Disability Across the Developmental Life Span
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For the Rehabilitation Counselor

Julie Smart, PhD, CRC, LPC, ABDA, CCFC, ABPC, LRC
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To my knowledge, there is no book that considers the experience of disability in relation to the grand theories of human growth and development. It is generally agreed that there are six grand theories, Freud, Erikson, cognitive learning, behavioral learning, Maslow, and Kohlberg. None of these theorists included people with disabilities (PWDs) in their theory development or in their research. On the other hand, the so-called “clinical” or “allied health” academic disciplines of medicine, nursing, physical therapy, occupational therapy, and rehabilitation counseling give little, if any, thought to stages of human development, concentrating solely on diagnoses and the resulting medical and rehabilitation treatment plans. In addition, the general counseling and psychology academic disciplines, and their textbooks, consider psychiatric disabilities and mental retardation, but not the developmental experiences and tasks of individuals with these disabilities. Unfortunately, the fields of psychology and counseling rarely include the experience of physical disabilities in their training.

The result is that the social developmental experiences of PWDs are not addressed in the university curricula. This may appear to be a broad, damning judgment. However, this lack of attention to the social developmental experiences of PWDs (and their families) has been longstanding, persisting for centuries. The disciplines of human growth and development, psychology, and counseling focus on the “normal,” or, better stated, a narrow, illogical definition of normal and the clinical and allied health disciplines have focused on the medical model of disability in which attention was directed toward only the physical, biological, and medical needs of the individual. Certainly, there was no intentional malfeasance in ignoring PWDs in academic curricula or in physicians focusing solely on medical needs. Both were acting on the mandate given them by the larger society. Nonetheless, university graduates have little academic training in disability and physicians often do not conceptualize PWDs as individuals negotiating developmental stages and tasks.

In contrast, most PWDs, after medical stabilization, think of themselves as normal, ordinary people with the same types of needs, emotions, goals, and developmental tasks as everyone else. The difficulty lies in persuading PWODs (people without disabilities) to think of PWDs as typical, ordinary individuals. An ethical guideline found in all professions is the injunction to practice within the scope of one’s training, education, and experience. Therefore, if PWDs are to be offered developmentally and socially appropriate services (in addition to the necessary medical care), it will be essential that university curricula include the experiences and needs of PWDs. Academicians, researchers, theorists, and scholars fall prey to the tendencies of the broader culture to sensationalize, exaggerate, and pathologize PWDs.
In some ways, the absence of PWDs in academic disciplines and the corresponding lack of professional services mirror that of other groups, such as women of all races and ethnicities, gay individuals, and those of racial and ethnic minority groups. Indeed, throughout this book, we shall learn that effective criticisms were leveled at the six grand theories for failing to incorporate the experiences of individuals who were not white, middle-class, straight men. This is not to suggest that white, middle-class, straight men were not worthy of study and research, only that there were other groups also worthy of study. Nonetheless, there are some differences between these other “disadvantaged” groups and PWDs. First, disability, until recently, was relatively rare. For millennia in medicine, the two-outcome paradigm of total cure or death dominated. Second, PWDs have been isolated, segregated, and institutionalized throughout history. In the United States, PWDs were not given their civil rights, protection under the law, and the right to a quality of life until 1990, long after other groups were enfranchised.

Obviously, the inclusion of PWDs into the social sciences and the addition of the social experiences of PWDs into the clinical disciplines will require an examination of the definitions of “normality” and “humanity.” Defining and operationalizing these concepts are not a boring semantic exercise for a graduate seminar, instead, examining long-held assumptions often leads to an understanding that faulty definitions have resulted in the type of daily, lived life of PWDs and, in some extreme cases, whether they lived or died. Most academicians and textbook writers initiate the study of disability by defining disability. In contrast, a more fruitful discussion would result if the consideration of disability began with defining humanity and normality.

Almost one-fifth of the American population has some sort of government-recognized disability. However, this statistic is based on the broadest possible definition of disability. Each government agency defines disability somewhat differently and, therefore, the numbers of PWDs varies, depending on the source. The broadest government definition of disability is the Americans with Disabilities Act, which includes a large number of disabilities and, in addition, states that an individual who is perceived to have a disability is protected under the law. Furthermore, many would be surprised to learn that such conditions as arthritis, depression, and other chronic illnesses are defined as disabilities.

In this book, we shall first review some of the basic, general aspects of theories of human growth and development. Juxtaposed with this view of development theories, we shall consider great demographic shifts. These demographic changes were predicted; however, both the pace and the extent of these changes surprised demographers. One demographic change that is not typically discussed is the rapidly increasing numbers of PWDs and the appraisal of these increasing numbers as progress, both for the individual and society. Briefly stated, for many of these individuals, the alternative to living with a disability would be death. The two-outcome model of medicine has progressed to a three-outcome paradigm—death, total cure, or long-term care of PWDs or individuals with disabilities and chronic illnesses. The combination of medical, scientific, and technological advances and better public health have resulted in more PWDs (and fewer deaths).

The middle section of the book provides brief, general overviews of each of the grand theories, with a brief outline of the theorists’ biographies, the main points of the theories, an evaluation of each theory and, finally, possible application to PWDs.
By necessity, each of these chapters is short, touching only on the main points and I hope I have not been simplistic, but rather concise and straightforward. Furthermore, most of these grand theorists had followers, often called “disciples,” who continued and expanded the work of their mentors. However, with one or two exceptions, it is difficult to name these disciples or the way in which their theories differed from or expanded on the grand theorists. The fact that these grand theories continue to be used today attests to their usefulness and enduring quality. For example, it would be a daunting task to list all of the doctoral dissertations written in a single year that attempt to validate some aspect of these grand theories! With the passage of time, advances in testing instrumentation and sophisticated multifactorial statistical models provide the means to test and assess the validity of these grand theories, some which were developed almost a century ago. In spite of all these research methodological advances, these grand theories remain worthy of study.

Following the chapters on the grand theories, a short chapter outlining some basic concepts of disabilities provides some introductory information. In the next chapters, the basic stages of life are presented, typically two stages to a single chapter. Included in these chapters are the typical developmental tasks, a discussion of the ways in which demographic and historical changes have affected these life stages, a brief outline of two or three disabilities that are common to this stage of life, and a discussion of the ways in which the experience of disability affects passage through these particular life stages. The inclusion of two or three disabilities in the chapters on the life stages is not to suggest that these disabilities occur only in one or two life stages; but rather to show that the typical age of onset or diagnosis coincides with life stages presented in the chapter. Obviously, the exception is congenital disabilities, or disabilities which are present at birth; their time of onset occurs at a single life stage, birth. Nonetheless, individuals with congenital disabilities negotiate all the succeeding life stages. Note: the preferred term is “congenital disabilities” rather than the negative, pathologizing term of “birth defects.”

