doing something that I have wanted all my life” (McNary, 1999, p. 98).

In the United States, approximately 15% of all parents of children younger than 18 years have disabilities (U.S. Department of Health and Human Services, 2002). Among single parents, 24% have disabilities (McNeil, 1993). In the United States, there is significant variation across major categories of disability regarding the proportion of disabled adults who are parents (Toms-Barker & Maralani, 1997): About 40% have sensory impairments, 26% are physically impaired, 24% are psychiatrically disabled, and 16% have cognitive disabilities. Differences between parents with and without disabilities include the following: parents with disabilities are slightly older, they are less likely to be married and more likely to be married to another person with a disability, and they have more children with disabilities. They are also more likely to be unemployed, 48% versus 22%, and living in households with income below the poverty level than are parents without disabilities (McNeil, 1993; Toms-Barker & Maralani, 1997).

In a study of 1,200 parents with disabilities, most (70%) of which were physical, participants indicated a number of parenting problems that included pressures to become sterile (14%) voluntarily and to have an abortion (13%). In addition to attitudinal barriers, other parenting problems were reported as

- The physical difficulty with chasing, carrying, and lifting their children; participation in recreational activities with their children; traveling with their children; and lack of space in the home and inaccessibility
- Child-care access because of cost, lack of transportation, and lack of services and information about appropriate child care
- Lack of knowledge, high cost, and low attainability of adaptive parenting equipment (such as wheelchair-accessible cribs and baby lifters)
- Although over half of the parents reported using personal assistants for help with child care, problems included difficulty with availability, reliability, and interference with parents’ role (Toms-Barker & Maralani, 1997)

In a study to examine the cognitive and behavioral outcomes of children raised by mothers who had intellectual impairment, Powell and Parish (2017) noted that the children had poor cognitive and behavioral outcome when compared to children whose mothers were not intellectually impaired. However, “families headed by mothers with intellectual impairments experienced multiple hardships related to socioeconomic factors, limited social supports and poor self-reported health” (p. 50). The authors conclude effective policies and programs needed to be implemented to support child development as well as assist with financial impediments.

A number of relatively recent changes have taken place that give recognition to the idea that parenting problems for PWDs are more likely related to lack of services and supports, low income, and knowledge deficits than to the abilities of people with disabilities to raise a child who is physically, intellectually, and emotionally healthy. Legislative changes have included the removal of discriminatory language from legal proceedings.
related to child custody, parent rights, adoption, and divorce (Callow, Buckland, & Jones, 2008). In addition, some websites are now available to provide parents with disabilities support and information, such as Parents with Disabilities Online (http://DisabledParents.net).

SEX EDUCATION, SEX THERAPY, SEXUAL SURROGATES, AND SELECTIVE ABORTION

Sex education is not a one-time event that occurs in the early schooling years, but rather a continued process of learning about physical, emotional, and psychological sexual interactions and functions. When changes to the body and psyche occur because of disability, aging, or other significant events, there is frequently a need for additional learning related to sexuality issues. Unfortunately, sex is an uncomfortable topic for many people, including health professionals and caregivers. Health providers may assume counselors are addressing the topic and counselors believe health workers are addressing these needs. Among cancer patients, only between 17% and 23% reported that sexuality concerns were addressed. However, 67% of men and 39% of women felt it was important to discuss sexuality. They wanted to be asked about their sex lives and wished for information on body image, libido, fertility, and general well-being (Southard & Keller, 2009).

Lack of knowledge about sexuality and sex has been reported about some disabilities and is reflective of the need for more sex education. Little sexual knowledge has been reported for persons with physical and intellectual disabilities (McCabe, 1999). In a qualitative study to examine sex education among youth with physical disabilities, East and Orchard (2014) found a “tendency for parents, educators and health professionals to place the responsibility of delivering sex education to young people with physical disabilities on someone else who they believe to be more appropriately qualified to handle these types of situations” (p. 335). This resulted in adolescents lacking comprehensive information regarding their sexual capacities as well as insufficient information to make informed decisions about intimate relationships and sexual health.

For people with intellectual disabilities, there are some concerns related to education. One fear is that talking about sexual issues encourages inappropriate sexual behaviors. This has led parents and schools to avoid conversations related to sex. Another issue centers around the feelings of the person; it is anticipated that talk about sexual issues leads to distress or embarrassment. Even researchers hesitate to conduct research to examine sexuality because they fear they may cause some emotional damage (McCarthy, 1998), or that the person may not be able to give consent, or that he or she may be accused of sexual abuse by the participant (Brown & Thompson, 1997). In their study to examine college students with learning disabilities’ reactions to sexuality research, Thomas and Kroese (2005) found that while a few participants were embarrassed, the majority of participants showed no embarrassment or distress and no inappropriate behaviors were apparent. In fact, several students reported positive effects related to having the opportunity to talk about sex.

