16

Behavioral Health Service Delivery Among Persons with Disabilities

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Introduction

Disability census figures indicate that one in five Americans, approximately 20%, live with a disability (US Census, 2010). As a collective, people with disabilities comprise the largest minority group, yet it is one of the least understood and discussed. Disability is a term used to describe any number of physical, mental, emotional, psychological, cognitive, learning, neurological, sensory, and health conditions that limits one or more major life activities (ADA, 1990). Examples, although not an exhaustive list, include spinal cord injury, traumatic brain injury, cancer, fibromyalgia, anxiety, depression, learning disabilities (i.e., ADHD), diabetes, chronic pain, vision impairments, deafness/hearing loss, posttraumatic stress disorder, mental health conditions (i.e., schizophrenia, bipolar disorder), and cardiac conditions. According to ADA's definition, disability may impact a person's ability to care for oneself, do manual tasks, see, hear, eat, sleep, walk, stand, lift, bend, speak, breath, learn, read, concentrate, communicate, and work (ADA, 1990).

Learning to live with a disability is a process and one that sometimes resembles a significant transition for the person and the family. While many people adapt to the disability and move forward in a positive fashion, some do not. Clinicians working with people with disabilities are likely to encounter people from both sides of the adjustment continuum. Some people may seek short-term services while others require more intensive supports. Still other individuals may not desire or require any sort of behavioral health services, and thus, they never seek the services of a clinician or behavioral health professional.

Professionals who work with persons with disabilities may have a number of questions or assumptions that have not been addressed as a part of their education or training. As result, some may unintentionally think that a person's disability and the changes they experience directly related to the disability are of primary importance to the individual when they are not. While it is true that some individuals and their loved ones have questions or concerns related to the disability and want assistance in moving past it, it is imperative for clinicians to understand that disability adjustment is *only* one piece of the coping equation and in learning to live life to the fullest. For many, learning to live well with a disability is much more involved and complex of a process, and many factors must be considered and

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addressed as a part of the therapeutic relationship. For this reason, clinicians and behavioral health professionals are encouraged to learn as much as they can about disability and the experiences of persons with disabilities. In an effort to help clinicians broaden their understanding and to enhance their effectiveness in working with this group of individuals, select topics are covered as a part of this chapter. It is our hope that as professionals read this chapter they digest and apply the content provided to expand their understanding of persons with disabilities and as a part of their clinical practice.

Language and Perspectives: Considerations for Clinicians

Living with a disability is about much more than a diagnosis or a lifelong condition. Too often, someone with a disability is viewed by society, professionals, and external bystanders as a person who is different and somehow not a "whole person" because of the disability. While many of these views date back several hundreds of years and are a part of our history and the nation's foundation (Rubin & Roessler, 2008), such perspectives are still present. In these instances, persons without a disability and society, as a whole, focus on the feature that makes the person different from other people. Thus, it is the disability and the noticeable functional differences brought about by the disability that become the most salient part of the individual rather than viewing the person as an individual comprised of multiple traits and characteristics (Stuntzner, 2012).

Clinicians who work with persons with disabilities are not exempt from holding negative beliefs and stereotypes about people with disabilities simply because they are in a helping profession. Despite their good intentions, clinicians are subject to engaging in undesired behavior such as focusing upon the person's disability or diagnosis as the most important feature of the person instead of on the individual as a human being. Some of this may be understood by the fact that people are shaped by their upbringing, earlier life experiences, lack of exposure, and professional training. However, clinicians working with this population need to do more, especially given the fact that most mental health and behavioral health programs do not incorporate training and coursework pertaining to people with disabilities. Programs that do may only cover one course and these may refer to "exceptional children, persons with learning disabilities or intellectual disabilities" and typically do not cover the broader range of conditions experienced by people nor do they consider ways to integrate the needs of people with disabilities into the professional curriculum (Olkin & Pledger, 2003, p. 297). Olkin and Pledger (2003) expand our understanding of the lack of adequate coverage of this area by stressing the findings of a large study of graduate psychology programs conducted by Bluestone, Stokes, and Kuba (1996). Bluestone et al. (1996) report that disability when compared to other diversity categories (i.e., ethnicity, gender, religion, socioeconomic status) was the least addressed among professional programs and throughout the curriculum. Such findings help us better understand that many clinicians and helping professionals graduate from their programs with no or limited information about the needs of persons with disabilities or potential strategies to assist them in their clinical practice.

Clinicians can increase their understanding and effectiveness in working with people with disabilities by learning more about this diverse group of individuals, their clinical concerns (i.e., self-concept), the obstacles and societal stigma they encounter, information pertaining to coping and adaptation, and therapeutic strategies (i.e., forgiveness, self-compassion, resilience) that can be employed. Furthermore, professionals have an opportunity to consider their own behaviors and approaches when working with this group of people, some of which includes examining the use of proper language, one's own beliefs about and expectations of persons with disabilities, and viewing people from a holistic perspective.