There are four sections found at the end of each chapter, presented with the intention to provide further learning experiences and to allow students to engage more fully in the information presented. It is hoped that students will be able to integrate the material in the textbook, class discussion, additional readings, and topics of personal interest. Students are not expected to complete all of these exercises; but rather to choose one or two. These four sections are “Terms to Learn,” “Videos to View,” “Learning Activities,” and “Writing Exercises.” It is hoped that students will use these exercises to individualize their learning experiences. For example, students in the Allied Health fields may wish to learn more about developmental theories while students in counseling, psychology, and human growth and development will wish to apply their knowledge of the developmental stages and tasks to the experience of disability. These activities may be completed individually or as a group. Obviously, I think writing exercises are important, not only as a practice of a highly critical skill; but also as a way to clarify one’s thinking to oneself.

I have attempted to write about these grand theories in a way that is congruent with the intent of the theorists and I have also attempted to write about disability from the perspective of PWDs and their families.
For a long time, I have wanted to write a textbook dealing with the developmental experiences of individuals with disabilities. This past year, writing this book has been both satisfying and challenging. However, I could not have succeeded and completed this book without the assistance, support, and encouragement of many individuals.

The books that I have written have often been termed “consumer oriented,” and I consider this to be a positive judgment of my work. Without doubt, this book could not have been written without the many excerpts of first-person accounts that describe and explain the disability experience. I do not think that the work of these individuals with disabilities has received the recognition and consideration that it deserves; but rather is a vast reservoir of hidden scholarship. These excerpts form the basis of this book.

I wish to extend my gratitude to Utah State University and my department for granting me the time to focus on writing. I also thank two of my friends and assistants, Sharon Melton and Kris Wengreen, for their enthusiastic help, often going far beyond the call of duty.

I teach in a graduate program in Rehabilitation Counseling, and I am grateful to my students for the many stimulating classroom discussions, that have strengthened and broadened the scope of this book. Knowing that I am always interested in issues related to disability, students send me articles and books, and these, too, are incorporated in this book. My students either currently work with people with disabilities or plan to do so upon graduation, and therefore, they assist me in viewing different aspects of the disability experience.

Sheri Sussman at Springer Publishing Company has been an enthusiastic advocate for this book throughout the entire process, and I am grateful to her. Finally, I thank my husband, David, a very patient and positive person, for his unflagging support and encouragement.
Major Developmental Theories
Every time we buy a greeting card we see many different types of cards. Most greeting cards are written and illustrated examples of socially sanctioned developmental stages. These cards encourage or console those who are beginning new developmental stages and congratulate those who have completed an important developmental stage. Birthdays, graduations, wedding anniversaries, retirement, and widowhood are all considered socially sanctioned developmental stages. We would not find a card for significant changes in an individual’s life that are not socially approved, such as a card wishing well an inbound prisoner.

In addition to greeting cards, significant changes are often marked by parties, gifts, special foods, and (occasionally) distinctive clothing such as wedding gowns, graduation robes, or military uniforms. Elaborate and expensive preparations are part of moving an individual from one developmental stage to the next. Gifts are given at some stages (think of baby showers) or family and friends travel great distances to attend ceremonies, all in order to help the developing individual assume new roles. At times the individual changes his or her name or gains a new title to reflect a major shift in identity; both self-identity and the ways in which others view the individual. Rites of passage are often part of one’s religious or spiritual belief system and signal that the individual has achieved adult status in a church or synagogue. Birthday parties may also be considered rites of passage, communicating to children that more mature behavior is expected. All these rites of passage serve to connect individuals to the larger society. Especially in young children, these rites help people find their place in the world and assist in self-definition (Austrian, 2002).

Children begin to replace their deciduous teeth (baby teeth) with permanent teeth between the ages of 6 and 12. In the United States when small children lose a baby tooth, they place the tooth under their pillow. During the night the mythical Tooth Fairy takes the tooth and leaves money under the pillow. In Europe, however, it was common to bury the baby teeth up until the beginning of the 20th century. One author described the process of losing a baby tooth as “most unusual”:

It is initially difficult [for the child] to imagine part of the human body becoming so fragile that it ultimately disconnects itself. Children will very likely have parted with hair and certainly with nails by the time they lose their first tooth, but deliberately, as part of normal grooming and self-care. Teeth are the only part of the anatomy designed to fall out naturally and then grow back. Once the tooth is out, the lure is not over. (Austrian, 2002, p. 76)
This continued “lure” led to the creation of the Tooth Fairy. These traditions could be considered rites of passage because the Tooth Fairy, a uniquely American phenomenon, communicates to children that they are growing up and also assists children in relinquishing part of their “baby” identity. Of course, the parents could take the tooth and give the child a quarter; however, the loss (of babyhood) and the challenge (of growing up) are eased by the idea of a loving, kind, and mysterious fairy who is ever mindful of the number of teeth of every child. At no other time in life when we lose teeth—such as when we have our wisdom teeth extracted—do we expect a visit from the Tooth Fairy. Perhaps by then losing teeth is no longer considered a change of identity. Of course, most of us have given up the idea of the Tooth Fairy by the time we lose teeth as adults. Austrian considered this dichotomy between losing baby teeth in childhood and losing teeth later in life.

Later in life, problems with teeth represent aging, the body’s decline. Throughout life, teeth remain something that connects adults to their early development—in this loss, in their symbolism, and in the memories provoked each time they see a child from this age period with missing teeth. (Austrian, 2002, p. 77)

Most socially approved rites of passage are considered to be signs of positive growth, development, and progress. However, there are some predictable, socially approved developmental stages and rites of passage that are not thought to be positive, such as the death of a loved one. Instead of parties, balloons, and cake, there are funerals, casseroles, and flowers. The death of a loved one is not hidden; others learn about the death by reading the obituary in the newspaper. The death of a loved one (especially a spouse) is a widely acknowledged (and somewhat predictable) stage of life.

Although the “hope you enjoy prison” card may appear funny, when an individual is incarcerated both the individual and his or her family experience “disenfranchised grief.” There are no flowers, casseroles, ceremonies, or parties. Going to prison requires a major change in self-identity, the disengagement from many current relationships and tasks, and entry into new relationships and tasks. However, it is not considered a developmental task because very few individuals actually go to prison, and (more important) imprisonment is the results of antisocial behavior. Going to prison is not a predictable developmental stage. There are very few parents who look at their infant and consider that he or she might one day go to prison.

There is no greeting card for the acquisition of a disability or the birth of a baby with a congenital disability. Especially if it occurs at a young age, the onset of a disability is not a socially sanctioned developmental task. Still, acquiring a disability, being born with a disability, or having a disability diagnosed can be considered a developmental stage that requires a change in identity and completion of certain tasks. In addition, simply because most other developmental stages have widespread social approval and the acquisition of a disability does not, the individual (and his or her family) who experiences disability must encounter denial at best, or prejudice and discrimination at worst. To those who do not have a disability, disability may appear to be pathology, deviance, and inferiority although disability is in fact none of these. Indeed disability is very “normative” and “natural” in the sense that disabilities are very common and are frequently a part of the human experience. Nearly one in five Americans has a disability
according to U.S. census data. Nearly 1 in 16 newborn infants has a congenital disability. Although it is true that parents never wish for their baby to be born with a disability and no adult ever wants to acquire a disability, most people with disabilities (PWDs) or parents of infants with disabilities state that a disability is not an unbearable tragedy; most report that they return to a “new normality,” and some relate that there are positive aspects to the disability experience.