Probably one of the most controversial topics for PWDs is the use of sex therapy, sex coaches, and sex surrogates. Sex therapy is a short-term psychotherapy that centers around issues of sexual intimacy, feelings, and functioning provided by licensed therapists who may be certified through the American Association of Sexuality Educators,
Counselors, and Therapists (ASSECT). PWDs might receive sex therapy for some issues related to sexual desire, arousal, functioning (anorgasmia, premature ejaculation, and dyspareunia), or intimacy problems associated with disability (Mayo Clinic, 2010).

From the standpoint that sexuality and sexual expression are human rights, Shapiro (2002) argues that sexual surrogacy is an appropriate means of sexual gratification for PWDs and an opportunity not only to be sexual but also to reclaim their bodies.

Simply put, sexual surrogacy is not prostitution nor is it simply gratification in its most vulgar meaning. Sexual surrogacy is a therapeutic process which attempts to have the patient begin a dialogue with their own body in an attempt to, in a meaningful way, transcend simple gratification. (Shapiro, 2002, New Thinking and Approaches, para. 1)

Shapiro further believes that surrogacy should be government supported as a “therapeutic mechanism in the on-going rehabilitation of persons with disabilities” (Shapiro, 2002, Introduction Section, para. 5).

In a brief description on Disaboom (www.disaboom.com), an information website for PWDs, Fulbright (n.d.) lists the advantages of working with a sexual surrogate as overcoming a sexual disorder, gaining self-confidence, and skills and attitudes for healthy sexual functioning and well-being. According to the International Professional Surrogates Association (IPSA, n.d.a):

In this therapy, a client, a therapist and a surrogate partner form a three-person therapeutic team. The surrogate participates with the client in structured and unstructured experiences that are designed to build client self-awareness and skills in the areas of physical and emotional intimacy. These therapeutic experiences include partner work in relaxation, effective communication, sensual and sexual touching, and social skills training. Each program is designed to increase the client’s knowledge, skills, and comfort. As the days pass, clients find themselves becoming more relaxed, more open to feelings, and more comfortable with physical and emotional intimacy. The involvement of the team therapist, a licensed and/or certified professional with an advanced degree, is a cornerstone of this therapy process. (IPSA, n.d.b, para. 1)

Some disadvantages exist, including access outside of the states of Florida, California, New York, and Pennsylvania. Owing to legal and ethical concerns, many surrogates keep their practice secret. In addition, sex workers may falsely present themselves as surrogates (Fulbright, n.d.). The cost of this service is prohibitive for many PWDs. Although individual session cost is said to mimic local therapist charges, the cost of intensive therapy for 1 or 2 weeks would range from $4,000.00 to $8,000.00 (IPSA, para. 6).

A final topic of controversy regarding disability and sexuality has to do with genetic testing, therapeutic abortion, and embryonic selection. In 1996, Glover and Glover explored the legal and ethical issues of post-viability abortions for fetuses who were found to have Down syndrome. They concluded, “Although viability is a strong legal and moral consideration for a presumably healthy fetus, it does not appear to be so for a fetus who has Down syndrome. Such inconsistencies strongly test ethical principles because society has chosen
to erect a legal double standard of unequal treatment that is fundamentally discriminatory and constitutionally impermissible.” A decade later, Adrianne Asch asked, “Is it possible for the same society to espouse the goals of including people with disabilities as fully equal and participating members and simultaneously promoting the use of embryo selection and selective abortion to prevent the births of those who would live with disabilities?” (p. 315).

Today both preimplantation and prenatal screening can allow prospective parents to decide which embryo to bring to term. Research suggests 85% to 90% of positive screens for Down syndrome result in abortion of the fetus. Similarly, embryos that are determined to carry deficient genetic makeup are discarded routinely. Although there is heated controversy surrounding trait-based selection (gender, eye color, etc.) selecting against disability is accepted. Those who oppose argue:

- Selection against disability suggests PWDs are unworthy of being born
- Encourages intolerance of human variation
- Selective termination is based on misinformation and myths about the experience of living with a disability
- Selective termination is based on a single trait and does not take into account the whole of a human being (Ouellette, 2015)

At the opposite end of the spectrum is the practice of selection for disability. If selective termination against disability carries an ethical concern, what of those individuals who seek a child with a disability? Philosopher Melissa Seymour Fahmy (2011) examines the ethics of deaf parents using preimplantation genetic diagnosis to select for deaf children. Although most persons consider deafness a disability, in the deaf culture it is not viewed as a negative attribute. Fahmy considers the central questions of harm to the child, the child’s right to an open future, the introduction of avoidable suffering and/or limited opportunity, and parental and civic responsibility. She concludes, “The lesson to be learned from the deaf case is that we need norms that govern not just the use of reproductive technology, but procreation and procreative decision-making in all of its various forms” (p. 1467).