Proper Use of Language and Diagnosis

Language is powerful and has the ability to help, heal, or hurt and suppress. While many of us may desire to use it for positive purposes, such as a healing agent or as a means to encourage others, it is important to be aware that language has the potential to offend or hurt others. No one understands the power of language better than the person who has been on the receiving end of other peoples' unkind words, slights, or derogatory comments.

Language, inaccurate descriptors, and the use of labels are valid and vital concerns of many persons with disabilities. Many of these negative descriptors include outdated words and phrases such the words "invalid, suffering, afflicted, abnormal, victim, moron, handicapped, wheelchair bound, and crippled" (Titchokosky, 2001, p. 127). Others include the infamous "D" words often associated with a disability such as deformed, diseased, and disordered (Stuntzner, 2015a). Such words, even if unintentional, have the ability to hurt the therapeutic relationship, create distance, and promote negative thoughts and feelings about people with disabilities among each other and as a part of the therapeutic relationship.

Being mindful of our word choice is important. Beyond the impact that it can have on the therapeutic relationship is the way words can negatively impact the person with a disability. People come to counseling in hopes of being unconditionally accepted for who they are and to be valued for the experiences they have had. When working with people with disabilities, these experiences often involve a history of being oppressed, disempowered, and not being valued or heard (Smart, 2009; Stuntzner, Dalton, & MacDonald, 2018). Many have a long history of being told what they can or cannot do, what is and is not realistic because of the disability, or some form of negative expectations and lack of support due to the specific type of disability or a person's gender (i.e., female) while living with a disability (Nosek & Hughes, 2003). Because of these experiences, people sometimes internalize, without recognizing it, the negative views and expectations held by society, family, and people they know. Thus, the last thing people need as part of the therapeutic relationship is more negativity or some sort of lowered expectations. Related is the notion that language has the ability to affect how people view themselves and their abilities. As clinicians and allied helping professionals, our goal is to help and empower people, not to be another set of experiences that resembles some form of barrier or hurdle to be dealt with or overcome.

Clinicians are encouraged to consider their own use of language and to further examine if and when a diagnosis is indeed necessary. A good place to start is with the use of "person-first" language. While it is true that some people with a disability may not use "person-first" language themselves, most people prefer to be known as a person with unique qualities and characteristics and not as the condition or the disability (Stuntzner, 2015b). Thus, it is important to separate the person from the disability/diagnosis and to become familiar with the person as an individual the same as we would anyone else without a disability. Even better of a practice is to address the person by his or her first name (Stuntzner & Hartley, 2014a). In the event that people describe themselves in ways that are not encouraged (i.e., "I am handicapped"), it is imperative that professionals respect the person's identity and description and take the time to explore what that means to the individual. Professionals who are uncertain of how to talk about a person's disability are encouraged to enlist the preferred method which is to simply ask the individual what his or her preference is (Stuntzner & Hartley, 2014a).

In terms of language as it pertains to diagnoses and labels, caution is encouraged. While many people desire to understand, classify, and categorize, as professionals we are held to a different standard and we must keep in mind the reasons and rationale for which diagnoses and labels are used. Clinically speaking, three criteria should be considered when it comes to the use of diagnoses and labels. These include the following (Stuntzner, 2015a):

- Is a diagnosis necessary for billing insurance companies?
- Is a diagnosis needed to determine or justify treatment of a mental health or physical condition? or
- Is a disability determination needed to be eligible or to qualify for a service or program?

Should our work with people address one of these questions, then the use of a diagnosis may be warranted. However, outside of the need to seek payment for treatment or services, or to qualify for services by an agency, professionals are encouraged to refer to the person as a person, not the condition, and to view the person in a holistic manner the same as they would the person without a disability.

Examining Our Own Belief and Expectations

Individual and personal differences are a natural part of the human experience and society. Each one of us has a different physical structure, facial features, personality characteristics, personal preferences, cultural and ethnic background, and personal beliefs and expectations. It is these differences that make life and the human experience diverse, interesting, and ever changing. Most people seem to accept these differences as a normal part of life and as acceptable. However, when we factor in the presence of a disability, the equation often changes along with people's perceptions, beliefs, and expectations. More specifically, disability is an experience that is often accompanied by low expectations, social and personal stigma, social isolation, loss or change in social and familial support, unemployment, and lack of resources and if unchecked leads to a continued path of inaccurate beliefs, perceptions, bias, and misunderstanding (Marini, Glover-Graf, & Millington, 2012; Smart, 2009). One feature of particular merit is the fact that persons with disabilities are often looked at as the disability, as previously mentioned, compounded by the fact that people are often viewed as individuals who cannot do or achieve something. For these reasons, as clinicians working with persons with disabilities, it is imperative that we step back from our own set of experiences and examine our own understanding and beliefs about disability, persons with disabilities, and what we think it means to have a disability.