When an individual acquires traumatic disability, receives a diagnosis of a disability, or experiences the first symptoms of a psychiatric disability, he or she often retains a strong, detailed memory of when life changed, often termed a “flashbulb memory.” The time of day or night, the exact circumstances (such as the color of the blanket when a patient awakes from a therapeutic surgical amputation), or the place in which the accident occurred divide the individual’s life in two—before and after the disability. Many PWDs have a party every year to observe the day their disability occurred, such as a “day-I-broke-my-neck party.” They invite friends and family members to gather together with balloons, party hats, cake, and ice cream.

We shall discuss disability as a developmental task at greater length and in much more detail. Following the six chapters on developmental theories, the remainder of this book will focus on an integration of disability concepts and developmental theories and stages of the life span.

WAYS IN WHICH DISABILITY AFFECTS DEVELOPMENTAL STAGES

Although there is some variation (both cultural and individual) in the definition and description of the developmental stages of life, these stages can be defined in a general way. Each stage will be discussed in greater detail in the third section of this book. For our purposes, the developmental stages are (1) pregnancy and infancy, (2) toddlerhood and early childhood, (3) school age, (4) adolescence, (5) adulthood and midlife, and (6) the young elderly and the old elderly.

None of the most well-known developmental theorists discussed in this book considered the development life span of PWDs. The absence of PWDs also mirrors the ignoring of women, racial and ethnic minorities, gays, and men and women with lower socioeconomic status. These grand theorists concentrated mainly on white, middle-class, straight males without disabilities, undoubtedly individuals worthy of study (Gilligan, 1977, 1982/1993, 1987). The criticism of these grand theories is a simple acknowledgment that other groups, often termed “minority groups” are also worthy of study. The absence of all these so-called “minority groups” is partially explained by the time these theories were evolving, when few societal opportunity structures were available for racial and ethnic minorities, women, gays, and PWDs. Without these opportunity structures, individual merit, hard work, and planfulness do not and cannot bring rewards. We shall learn that most of these grand theories are based on a range of choices available to the individual. Although no range of choice is ever unlimited, it is true that white, middle-class, straight males without disabilities experience a wider range of choices. It should be noted that all the longitudinal studies conducted in the 1920s, 1930s, and 1940s included both gays who chose not to disclose and men with invisible disabilities who also chose not to disclose.
Disability also presents another dimension: the concept of normality. Without doubt, disabilities often involve functional losses; disability is expensive, requires management, and is difficult. However, disability is not as tragic as most people without disabilities (PWODs) think. Disabilities appear to be an assault on Americans’ glorification of health, vigor, autonomy, freedom, and individualistic self-reliance. Disability makes PWODs uncomfortable because it is a visual reminder that anyone can acquire a disability at any time.

Nevertheless, three factors combine to bring PWDs into the American culture, including the study and research of “normal” development and growth. First, the sheer number of PWDs is increasing. Just as the population explosion of elderly people in the 1980s resulted in the creation of a new academic discipline and profession—gerontology—the population explosion of PWDs will result in more professional services for PWDs and greater awareness of the experience of disability in the university curriculum.

Second, PWDs resemble many other American minority groups by moving from a position of stigma management to one of identity politics. More than any other event, the passage of the Americans with Disabilities Act (ADA) (1990) and the Amendments to the ADA has produced an “identity cohort” of PWDs who were born after the ADA and thus have no memory of or experience with widespread prejudice and discrimination, institutionalization, or lack of opportunity. Frieden (2010) undertook a survey of leaders in the disability community in all 50 states and concluded:

Overall, 90% of survey respondents believe that the quality of life for PWDs in communities across the United States has improved greatly since the passage of the ADA….Two-thirds of survey respondents with disabilities believe that the ADA legislation has had more influence on their lives than any other social, cultural, or legislative change in the last 20 years. (p. 4)

The third and last factor is changes seen in media in the United States. The way in which books, films, and television portray a group of people has a powerful influence in either challenging or maintaining the social status quo of prejudice, discrimination, and limited opportunity. The media are forging an evolutionary path in portraying PWDs as people, rather than as a symbol for tragedy, pity, and deviance. For example, there is now less sad background music played when a PWD is shown onscreen.

In the not-so-distant future, PWDs may dominate the American social agenda as the Baby Boomers have for the last 60 years.

Three Factors That Will Bring PWDs Into the American Culture

• The population explosion of PWDs
• PWDs as a group moving away from stigma management to a political identity group
• The media changing its portrayal of PWDs
DISABILITY AND DEVELOPMENTAL STAGES

Some transitions in life are reversible, while others are irreversible. Birth and death are irreversible, while the transition to adulthood may not be. Adult children drop out of college, return to live in their parents’ homes, and fail to enter the job market. Marriage is reversible. In contrast, disability and chronic illness are irreversible transitions. The very definition of disability and chronic illness means life-long, day-to-day management. The irreversibility of a disability is an aspect of acceptance of the disability, understanding that disability and chronic illness may have some opportunities for improvement through medical management, assistive technology, and social support. On the other hand, even the most stable-course disabilities have the probability of degenerating due to the acquisition of secondary conditions and the effects of aging. Therefore, birth, death, and disability are irreversible transitions.

For everyone, there are certain achievements and task completions expected at each stage. Many of the grand theories, especially Erikson’s, include social expectations. However, there has historically been little social role guidance for PWDs, and the few social expectations were negative ones imposed upon PWDs by PWODs, such as (1) unquestioning compliance with all medical recommendations, (2) hiding or minimizing the disability, (3) showing the “public” that the individual is accepting of the disability to reduce the discomfort of others, and (4) keeping one’s expectations at a modest level, thus accepting society’s definition of oneself.