SEXUAL ABUSE OF PERSONS WITH DISABILITIES

Frequency of Sexual Abuse

A limited number of studies have attempted to estimate the prevalence of abuse against PWDs. Lund and Vaughn-Jensen (2012) conducted a meta-analysis of victimization studies of PWDs, and determined children with disabilities are 2.9 times more likely to be sexually abused than children without disabilities. Similarly, in a study of approximately 9,000 women and 7,000 men, women with disabilities were at greater risk of rape and men with disabilities were at greater risk of being forced to penetrate a perpetrator (Basile, Breiding, & Smith, 2016).

Children with mental health and intellectual disabilities are at even greater risk and are 4.6 times more likely to be sexually abused as children without disabilities. According to Smith and Harrell (2013):

Sexual abuse of children with disabilities has not garnered the attention of policymakers, practitioners, advocates, or community members. These children
are also less likely to receive victim services and supports that are more readily available to other victims because of a variety of factors including barriers to reporting and a lack of responses tailored to meet their unique needs. Without receiving support, these children suffer serious long-term aftereffects, including post-traumatic stress disorder, anxiety, and depression, as well as an increased risk of victimization in adulthood. (p. 102)

Sobsey (1994) estimated that WWDs are raped at least one-and-a-half times more often than women in the general population. WWDs, like WWODs, are most frequently assaulted by a familiar person, in a familiar place, such as at home or work (Andrews & Veronen, 1993). In reviewing the prevalence of abuse, it is apparent that the less likely a person is to defend oneself, either physically or psychologically, the greater is the chance of one's being abused. The less credible they are considered, such as those with cognitive or physiological impairments, the more likely they are to be abused and the less likely they are to prosecute. Several studies have found that prosecution of cases of sexual abuse for victims with cognitive impairment is only between 5% and 9% (Brown, Stein, & Turk, 1995; Mansell, 1995).

Among persons with DD, sexual abuse is particularly high. Civjan (2000) found a rate of sexual abuse among women with DD of 83% and Wilson and Brewer (1992) found that women with DD were 10.7 times more likely to have been sexually assaulted than WWODs. Brown et al. (1995) noted that victims ranged from profoundly to mildly disabled, but that most (61%) fell into the severe-to-moderate (IQ: 21–50) categories. Interestingly, among this disability group, males and females were equally likely to be abused, but almost all of the perpetrators were male and known to the victim. Several studies have noted that only 2% to 3% of perpetrations are committed by persons unknown to victims with mental retardation (Brown et al., 1995; Furey, 1994); 53% of identified perpetrators of sexual abuse against people with DD were other consumers, and 20% of perpetrators were identified as staff/volunteers (Brown et al., 1995).

Institutionalization also increases the risk of abuse. Sobsey and Mansell (1990) found that the risk of sexual abuse among people living in institutional settings was two to four times higher than for those living in the community. Perpetrators who are staff members may use threats or bribes (Andrews & Veronen, 1993) or may sexually victimize people while they are unconscious, medicated, or restrained (Musick, 1984), and the risk of exposure to multiple offenders is increased by high turnover rates because of low wages and minimal employee screening.

People who have sensory impairments are also sexually abused at high rates. Welbourne, Lipschitz, Selvin, and Green (1983) reported that among women who were blind from birth, 50% had been sexually abused. However, studies of people with a sensory impairment are scarce and tend to be limited to clinical populations that are not generalizable to the general population. Another study found that the overwhelming majority of deaf children and adolescents admitted to a psychiatric facility had histories of sexual abuse (Willis & Vernon, 2002).

The rate of sexual abuse of WWDs is similar to that of WWODs (Young, Nosek, Howland, Chanpong, & Rintala, 1997), but Nosek, Foley, Hughes, and Howland (2001) concluded that these abusive relationships tend to continue for longer durations. Unlike other disabilities, much of the research conducted with women with substance abuse
disabilities examines abuse that occurred before the onset of the disability. Abusive histories have been found to be prevalent among the majority of women in treatment for chemical dependency (Glover, Janikowski, & Benshoff, 1996; Wadsworth, Spampneto, & Halbrook, 1995), and believed by many researchers to be a contribution to the onset of chemical dependence.

The Dynamics of Abuse Against WWDs

Sexual abuse is motivated by a need for a feeling of power and control, and it is frequently maintained by manipulation, coercion, and threats. Most perpetrators share similar characteristics, including a need for immediate gratification, poor impulse control, and anger. Girls with disabilities may be particularly vulnerable to abuse because they are frequently unwelcome in social activities and have less exposure to social interaction. When they reach dating age, they may have confusion associated with their own needs and desires. Their desire to feel like “normal women” may lead to relationships that make them more susceptible to abuse. They may come to believe that their choices are limited to celibacy or sexually violent relationships and that they should be grateful for any sexual attention (Womendez & Schneiderman, 1991). Cattalini (1993) noted additional factors that may increase vulnerability to abuse as physical and emotional isolation from others, feelings of powerlessness, low resistance to bribery and coercion, sexual repression, little understanding of abuse, and poor self-protection skills. In a qualitative study of 72 women with physical and cognitive disabilities, Saxton et al. (2001) identified difficulties with personal boundaries, imbalances of power, and a sense of loyalty and obligation to service providers as interfering with the willingness to end or report the abuse, particularly if the perpetrator was a family member.