Most of the developmental theories view individuation as one of the end goals of development. Individuation is the process of becoming a unique individual, a result of one’s experiences and pursuit of self-identified goals. Often PWODs view PWDs not as individuals but only as their disability. This categorization (instead of individuation) often leads to inaccurate stereotypes, such as “all deaf people are shy.” PWDs recognize when they are seen only as a disability and not as individuals. Irving Zola illustrated the “all you PWDs look alike” experience:

I use a cane, wear a long leg brace, and back support, walk stiff legged with a pronounced limp. All in all, I think of myself as fairly unusual in appearance and thus easily recognizable. And yet of years, I have had the experience of being “mistaken” for someone else. Usually I was a new place and a stranger would greet me as Tom, Dick, or Harry. After I explained that I was not he, they would usually apologize, saying, “You look just like him.” Inevitably, I would meet this Tom, Dick, or Harry and he would be inches shorter or taller, 40 pounds heavier or lighter, a double amputee on crutches, or a paraplegic in a wheelchair. I was continually annoyed and even puzzled how anyone would mistake “him” for the “unique me.” What eventually dawned on me was that to many I was handicapped, first and foremost. So much so that in the eyes of the “able-bodied,” I and all the others “looked alike.” (1991, p. 158)

Nevertheless, PWDs must negotiate all the developmental stages that PWODs experience and also manage the disability. In the last section of this book, we shall discuss each of these developmental stages in detail and how these stages interact with a disability. For now we shall discuss some general experiences of PWDs and developmental stages.
Ways in Which Developmental Stages Are Affected by Disability

- The developmental disorders, such as autism spectrum disorder, are diagnosed in relationship to normal developmental functioning.
- The developmental stage of the individual at the time of onset or diagnosis of a disability has an important effect on the individual’s response to the disability.
- The acquisition or onset of a disability has a powerful impact on the individual’s negotiation of developmental stages.
- The onset of a disability can define transitions of developmental stages.
- The onset of a disability or the treatment of the disability can cause the individual to miss out on important developmental learning and task completion.
- Society has traditionally not accorded adult PWDs adult status, infantilizing them and making them “eternal children.”
- Observing friends and siblings achieve important developmental milestones is difficult for PWDs who understand that they will never be able to reach these milestones. As PWDs age they fall further and further behind, and the developmental gap continues to widen.
- There is little positive social role guidance for PWDs.

An obvious relationship between developmental stages and disability is seen in the developmental disorders. Developmental disabilities are diagnosed during childhood when deviations from typical or expected patterns of development are first noticed. Two general types of developmental symptoms now lead to a diagnosis. Mental retardation (now commonly referred to as “intellectual disabilities”) is a developmental disability because there are two components of the diagnosis. The first is below-average intellectual functioning, and the second is below-average adaptive or developmental functioning. Sub-average adaptive functioning includes deficits in self-care and social skills.

The second general type of developmental disorders is characterized by behavioral and functional characteristics that are not typical of children of a particular age group, such as the pervasive developmental disorders of autism and Asperger’s syndrome. Although there are far more individuals with intellectual disabilities, the autism spectrum disorder is the fastest-growing disability group in the nation.

Most developmental disabilities are diagnosed in childhood, which indicates that the signs or symptoms of these disabilities originate in childhood; however, this does not imply that developmental disorders disappear when the child grows older. Developmental disorders have lifelong consequences resulting from two sources. The first source is the continuation of characteristics or symptoms throughout life, and the second source is the disruption in learning childhood developmental and adaptive skills, such as social skills and communication abilities. Because childhood is an important time in which the brain changes and matures significantly, most children develop in a hierarchical, sequential pattern, learning one skill, then a more difficult one, and so on. Many development disabilities cause the individual to “lose out” on the typical learning
and growth of childhood. When a young child is diagnosed with a developmental disability, some parents mistakenly think that their child will “grow out of it.” However, the child never does outgrow the disability, and the effects of the disability in some ways become more pronounced in relation to the typical development of other children, including siblings. Thus when the child with a developmental disability is an infant, he or she may not seem very much different from other babies. However, the discrepancy gap becomes larger and more obvious as these infants become older. At each developmental stage of life, when other children ride bicycles, go to birthday parties, or attend school, both the child with a developmental disability and the child’s parents may be confronted with more losses.

In order to determine developmental abnormality, it is important to understand normal development. Therefore, the study of disability must include some attention to the concept of normal development. There are universal, identifiable biological, psychological, and social milestones that are achieved at approximately the same age. Understandably, no definition or diagnosis of abnormality is without some flaw. However, there are basic guidelines that are followed, so an individual who displays only one aspect of abnormality would probably not receive a diagnosis of a developmental disorder. It is therefore important to understand what is “normal,” “typical,” or “expected” developmental growth. When making a diagnosis, a team of professionals will also take a detailed and thorough developmental history of the individual. Understanding the developmental history assists in both diagnosis and development of a treatment/service plan.

Most disabilities involve functional loss; generally, the older the individual, the greater the loss. Typically midlife is the time of peak professional and familial success when the individual has attained success as a result of hard work and sacrifice. Acquiring a disability in midlife often results in major losses. Of course, there are more losses in old age than at any other time of life, but these losses are offset by the social expectation of late-onset disability. Indeed, the acquisition or diagnosis of a disability at any developmental stage before old age is considered to be an “off-time” transition.

The type of disability has an impact upon the individual’s negotiation of developmental stages. Degenerating and episodic (meaning having periods of symptoms alternating with periods of remission) disabilities make planning for the future difficult; indeed, planning for next week or tomorrow is difficult. A professor of English who was diagnosed with multiple sclerosis (MS), a chronic degenerating illness, described her MS as “global uncertainty” when she said:

Our sense of who we are is intimately related to the roles we occupy, professional and personal…and to the goals we hold dear. Chronic, progressive disabling disease necessarily disrupted (or threatened to disrupt) my every role in ways that, at the outset, seemed to reduce my worth as a person. Moreover, the uncertainty of the prognosis transformed my goals and aspirations into foolishness. (Toombs, 1995, p. 16)

The public’s reaction to the disability—which has nothing to do with the disability itself—also changes the individual’s developmental growth. For example, most PWDs in the United States are unemployed. Perhaps it is thought that the disability makes the person unemployable; however, most PWDs express a desire to be employed. It is only
society’s misperceptions, the lack of accommodations, and the institutional financial disincentives that prevent PWDs from working. Eric Weihenmayer is blind and succeeded in climbing Mt. Everest. His “force of will, ingenuity, and tenacity” helped him to achieve the summit. However, he failed to obtain a job as a dishwasher while he was in college. In this excerpt, Weihenmayer (2001) described societal limitations as a locked door and concluded that this was the most difficult lesson he learned about blindness:

Too big, too small, too fast, too hot, like a twisted version of the three bears—the story repeated itself again and again. I had thought somehow, that with my force of will, with my ingenuity, with my tenacity, I could eventually win people over and get what I wanted out of life. I hadn’t realized there were doors that would remain locked in front of me. I wanted so badly to break through, to take a battering ram to them, to bash them into a million splinters, but the doors were locked too securely and their surfaces were impenetrable. I never got a dishwasher job in Cambridge, but I did choke down an important lesson, that people’s perceptions of our limitations are more damaging than the limitations themselves, and it was the hardest lesson I ever had to swallow. (pp. 127–128)

The onset of a disability can define a transition. In her autobiography, the movie actor Mia Farrow stated, “My childhood ended at age 10. I contracted polio” (Farrow, 1997, p. 1). Farrow was transported to the adult world of hospitals, doctors, and physical therapy. Her disability provided a sharp boundary between two developmental stages, childhood and adulthood. While simply being elderly is not a disability, acute-onset (a sharp, sudden, clear-cut onset) disability often moves a middle-aged individual into old age.