It is also important to note, especially for women, that abuse may have caused the disability. More than 2 million women are seriously assaulted by their male partners every year (Coble et al., 1992). Sobsey (1994) estimated that violence was a contributing factor to the cause of 10% to 25% of developmental disabilities. For women with violence-induced disability, it is important to consider who caused the disability and whether the perpetrator is now a caretaker (CALCASA, 2001).

Contributing Factors to Sexual Abuse

The sexual abuse of PWDs must be viewed within the framework of societal attitudes and structure. Historically, WWDs have been sexually regulated by society through forced sterilization, forced contraception, and forced pregnancy termination. Some physicians continue to recommend sterilization for WWDs but rarely suggest the same for males with similar disabilities (Beck-Massey, 1999).

The societal view that WWDs are asexual and roleless has further served to devalue and dehumanize WWDs, making it easier for caregivers and perpetrators to excuse abusive behaviors with the rationalization that WWDs do not understand perpetrated sexual acts as negative or even that they are helping their victim in some way. Additional stereotypical assumptions and stereotypes that contribute to the vulnerability of WWDs were outlined by Chenoweth (1993) as promiscuity, unattractive and grateful for the
attention, childlike, compliant, maternally inept, and insensitive to sexual trauma. These perceptions have led to a lack of sexual education, learned passivity, low reporting, exposure to multiple people without preventative measures, and low help-seeking.

The view that WWDs are asexual has also contributed to making WWDs vulnerable because little to no attention is given to training women as far as recognizing potentially abusive situations, practicing self-defense, or reporting abuse. Nosek (1996) found that vulnerability to abuse was increased through architectural barriers, inappropriate mobility aids, and exposure to medical and institutional settings because these limited the ability of PWDs to escape. Unfortunately, even exposure to disability services has been found to increase sexual abuse. Sobsey and Doe (1991) found that 44% of their sample of 162 PWDs who were sexually abused had perpetrators who gained access to them by way of disability services, including paid service providers, psychiatrists, and residential staff. They estimated that exposure to the disability service system increased the risk of sexual victimization by 78%.

In a review of the literature, Andrews and Veronen (1993) identified eight areas that contribute to greater vulnerability to abuse for WWDs: (a) dependency on others for care, (b) perceptions of powerlessness, (c) lower risk of perpetrator discovery, (d) lower believability, (e) lack of appropriate and comprehensive sexual education for PWDs, (f) social isolation, (g) physical helplessness, and (h) mainstreaming without consideration for self-protection. They also concluded that sexual involvement with personal attendants was not uncommon. Other contributing factors to sexual vulnerability include the imbalance of power, difficulties in recognition and reporting of abuse, and the dynamics involved in using relatives and friends to provide services (Saxton et al., 2001).

When PWDs are abused, crisis intervention may include having an escape plan in place, a temporary stay at a confidential women’s shelter, and making permanent plans to separate from the abuser (Nosek, Howland, & Young, 1997). Unfortunately, services such as those within the justice systems, women’s shelters, and medical services can present barriers that inhibit access and participation. Barriers to acquiring assistance after violence is identified by the Center for Research on Women with Disabilities (CROWD) from WWD reports as including (a) they were not believed, (b) they were discriminated against, (c) transportation was not available, (d) referrals were inappropriate, and (e) services were inaccessible. Many existing programs and shelters frequently do not include alternative formats such as Braille, do not provide attendant care, and are not fully accessible.

**Legislation and Trends**

Originally enacted in 1994, the Violence Against Women Act (VEWA) was reauthorized in 1998 and again in 2000 with new language that specifically includes WWDs, allocating millions of dollars for research and programming to enhance protection, strengthen education, and end violence and abuse (Whatley, 2000). Included in the office funding stream are grant competitions related specifically to WWDs. In 1998, the Crime Victims with Disabilities Awareness Act was passed, which mandates that disability status needed to include information gathered from crime victims. Accurate data on the prevalence of crime and violence perpetrated against WWDs would strengthen calls for more services and supports.
For PWDs, current legislative issues related to sexuality are related to marriage penalties, child custody, and child care. For PWDs, the decision to marry and cohabitate may be a costly one that they simply cannot afford because funding decisions are based on combined income. Marrying can cause Social Security benefits to be reduced or lost, and couples are at risk of losing Medicaid and personal assistant benefits. Couples who cannot afford to lose these benefits are put in the position of living together in secret, which impacts employee health benefits coverage (Fiduccia, 2000).