On the other hand, many other PWDs feel that they are infantilized because of the disability. Society does not allow them to be adults. “PWDs have often been viewed as ‘eternal children,’ in need of control, management, and spiritual guidance” (Smart, 2009, p. 329). Infantilization of PWDs is practiced both on an individual level and an institutional level. In the film My Body Is Not Who I Am, a woman states, “It’s as if I am a child and I have no boundaries.” PWODs feel free to ask strangers with disabilities very personal questions and to touch PWDs and their assistive devices. Neither the questions nor the intrusive touching would be tolerated by someone without a disability. The medical model of disability in which PWDs are expected to be dependent recipients of services—in an inferior and subordinate position with little input into their treatment choices—also contributes to the infantilization of PWDs. Lack of physical accessibility infantilizes PWDs, including adults. An architect explained,

[the built environment is designed for] adult, literate, numerate, physically fit specimens, with good hearing and 20:20 vision…As an architect, I am often struck how little people register about the spaces they are in and why they feel uncomfortable or otherwise. In a way, this lack of awareness places the individual in a child-like reliance on the spaces to contain them, as an infant does of its mother…. (Van Royan, 1997, p. 5; cf. Marks, 1999, p. 83)

The developmental stage of the individual at the time of acquisition of a disability is very important. The disability can be the same type of disability with the same level of severity. However, it is the time of life at the time of acquisition that is important.
For example, congenital deafness (deafness present at birth) is very different from old-age deafness. The level of hearing loss may be identical for two individuals of different ages. However, the individual who was born deaf and lived life as a deaf person would be very much different from an individual who developed deafness in old age. Another example of the importance of developmental stage is disfiguring disabilities. Because body image and attracting a romantic partner are important during the teenage years, adolescence would be a very difficult time to acquire a disfiguring disability.

Disappointment often accumulates when PWDs realize that they will never be able to achieve significant life tasks. Those with intellectual disabilities, seizure disorders, or legal blindness understand that they will not be able to obtain a driver’s license. Thus the PWD falls further and further behind as his or her friends and family members continue to progress. The developmental gaps and performance discrepancies between the PWD and others continue to widen. Therefore the individual and his or her family must develop great coping skills and find different types of accommodations. For example, a mother described experiencing a sense of loss when her son reached “bicycle age.”

When my son Doug, whose disabilities were present from birth, reached bicycle age, I was dismayed that he could not ride a bike—something that had given me great pleasure as a child. And he couldn’t climb trees. I spent many happy times as a little girl sitting and daydreaming in treetops. (Berry, 2009, p. xi)

A mother of two children—one with a disability and the other without a disability—described these developmental discrepancies between her “normal” child and her child with a disability:

Without realizing it the process of parenting this normal child becomes a double-edged sword. We are thrilled and delighted with each accomplishment. It brings us great joy to see this child developing and progressing so well. However, at the same time, the experience can be one of pain—a spark that ignites the flames of chronic sorrow. This is especially true when the normal child surpasses the sibling with a disability. It is a very happy time that can produce, without warning, sadness. (Michalegko, 1993, p. 52)

A brother shared this story of his mother and his brother Marc, who has autism.

My mother often told me how devastated she felt bringing Marc home after they had dropped me off at school. Watching other children his age getting dropped off with their siblings reinforced this pain. (Siegel & Silverstein, 1994, p. 8)

Many of the hardships of life can be anticipated; furthermore, role models are available from whom we can gain some insight into the management and negotiation of hardships, like death, divorce, and job loss. In the past few role models were available for PWDs because of the way society structured the lives of PWDs, keeping them hidden away, failing to provide physical accommodations for access into the community, or not allowing them to participate in education or the workplace (Imrie, 1996; Marks, 1999). Another difference between the hardships of death, divorce, and job loss is the relative lack of prejudice associated with these losses and the provision of a great deal of social
support. Although the situation is improving, the acquisition or onset of a disability is often met with prejudice, discrimination, and blaming the individual for the disability (Martinelli & Dell Orto, 1991). Some PWDs are met with the remark “what did you do to yourself?”

**ADAPTING TO A DISABILITY**

There are three major theories on adaptation to disability. The first is a developmental stage model, similar to the stages of death and dying, first advanced by Kübler-Ross (1969). In the stage model, the individual—and often his or her family—experiences certain predictable stages in coming to terms with the disability (Livneh & Antonak, 1990, 1997). The stage theory is the most commonly used theory of adjustment to disability. In the second model the individual experiences a “social moratorium” or a “rupture.” In this social moratorium the individual and his or her family engage in a period of introspection, most often during hospitalization and medical stabilization and perhaps during a long period at a physical rehabilitation center. During this time, the individual is released from his or her familial, occupational, educational, and social responsibilities. The third model of adjustment takes only physical disabilities into consideration. Wright (1960), a pioneer disability scholar who interviewed World War II veterans with physical disabilities, devised her theory of “cognitive restructuring,” in which the individual redefines reality.

It is important to note that the correct term to use is *response* to disability rather than *adjustment* or *adaptation*. Choice of words is powerful. The use of adjustment and adaptation pathologizes disability, implying that a disability is automatically an undesirable experience. Also, the idea of adjustment and adaptation may imply that responding to a disability is a one-time event, rather than a lifelong process. Arnold Beisser clearly describes the constant, ongoing process of responding to a disability. Beisser (1989) was a physician traveling on a train to report for military duty during World War II. On the trip he became very sick with polio and was paralyzed from the neck down. He described his response to polio as a long-term marriage because it always changes. Nonetheless, adjustment and adaptation to disability are the most easily understood terms, so we shall use these terms in this book with the understanding that there are more accurate words to describe this experience.

It is also important to note that we are discussing only the individual’s response to a disability without consideration of the environmental resources available. Good medical care, assistive technology, a caring and supportive family, and an accessible environment are resources that assist the individual in responding to a disability (Dunn, 1996;
Equal Access to Software, 1999). However, not every PWD had or has all of these resources. Nonetheless, we will consider these three models of adaptation to disability, understanding that an individual adjusts and society accommodates.

THE STAGE THEORY OF ADJUSTMENT TO DISABILITY

The stage model of adjustment to disability provides some helpful guidelines in the way an individual assimilates the disability into his or her identity and reorients his or her priorities and relationships. Similar to Kübler-Ross's (1969) stage theory of death and loss, the disability stage model differs in two important aspects. First, most people who die have some preparatory time, but for acute-onset disabilities, there is no time for preparation. Second, in losses such as death and job termination, the individual does not experience prejudice and discrimination as PWDs do. These stages are not irreversible, and not every stage is necessary. Some individuals skip stages or cycle back through the stages. This stage theory of adjusting to disability cannot be considered hierarchical (meaning that the preceding stage must be completely resolved before moving on to the next higher stage).