Issues of child-rearing can be complicated by regulations related to personal assistance services. Only a few states include child care as an activity of daily living, and that has profound implications for child care when there are functions related to children that cannot be provided by a parent with a disability. Many states prohibit personal assistants from providing child-care activities, which has implications for both child care and child custody should the couple divorce (Fiduccia, 2000).

Finally, until recently, little attention has been paid to providing persons with physical impairment alternative self-defense strategies. Recent training has emerged in self-defense from the seated position while in a wheelchair and self-defense using the wheelchair and mobility aids as weapons against would-be perpetrators. In addition, specific weapons training is also emerging for PWDs that takes into account their strength and mobility (Madorsky, 1990; McNab, 2003). These training methods are available to PWDs through associations such as the International Disabled Self-Defense Association (http://www .defenseability.com/index.htm).

CONCLUSION

Issues related to sex and sexuality for PWDs incorporate some important topics that can affect how people with disabilities view themselves and live their lives. This chapter discussed the social construction of gender identity and body image and the role that social construction plays in the sexual stigmatization and abuse of PWDs. Societal attitudes additionally play a role in self-esteem and body image for PWDs and affect their intimate partnering choices. Additionally, PWDs have some issues and concerns that are specific to the type and severity of their disability and may impact their sexual functioning, reproductive choices, and feelings about parenting.

REFERENCES


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### INSIDER PERSPECTIVE

**The Story of Jennifer L. Addis**

When I woke up on the morning of March 15, 1997, I had no idea that it would mark the last day of my independence. It was a typical Saturday morning for me other than the fact that I was having a bachelorette party for my future sister-in-law. I was the maid of honor, so I wanted things to be just right. That afternoon all the girls had gotten together and discussed who would be the designated drivers. I volunteered myself and was responsible for picking up the bride-to-be. Later she decided to drive herself, which left me driving alone and that was when my boyfriend/fiance at the time had volunteered to be my designated driver. I knew we would be drinking and it seemed to be a responsible decision at the time, and so I agreed. He showed up later with two of his friends and we all piled up in his single cab pickup truck and headed home.

We were only minutes away from home when I realized that my life was in jeopardy. My designated driver started driving erratically at a high speed. We approached a bend in the road when he made a critical decision that profoundly changed my life forever. He decided to pass another vehicle on the right side of the road, at approximately 80 to 85 miles per hour. We began to fishtail. He counter-steered, but the truck lost traction and we soon were out of control. The gravel consumed us and sucked the truck in. The last thing I remembered was seeing the gravel on the right side of the road. We went up and over the ditch, rolling several times before smashing into a tree. The truck landed upside down, and sometime during the impact I was thrown out of the vehicle. The truck was crushed like a tin can.

I woke up barely able to breathe. My body was numb and frozen. I heard people desperately calling out my name and scrambling all around me. I tried to call back, but my voice was just a whisper. Finally, I felt the warmth of someone’s hand against my left cheek.
attempting to protect my face from the frost-bitten ground. I remember feeling a sense of security, but yet a little uncertainty, because at this point I was not sure whether I was imagining it all or not. I cautiously opened my eyes and sighed with relief. I am alive.

The fire and police departments arrived at the scene and were very cautious about moving me, because of a possible neck injury. They successfully stabilized me and transported me by Flight for Life to Froedtert Memorial Hospital in Milwaukee, Wisconsin.

My designated driver was arrested at the scene for driving under the influence of alcohol and later was charged with first-degree reckless endangerment and causing bodily harm while intoxicated. His blood alcohol level was 0.21, more than 2 times the legal limit. I was the only one injured and of course the designated driver, who irresponsibly put so many lives in danger, was completely unharmed.

In just mere seconds my life changed without any warnings, and I was now forced to live my life as a quadriplegic at the age of 24 years. Imagine somebody chopping your head off, putting you in bed, and turning the lights off. It was a very traumatic experience. I felt almost child-like.

The next time I woke up, I was in the hospital in the intensive care unit. That strange numbness continued to flow throughout my body. C3, C5, and C6 of my spinal cord were injured, which basically meant that I was paralyzed from the chest down, also known as quadriplegia. I spent the subsequent 2 months in the hospital with a vigorous schedule everyday consisting of intense occupational, physical, and recreational therapy.

The capabilities I once took for granted, like brushing my teeth, writing, doing my hair and makeup, going to the bathroom on my own, and walking, all had new meaning to me. It was like starting my life all over again, only in a much harder sense. The main difference was that this time I knew what I was missing and it was a hard concept to grasp on to.

At such a young age it was hard to accept the fact that I would not be able to do any of these activities on my own, but I chose to keep fighting. I chose not to look back, not to change, and just be myself. I do not blame anyone for what has happened to me because my situation is not going to change if I did. I just look forward and move ahead. I am still the strong, determined individual that I was before, but I am in a wheelchair now. I have the same personality, attitude, and ambition. I keep my hope and faith and I do not let anyone take that hope away from me. I stay optimistic, because in my heart I know that the future holds something good for me. I truly believe that my faith has been the number one ingredient in getting through these difficult times for me.

Today, after many hard and painful days of therapy, I am at a C-6 level in my right arm and at a C-5 level in my left, which means that I have both wrist and biceps, but I am much stronger on my right side. With therapy and determination I have learned how to brush my teeth, apply my makeup, write, and work on my computer; all completely independently, just to name a few. It has not been easy and it has been a painful journey, but I stayed focused and I did not give up.

One very important piece of advice I would like to share with everyone is how critical therapy is in moving forward and learning how to simply live life again in this capacity—in a wheelchair. I think this issue needs to be strongly addressed to every patient. I had and continue to have a great support system between my friends and family, but most of all I had the most dedicated and qualified occupational therapist, Debbie, who gave me the motivation and encouragement I needed to persevere. Debbie reminded me every day that no matter what had happened to me physically,
I was still the same Jenny and my body may have changed, but my paralysis did not have to define me as an individual. She believed in me when I needed someone to believe in me the most and helped me to stay focused on what was important during the most critical time of my recovery. She reassured me that my life did not have to end just because I was now physically challenged. This was just a new chapter in my life and a new beginning.

Another very important aspect to a successful recovery is that I work hard at keeping relationships as much the same as before the accident as possible, for example, my relationship with my boyfriend at the time. This is not easy because of course there are always unexpected problems and obstacles when dealing with a spinal cord injury. I have caregivers come every morning and night to help me with my bowel program, catheterizing, showering, dressing, and whatever other personal cares I may need. My boyfriend and I were living together, and so it gave him the opportunity to go to work or go to the gym and personal space. This is so important for any personal relationship. Sometimes this type of situation is harder on the caregiver than it is for us, the ones being cared for. Of course, there were situations when I needed personal help and care from him, such as catheterizing, which I did every 4 to 6 hours, and when dealing with an injury of this magnitude, there is always the unexpected, such as your bowels working voluntarily. When something like this happens to a person, there is a loss of dignity and privacy. He never made a big scene about any personal situations and I needed that, especially in an intimate relationship. At the time, I did not know what I would have done without him. He helped to give me the strength and confidence that I needed to keep going.

Over time, our lives became very strained and stressed, but I tried to make the best out of such an unfortunate situation. A couple of years after the accident my boyfriend, the designated driver on the night of my accident, and I broke up for many reasons. I was growing up and changing, but he was staying the same. Every promise he had made to me after the accident, from a wheelchair-accessible home to practicing total sobriety or to never drink and drive again, kept going unanswered. I was so unhappy and knew that I needed to make some changes for happiness to exist in my life again. Of course, I had many concerns, such as where I was going to live, finances, and dating. Why would anyone want to choose me as a partner over an able-bodied woman? I felt like we were distant as a couple as well. I did not see him look at me the same anymore and felt myself falling completely out of love with him. We did not even kiss anymore. I knew that I deserved more than he was giving me. I felt like I was headed down a road of despair and depression. I could not go down that same road and watch him continue destroying my life or yet someone else’s. It was very confusing to see him drink again, and it was even more confusing to hear that he had gotten behind the wheel drunk again. I was realizing qualities about this individual that I had never noticed before, such as his lack of care for me, and I needed to get out. So after he neglected me on many levels, I found the courage to leave. I left before he destroyed my life even more than he already had. Along with a disability comes significant financial needs, and from the moment this all began he promised that no matter what, he would always take on the financial responsibilities I had in the future because of the car accident, as he was the driver who was responsible for causing my injury. Plus, he did not want to be sued and he did have the means to help me financially. So I had no
reason not to believe his promises. I was entirely wrong, though; he did not see that promise through. I should not have put so much trust in him, should have sued him from the start, and should have looked after myself. If only I knew back then what I know now.

I think intimate relationships and dating are huge concerns for people in wheelchairs. Although I may be paralyzed, it does not mean that I do not have the same needs and urges as every other individual, disabled or able-bodied, has. Everything on the inside works exactly the same as before. My menstrual cycle works the same, and I can still get pregnant. Believe it or not, I can still have an orgasm! People forget that sexual urges are controlled by your mind, and so if you are emotionally, as well as physically, invested in a partner it can be just as, if not more, rewarding being in a relationship with someone disabled.

I am currently dating someone who is one of the most sincere and genuine people I have ever met. A lot of people are intimidated by the wheelchair, but in my experience I have found that if the opposite sex approaches me, they are most likely very caring, sincere, and genuine people. It takes a lot of guts and a very special person to get involved with an individual who has a disability, and so when it happens to us we need to take advantage of the sincerity, open up, and let them in. I did, and it is the best thing that has ever happened to me.