The Stages of Adjustment

- Shock
- Denial
- Depression
- Regression
- Anger, personal questioning
- Acceptance

Also, for some PWDs it is not the onset of the disability that requires adjustment, but some other meaningful event, such as being required to use a wheelchair or entering a residential care facility. The stage theory of adaptation to disability is more applicable to physical disabilities than to intellectual or psychiatric disabilities. Furthermore, the stage theory is more useful for physical disabilities that have a stable course.

The first stage is shock, in which the individual's thinking is often disorganized and the individual feels overwhelmed and confused. A woman whose husband acquired a disability after they had been married for 16 years described the state of shock as being "in the midst of a hurricane."

When everything is over, I think I will be able to really sum up a lot of the feelings that I have inside that I find hard to express or I don't have the words for. When everything is over, I think I'll probably find a lot of things inside of me. Isn't that what happens? Like when you are in the midst of a hurricane it's real hard to kind of...figure out everything. But once you are out of it, you can kind of go, “Hey, yeah, I was in the middle of that hurricane, and this is what happened.” (Buki, 2007, p. 339)
The second stage is denial, often called “defensive retreat.” As the word *defensive* implies, this stage can be therapeutic because it may allow the individual to maintain his or her self-identity. However, denial is considered therapeutic only if the denial does not continue for too long (Naugle, 1991; Stewart, 1994). Denial of the disability is very rare, but denial of the permanence of the disability or the implications of the disability is more common. Remarks such as “I’ll soon be my old self” are a denial of the permanence of the disability. President Franklin Roosevelt, who contracted polio, engaged in denial of the implications of his paralysis when he said, “I will walk again” (Gallagher, 1985). He never did walk again because the polio virus destroyed his hip and leg muscles. However, a few childhood disabilities, such as asthma, are not permanent, and the child eventually outgrows the disability. Still, most developmental disabilities are chronic, lifelong conditions.

A young man diagnosed with schizophrenia related the way in which the combination of the symptoms of the disability and society’s prejudice and discrimination made shock and denial difficult to overcome.

I cannot tell you how difficult it is for a person to accept the fact that he or she is schizophrenic. Since the time we were very young we have all been conditioned to accept that if something is crazy or insane, its worth to us is automatically dismissed…. The nature of this disorder is that it affects the chemistry that controls your cognitive processes. It affects your belief system…. It is exceedingly difficult for you to admit to yourself that the mind does not function properly. It fools you. (Frese, 1997, pp. 145–146)

A pediatrician (Batshaw, 1998) stated that physicians and other medical providers may engage in denial. Batshaw told of the tendency of many professionals to use the term *developmental delay* rather than *developmental disability* or *mental retardation*. Although Batshaw clearly states that it is not appropriate to use the diagnosis of a developmental delay for a child older than two to three years, it may be a type of denial on the part of physicians (which then perpetuates denial in the parents). Batshaw concluded: “It [the use of developmental delay] then becomes a way of avoiding the reality that may be painful both to the parent and to the professional” (p. 54).

The third stage is depression, in which the individual attempts to retain his or her former identity. The future is uncertain, and the individual may feel that he or she no longer has an identity. Often PWDs feel that “my family would be better off without me.” In this stage, the individual does not have the motivation or energy to invest in a rehabilitation program. One man with a spinal cord injury stated,

If someone is stuck in the grieving process….it’s like an adjustment to a death. The only thing is, for an injury or disability, it’s not as easy to adjust as with a death because with a death, the person’s no longer there. With a disability, you have a constant reminder. So, sometimes, it takes even longer to grieve and adjust. A lot of people turn to alcohol and drugs, which is a way of going through denial. As long as you’re smashed, you can forget about your disability. (Scherer, 1993, p. 115)
Another man, paralyzed from a diving accident as an adult, described his physical rehabilitation and the total lack of attention to his emotional needs. He, too, describes his depression as experiencing a death of a loved one (Hofsiss & Laffey, 1993):

The one thing that surprised me through all of this was the real lack of either interest or concern about depression after an accident. There is much more concern about your physical therapy, making sure that your lungs are clear, all the things that might physically have happened to you. “Can you move this? Can you feel that?” But, for the emotional things, no psychiatric help was offered by the doctors who had been treating me and certainly knew my case very intimately.

I began to see a therapist. I talked to her very much the way I think one would if one had gone through the death of someone close. Because there is that grieving process you must allow yourself—very essential to anybody whose life is altered as severely as mine was. (p. 86)

The fourth stage is regression, in which the person gives up and regresses to an earlier, less mature stage of life. Cohen (2004), who has multiple sclerosis, related that he received the diagnosis from his doctor by telephone and described his reaction to the diagnosis. “After the phone was returned to the cradle, immediately I wished I could be also [returned to the cradle]. This would be a great time to be an infant again, to be picked up and rocked” (p. 18).

The fifth stage is anger or personal questioning, in which the person may ask, “Why me?” or “Why did God allow this to happen to me?” Often PWDs will replay the accident or the prediagnosis period endlessly, trying to find someone to blame or looking for ways to have avoided the disability (Bordieri, 1993; Bordieri & Drehmer, 1993). Frequently PWDs believe in the erroneous assumption of a fair world in which everyone receives what he or she “deserves.” Obviously, misguided belief in the “fair world” fallacy can lead to anger. A man with a spinal cord injury spoke of:

anger that just sits there and grows. I wish I’d had counseling…on a fairly regular basis. I’m not sure what would’ve come out of it, but if you see someone enough, eventually you’re going to say something. Try to bring things out, some of the anger, and things like that. That was something that was never done, and that anger just sits in there and grows. (Scherer, 1993, p. 160)

The stage model assists PWDs, their families, and their caregivers in understanding the process of accepting a disability. They can understand that these stages are “normal,” or better stated, typical and to be expected. While some of these stages, such as anger and depression, are not pleasant to experience or to watch a loved one experience, understanding and tolerance can be given rather than abandoning the PWD. In addition, treatment plans can be developed. The man with the spinal cord injury stated that counseling could have helped him deal with his anger. However, the stage theory is not as useful with episodic disabilities, degenerating disabilities, or psychiatric disabilities such as mental illness.

Many practitioners and researchers are beginning to question the stage model of adaptation to disability asserting that the adaptation process is influenced by a broad
array of factors, such as visibility of the disability, developmental stage and chronological age at onset, and functional limitations. Therefore, these individuals do not provide a “road-map” approach as does the stage theory of adaptation. Instead, an undefined, individualistic process is advocated. Harper and Peterson (2000) explained: “There are complex relationships among these variables between their rate of progression, pattern, and sequence, level, type, and context of adaptive functioning. Individual differences and variation is the rule between individuals with common phenotypic, chronic, physical disorders” (p. 127). It seems that the stage model accommodates and considers all of these factors.

Kübler-Ross’s stage theory of death and dying is also being questioned for many of the same reasons as the stage theory of adapting to disability. However, even the sharpest critics of Kübler-Ross credit her theory and the interventions based on her theory with three positive outcomes. Kübler-Ross’ theory (1) changed the way in which both professionals and the general public viewed death (as a process rather than a one-time event), (2) changed the way in which dying individuals were treated and cared for, (3) provided support to the family of the dying individual by allowing her to see her loved ones’ responses to the dying process as “normal” or typical, and (4) created an entire profession and a system of caring for terminal patients: the hospice and death and dying counselors.

In the same way, even though criticism of the stage theory of adaptation to disability is growing, this theory can offer the same four benefits: (1) changing the way in which professionals and the general public view disability, (2) changing the ways in which PWDs are treated and cared for (by providing counseling and other emotional support), (3) providing support to the families of PWDs, and (4) creating a new set of professionals—disability counselors.

The Social Moratorium

The second model of adjustment to disability is called the “social moratorium,” in which the individual is given time away from responsibilities. There is a clear separation between life “before the disability” and life “after the disability.” This time is used to redefine oneself and (occasionally) to separate from past disadvantages, such as economic poverty, lack of education, difficulties with the legal system, or substance abuse. Marsh and Leffy (1996) explained: “A catastrophic event [such as a disability] generally results in disintegration of existing patterns, which in turn offers the opportunity for constructive reintegration” (p. 3).

Cognitive Restructuring

The third model deals only with physical disabilities and is considered to be the first model of acceptance of disability. Beatrice Wright developed her theory of cognitive restructuring immediately after World War II and published her seminal work in 1960 (McCarthy, 1993). Wright’s theory is composed of four points. The first is enlargement of the scope of values that are not in conflict with the disability. First-person accounts of people with physical disabilities often have this statement: “I escaped into my mind,” giving an example of an enlargement of scope of values. Individuals with
more education, a longer work history, and a supportive family have been found to be accepting of disability simply because there are more options available to them and they are able to pursue a different type of life.

The second point is “subordination of the physique.” Many people consider their body to be a symbol of worth, desirability, and competence, which is not surprising because we live in a culture that is obsessed with physical appearance. The acquisition of a physical disability prompts the individual to consider his or her self-identity. What makes you, you? What makes me, me? Intellect, personality, character, a spiritual soul, or past history often becomes the PWD’s self-identity, rather than any physical characteristic or appearance. Incidentally, elderly individuals without disabilities also experience a subordination of the physique. Charles Mee, a writer who contracted polio as a teenager, resented his father’s failure to see the way in which Charles’s disability changed his identity. Mee stated that he “was filled with rage.”

For the rest of his life after I had polio, my father carried a picture of me in his wallet that he had taken at the halftime of a football game. I was sitting on the grass with my teammates while the coach talked to us. My father had come around to the side of the group, and as I turned to look at him, he took the picture: an adolescent boy in the vigor of youth, a strong jaw and neck, a crew cut, massive shoulders with the football pads…. I always took the fact that he carried that picture with him as a sign of disappointment in me, and it filled me with rage…. The photograph was still on a table not far from his bed when he died at the age of ninety-four. (1999, p. 170)

The third point of Wright’s model is “containment of disability effects.” The individual does not deny the disability but contains or limits the effects of the disability. This requires active management of the disability, the avoidance of secondary disabilities, and an active search for opportunities that are available. The PWD has a realistic view of the disability and neither exaggerates nor minimizes it. The individual wishes to return to normality—a new, redefined version of normality in which the absence of the disability or a cure for the disability is not considered necessary. Normality means the return of the individual’s family life, work life, and social life, all with a disability. In a recent oral history of Canadian World War II veterans with spinal cord injuries, titled “Going Back to Civvy Street,” the veterans describe the way in which they self-described normality.

It didn’t make much sense spending all that energy covering a short distance (on crutches)…. when you could do it quickly and easily with a wheelchair…. It
didn’t take long for people to get over the idea that walking was that essential. (Tremblay, 1996, p. 153)

The fourth and final point of Wright’s model is “transformation from comparative to asset values.” This is also termed “asset orientation,” meaning that rather than considering one’s losses, the PWD should focus on what he or she can do. Two aspects of shifting from comparative values include the necessity of not comparing oneself to PWODs and actively discovering one’s strengths and talents. Randy Souders felt that his disability rescued him from a life in a “mediocre little ad agency.”

It’s odd. If I had a crystal ball to see what would have happened had I not had the injury, I don’t see myself having done what I’ve done at all. I would probably have a mediocre position in a mediocre little ad agency and be like the rest of society—up to my ears in debt, just trying to get by—and frustrated that I didn’t go for something that would have truly inspired me all along. . . . I don’t know that I would have dedicated myself to art. Art was a vital part of my recovery from my injury. I found myself in a situation of being the same person in a new body, one that didn’t work, along with the loss of self-esteem and self-confidence and all the things that come along with a traumatic injury. Once I realized that I still had a chance at being creative and of value through my artwork, I just really focused in on that. It was a real part of my recovery. (Smith & Plimpton, 1993, p. 153)

**DISABILITY AS GROWTH AND DEVELOPMENT**

Most theories of human growth and development consider the process of development to be represented by an upward line and the goal to be greater competence, autonomy, and individuality. In contrast, disability is incorrectly thought to be deviance, weakness, and pathology, so life with a disability cannot be a life of competence, autonomy, and greater autonomy.

Erikson, a developmental theorist, viewed “ego disequilibrium” as a motivation to higher stages. Ego disequilibrium, or imbalance, is the result of wanting to progress to the next development stage, learning new skills, and conforming to societal expectations, while at the same, desiring to remain in the security and familiarity of the present stage. The “crises” of each of Erikson’s stages are periods of great potential and heightened vulnerability. The onset or diagnosis of a disability can be considered a developmental task or crisis, or a turning point in an individual’s life. There are PWDs who consider their disability to have been a catalyst for a transformation to becoming a better person and living a different type of life.

The idea that different people reach the same goals through different pathways seems appropriate to the disability experience. This is termed the model of diverging pathways (Kerckhoff, 1993). Longitudinal studies have the capability to show the effects of the model of diverging pathways. There have been no longitudinal studies conducted on individuals with a wide array of disabilities.

Finally, the concepts of growth, development, and maturation in old age have parallels with the disability experience. In the past, life-span theorists considered old age to be a period of decline and loss, which was and is true in a solely biological sense. However, some theorists assert that other types of growth and development occur in
the presence of biological loss, such as the growth of wisdom and a wider and less judgmental understanding or view of the world and others. A mother of a man with a psychiatric disability described her son:

Well, he is the most kind, wonderful human being—probably because all he has been through. He volunteers at our local crisis unit. Patients will go in because he is there. Other families request him to speak to their mentally ill loved one. Because of Clozapine (an anti-psychotic medication), he is in a master’s of social work (MSW) [program] at our university, and he wants to work with severely mentally ill patients when he graduates. Our mental health center said they want him to work there. (Marsh & Lefty, 1996)

In another first-person account, a woman thinks of her missing arm as a Zen Buddhist koan, a paradox that is used to meditate upon in order to gain enlightenment.