Before my accident I had worked at a bank for 6 years. I started there as a bank teller, received multiple promotions, and then 2 months before my accident I reached my goal and was promoted to an officer of the bank. Immediately after my accident my intentions were to go back to work at the bank, but when the time came after a year and a half, the home office wanted to send me to another location doing a totally different job. My job functions would consist of answering telephones in the basement with no face-to-face contact with the customers. My occupational therapist looked over my job functions and duties and found that everything could be adapted to qualify me to go back to my original position. There was only one duty, tearing a traveler’s check out of a book, that they found to be a problem and the home office focused on that like a sore thumb. I was extremely upset, because before my accident I did above and beyond what was expected of me and I was a very dedicated employee. I felt that I earned and deserved more than they were giving. I was very disappointed and walked away without making an issue out of it. Now, I wish I would have pursued it legally and set an example for others in similar situations.

Through my experience I have found that it does not matter whether or not you have a disability, how old you are, your race, or your sex. We are all equal. You should always treat others with the respect they deserve and the way you would like to be treated. No one should be discriminated against for any reason. I would not have decided to go back to work if I did not think I could handle it. I wanted to succeed and I know it would have worked out. To this day after seeing how far I have come, I have realized that they are the ones missing out, not me. I am very disappointed in them, and I cannot believe how ignorant and insensitive they are. I realized that it is not a place that I want to work or even be associated with.

I sometimes become very sad over the loss of not only my job but also my dignity, control over everyday functions, and independence, and of many feelings and emotions that go along with everyday living. When these unfortunate feelings find their way out, I realize how easy it is to give up, but I know that once I let these feelings take
over, it could mean the end of my progress, happiness, and everything I have worked so hard for. I would eventually go downhill, and this injury would get the best of me, but I am not giving up that easily! I try to stay focused and I remember the goals I have promised myself.

On May 6, 1999, I was chosen to represent the state of Wisconsin as Ms. Wheelchair Wisconsin. That experience gave me the opportunity to become more involved in my community and the state as an advocate, not only for women in wheelchairs but also for the physically challenged in general. I was also given the opportunity to represent the state of Wisconsin in the national pageant, Ms. Wheelchair America, in Fort Lauderdale, Florida. My platform was simple—the consequences of drinking and driving.

Since the pageant, I highly promote and advocate for the Ms. Wheelchair Wisconsin’s Association. I believe that we need to bring public awareness to this accomplishment and make the public aware of the meaning behind this pageant. It is not a beauty pageant and you are not judged on how you look in a bikini, but on your personal achievements since the onset of your disability, your attitude, and your inner beauty. We need to stress that having a disability is not the end of the world, but an opportunity to share the privilege of life and all it has to offer.

I have gone back and forth with my career since I began this journey, and struggled with whether I could have a purpose on this Earth again, in this capacity, in a wheelchair. I’ve always wanted to know that what I am doing with my life is working to the most of my potential and is making a difference in the world. Nothing will change the fact that I am paralyzed, and so I know that I have two choices, either to be angry and confined to a wheelchair or to be happy and confined to a wheelchair. I chose the latter.

Today, I am a motivational, inspirational, and educational speaker. I speak at a countless number of schools, colleges, universities, churches, conventions, and conferences on issues such as drinking and driving, abusive relationships, overcoming adversity, good decision making, and overall the car accident itself, just to name a few. I want these young adults to see that this can happen to anyone. I did not think it would happen to me, but it did.

I have been a board member for the Bryon Riesch Paralysis Foundation for about 10 years. Our sole purposes are to raise money for SCI research and work to promote the quality of life for the physically challenged. I hold my faith and hope for a cure someday close to my heart, not necessarily for myself, but for my nieces, nephews, and future generations.

I am a model and committee member for the Fashion Show for All Abilities. The fashion show’s purpose is a community awareness event, highlighting the reality that persons with disabilities are valuable customers and that businesses benefit by extending courtesy and respect to them. It focuses on issues such as too narrow aisles, inaccessible dressing rooms, and poorly trained salespeople. The mission is to educate and bring awareness to society on the concept that “fashion is for everyone.”

I currently work with an online magazine for women in wheelchairs called mobileWOMEN.org, as an advice columnist. My column, “Hey Jen,” is a safe, interactive forum, whether physically challenged or not, to discuss anything and everything that may be on your mind, such as fashion, dating, sex, or serious real-life issues. It is a site that gives
you a boost of inspiration if needed or someone to listen to your personal struggles who truly understands. If you feel it, live it, hurt from it, are interested in it, or are just curious about it, I encourage people to share it and discuss it with me, because I have either felt it, have lived it, was hurt by it, am interested in it, or had the curiosity about it myself! Nothing is too personal in my book!