Being disabled is a deep wound, a source of pain. But like all wounds, it is also a gift. As Eastern wisdom has always known, it is hard to tell good luck from bad luck. . . . Having one arm is an endless koan. It is what it is, which is unknowable, and it attracts a lot of ideas, stories, and images. Caught up in the negative story, I felt ashamed, incomplete, and not okay. I drank to die. Later on, caught up in a more positive story, I felt pride and a sense of identity. . . . In such open being there is freedom and possibility for the new. (Tofflison, 1997, p. 111)

One article (Boerner & Jopp, 2007) discussed major life change and loss and how three major life-span theories describe adjustment to loss. Although disability is not specifically mentioned, one example provided considers two types of disabilities: blindness and arthritis. This may be because one of the authors (Boerner) is affiliated with Lighthouse International, a large research and service agency for individuals with all types of vision loss. This article is unique in human development literature because the authors refer to the acquisition of a disability and ways in which to respond:

Life changes or losses (e.g., a physical impairment) often involve coping challenges that are both within and beyond one’s control. For example, a person with a functional loss due to arthritis or vision impairment may be able to maintain prior levels of functioning in certain life domains by using technical aids, while having to reevaluate the importance of those life domains which are no longer manageable even with the help of such aids. Furthermore, it may be critical to achieve developmental gains during periods of loss. (p. 172)

Discussing the possibility for growth and development during old age, Baltes, Staudiner, and Lindenberger (1999) asserted:

Deficits in biological status can also be the foundation for progress, that is, antecedents for positive changes in adaptive functioning. . . . In this line of thinking, the human organization is by nature (Gehlen, 1956) a “being of deficits” and social culture has developed or emerged in part to deal specifically with biological deficits. This “deficits-breeds-growth” mechanism may not only account for cultural–biological evolution, it may also affect ontogenesis. Thus it is possible that when people reach states of increased vulnerability in old age, social forces
and individuals invest more and more heavily in efforts that are explicitly oriented toward regulating and compensating for age-associated biological deficits, thereby generating a broad range of novel behaviors, new bodies of knowledge and values, new environmental features, and, as a result, a higher level of adaptive functioning. (p. 478)

Baltes et al. (1999) clearly stated that (1) biological deficits are natural (“by nature”) and universal; (2) society should “invest” in people with biological deficits, assisting them to compensate and regulate these deficits; and (3) investing in people with biological deficits will benefit both these individuals and society as a whole due to “new bodies of knowledge and values.” If the word disability is substituted for “biological deficits” and “old age,” then PWDs will be viewed as valued members of the larger culture and society and the disability experience will become valued and less frightening. These authors clearly advocate for the “deficits-breeds-growth” approach.

In this short introduction we have touched on the topics of developmental theories and disability and chronic illness. Each of these two topics will be discussed in greater detail later in this book. The purpose of this book is to understand the relationship between developmental theories, developmental life stages, and disability.

This book consists of three major sections:

• Explanation and description of the major developmental theories and their importance and utility.
• Presentation of the major stages or periods of life, such as infancy, childhood, adolescence, adulthood, elderly, and how the acquisition or diagnosis of a disability influences each stage of life.
• Discussion how the major developmental theories can incorporate the experience of disability.

Terms to Learn

- Cognitive restructuring
- Containment of disability effects
- Enlargement of the scope of values
- Infantilization
- Rites of passage
- Social moratorium
- Transformation from comparative to asset values
- Subordination of the physique
- Transformation from comparative to asset values

Videos to View

• View the 24-minute video A Full Stride: Overcoming the Challenge of Amputation, by Films for the Humanities and Sciences. The producers describe this video as follows: “Focusing on three people, this program shows the many sides of what is often a generic label: disabled or amputee. Old, young, partial loss, complete loss, each story is different. From the time of hospitalization to
the triumph of accomplishing small and large tasks, we see the many challenges and the small victories: the psychological pain of losing a limb, the stigma of being ‘disabled,’ and the vivid ‘phantom’ pain of a lost limb, but also the process of adjustment to a prosthesis and the freedom and mobility it can bring.”

- View the 30-minute video *Open to the Public: Complying with the Americans with Disabilities Act*, from Aquarius Productions. The producers describe this video as providing “an overview of the ADA as it applies to state and local governments. The ADA does not provide recommendations for solving common problems, but this film could provide enough information…to solve common problems.”

### Learning Activities

(Note: Some of these may be used for class presentations.)

- Read Beatrice Wright’s book *Physical Disability: A Psychological Approach* (1960), published by Harper and Row. Write 10 paragraphs about her work with PWDs and her groundbreaking book. Why do you think Dr. Wright focused only on physical disabilities?

- Read and review the ADA, and learn the five titles of this law. Why were the 2008 Amendments necessary? ADA can be found at: [www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm).

- Obtain the ADA technical manual, which will give precise measurements and specifications for accessibility. Visit various places in your community, such as entertainment facilities, sports facilities, schools, and churches or other places of worship, then give a class presentation on your findings. Explain the way in which your awareness of lack of accessibility has increased.

- Interview an individual who has acquired a disability. Explain the stage theory of adaptation and ask this individual if these stages apply to him or her. Explain Wright’s theory of adjustment, and ask if this applies to him or her.

- Interview a parent or parents of a child with a congenital disability. Explain Wright’s theory of adaptation to disability and the stage theory of adjustment to disability, and ask these parents if these apply to them.

- Read the article “An Integrated Model of Psychosocial Adjustment Following Acquired Disability,” written by Kendall and Buys in 1998 and published in the *Journal of Rehabilitation*. Kendall and Buys raise serious questions about Wright’s stage theory of adjustment to disability. Do you agree or disagree with these authors?

- Complete the *Acceptance of Disability Scale* (ADS). This instrument was developed using Wright’s theory of adaptation to physical disability. Place each question on this scale into one of four categories based on Wright’s four components.

Writing Exercises

- Write a six-paragraph paper defending this statement: “People with disabilities will soon dominate the national agenda.” Consider services and public funding.
- Write a five-page paper describing a rite of passage of your religion or of some group you belong to. For example, how does your religion define, celebrate, and observe a wedding? What are the bases for this particular rite of passage? How does this rite of passage change the self-identity of the individual and change the identity of the individual in the view of others?
- Write a six-paragraph paper defending this statement: “Those hardships in life for which an individual can make preparations are typically easier to negotiate.”
- Interview an individual who is 20 years old or older who has sustained a disability. Ask him or her about the adjustment period. Did this individual seem to follow the stage theory, the social moratorium theory, or the cognitive restructuring theory? Write a 10-paragraph paper explaining your findings.
- Do you think that using the phrase “response to a disability” rather than “acceptance/adjustment/adaptation to a disability” is important? Write three paragraphs that explain your reasons for agreeing or disagreeing with this statement.
- Write a three-page paper on the type of party you would have every year if you were involved in an accident and became quadriplegic. Name the party “the-day-I-broke-my-neck” party. Which people would you invite? What would be the activities? Do you think your party would be fun?