I am a volunteer member and membership coordinator for the Waushara County Chapter. Our goal is to help create, support, and protect just one small portion within our county of the Wisconsin Ice Age Trail. I came on board when the chapter asked me to help fundraise for the Bohn Lake Accessible Hiking Trail Project in Waushara County. I am proud to say that the accessible hiking trail is no longer just a vision; it is a reality! I am also a volunteer and member of the Ice Age Trail Alliance (IATA). The IATA is a volunteer- and member-based organization working to create, support, and protect the Ice Age National Scenic Trail. The 1,200-mile trail, winding through Wisconsin, traces world-renowned Ice Age features. The trail serves as both a monument to the state's glacial heritage and a premier recreational resource. The IATA is a nonprofit organization dedicated to preserving Wisconsin's glacial heritage for the education and enjoyment of present and future generations.

I have been an advocate and volunteer for groups such as the National Spinal Cord Injury Association (NSCIA), Home Care Consumer Advisory Committee (HCCAC), and the Aging and Disability Resource Center (ADRC). My goals in the future include publishing my biography and a new piece called “A Note to God.” I also hope to have a family and children of my own someday!

Some of my greatest assets include my positive attitude, outgoing personality, and a very optimistic outlook on the future. I am confident that medical research is close to finding cures for so many neurological diseases and disorders, and optimistic that the quality of life will keep improving for so many deserving people. I truly believe that if a person has the hope, miracles can happen! I hold my faith close to my heart and I do not let anyone take it away. Therefore, no matter what, I wake up looking forward to a new and prosperous day.

One of the greatest barriers I face on a daily basis, as do others living with a physical challenge, is the lack of wheelchair accessibility all over the country. I love to travel, and more than once I have experienced problems with airports breaking my wheelchair, rude and insensitive employees, unaffordable prices, and delayed pickups. I have also had to call 24 hours in advance to reserve accessible transportation and even then it is sometimes impossible to find. I believe that education and public awareness are the keys to progress and making wheelchair accessibility consistent and successful. Stronger and more powerful legislation and new laws are the answer. We must demand that these laws be implemented and enforced in order to end discrimination and to provide equal opportunities. The disabled are contributing citizens and deserve ready access to all the promises of American life. Unfortunately, this is an issue that is around for a long time, so as an individual who is physically challenged, I understand that there may be situations I have to work around, try to deal with them appropriately and effectively at that moment, and work on changing them. Some advice I would suggest is patience and understanding. With education lacking in this area, the best thing to do is to bring awareness to the issue within the community and demand that the necessary changes are made for the future.
One of the biggest messages I want to convey to society is that just because a person may be in a wheelchair or dealing with a physical challenge does not mean that he or she is different from anyone else. We have the exact same needs and wants as any other individual in society. I am a motivational speaker for many reasons: one being to change these misperceptions and stereotypes about others who may be living life with a physical or mental challenge. I personally do not want to be defined by my disability. Everyone is molded together differently, which makes us the unique individuals we are. Our individuality should not be judged as being normal or not normal. I believe that as a society, we need to get past the outer appearance of a person and look at his or her inner beauty. Inside everyone has similar feelings and deal with the same issues of everyday living. If you pay close attention you find that we all have a lot in common and everyone is dealing with some type of handicap; mine happens to be physical, which is easy to connect with visually, but someone else may be struggling with depression, alcoholism, or obesity, just to name a few. This is something we, not only the disabled population but also the able-bodied as well, need to work on, educating and bringing awareness within our communities to the fact that people in wheelchairs or with any disability are their equals.

Overall, considering the obstacles and struggles I face each and every day, my life is headed in a positive direction. I think about how close I came to losing the opportunity to spend time being an auntie to my six nieces and nephews, another moment reminiscing with family and friends, developing a new healthy relationship with my boyfriend, cuddling with my puppies, or even just watching the sunset. We all take these things for granted, which is a natural response, but sometimes we need to step back and remember that these are God-given gifts, privileges, not rights. We all need to work on respecting the value of life and to understand that it can all be taken away faster than the blink of an eye. My goal is to help bring awareness to the community and remind every person I interact with just how precious life is. To most, I have lost everything to this tragic accident, but really God has blessed me with understanding something most people never realize in a lifetime...the significance of life.

DISCUSSION QUESTIONS

1. Have students make a list of the top personal attributes they find most desirable in a partner and then discuss the impact of personal values on partner selection.

2. Discuss anyone’s experience with a family member or friend with a disability, specifically related to dating attempts or experiences.

3. Ask students to discuss their own feelings about the impact of media on body image and how it has affected them personally.

4. Discuss the case of a person who chooses to raise a child without the use of arms. Then watch “Amazing Woman With No Arms” on YouTube at https://youtu.be/Vem_bHsxL40
EXERCISES

A. For a class activity, have students role-play an interview with a person who is disabled asking about sexual issues or concerns.

B. For a class group activity, have students debate the topic of parenting for persons who have severe disabilities, with one group supporting parenting and another group arguing against.

C. For a homework assignment, have students interview a person with a disability using an online support group about what is important in a long-term relationship with a partner.