One method Stuntzner and colleagues (Stuntzner, 2012; Stuntzner, Hartley, & Ware, 2014) use as an educational tool among students, professionals, and society at large to promote sensitivity and awareness about disability and the ways we relate to people based on one identified feature is a visualization exercise called, "A Time to Reflect and Remember." In this exercise, people are asked to think about their life and to recall one specific event that was hard and that they would not want to relive. Throughout this visualization, people are encouraged to remember the event, their thoughts and feelings associated with it, and how they were treated by other people and to explore what stands out or is most salient about the situation. When people are finished, they are directed to consider how they would feel if people, everyone they knew or met, identified and related to them based *solely* on that time in their life. Following, people are asked to get in touch with how that would impact them if this "identified event" became the "sole feature" of who they were to those around them and were not allowed to move past it. As you can imagine, many people would not like it. Our response to that is, "Knowing this, how might some people with a disability feel when people see them as the disability and focus on that as the person's identity rather than as a person with several interests, capabilities, and worthwhile characteristics?" Such an activity, becomes a springboard for professionals to gain insight into the value of treating people as holistic, valued individuals as well as a means to begin exploring their own beliefs and expectations about persons with disabilities.

Beyond this visualization exercise, clinicians are encouraged to embark upon the personal journey of exploring their upbringing, prior experiences and understanding of disability and persons with disabilities, and their personal and professional beliefs and expectations. Questions for consideration may include:

- What beliefs do I hold about living with a disability?
- Would I consider myself as a person who sees a person's strengths and abilities despite the disability or do I focus on what people may not be able to do? What evidence do I have to support my views?
- Are there specific life experiences or situations that influence how I personally or professionally view the phenomenon of disability and/or persons with disabilities?
- How do these beliefs and expectations influence the interactions I have with people, the therapeutic relationship, and/or the behavioral health services I offer?
- What areas, if any, might I consider exploring and expanding to improve the therapeutic alliance I develop with the people I serve?

Examining our own beliefs and expectations is important because without getting in touch with our own thoughts, feelings, and experiences, clinicians may unintentionally alienate themselves from the people they are trying to serve and may promote additional barriers as a part of the therapeutic relationship. Compounding this situation is the notion that people with disabilities "sense" and know when they are unconditionally accepted by others and when they are not. Much of this is due to the reality that people, regardless of disability type, are surrounded by inaccurate societal attitudes, expectations, and bias (Smart, 2009), and throughout the process of living with a disability, they learn to recognize "the face" of this and what it looks like in others (Stuntzner et al., 2018).

Exploring a Person's Disability Identity and Self-Concept

A key component of coping with a disability is about an individual's identity and self-concept. When people live with a disability, persons without a disability frequently think that dealing with the disability is the person's primary focus and identity. Part of this phenomenon can be understood since disability is a term that conjures up many inaccurate perceptions and is often misunderstood by "outsiders" (Wright, 1991). According to this definition, outsiders are depicted as people without a disability who are not intimately familiar with the experience of living with a disability.

Regardless of other people's perception and view of disability and what it means to live with a disability, disability is an experience that can positively or negatively influence how people view themselves (Dunn, 2015). People who view the presence of disability as negative may be challenged in how they perceive themselves because of the disability itself and what the disability means to them (Smart, 2009; Stuntzner, 2015b). In these instances, people may view themselves as the disability or as a person whose life is consumed with the presence of a disability (Dunn, 2015) (see Fig. 16.1). When this happens, people may refer to themselves according to what they cannot do or as the disability or condition itself rather than as people who have a full life filled with many interests and abilities of which living with a disability is only one component (Stuntzner, 2012; Wright, 1983). It is these individuals who may come in for help because they do not know yet how to "right size" their disability. When we speak of "right size" we are referring to the ability to acknowledge and accept they have a disability, but instead of the disability being their whole existence, it is one piece of

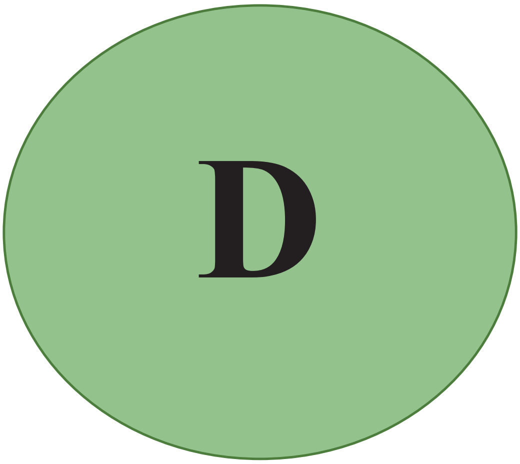

Fig. 16.1 Disability as the person's whole identity

them along with many other features and characteristics (Stuntzner, 2012).

Beyond the negative perception of disability are the positive views and self-concepts. While is it not a given that all people reach a place of acceptance with their disability, many do eventually learn how to accept the disability and the associated changes that accompany it. Behavioral health professionals working with people on adjustment and disability issues are encouraged to help people explore ways to "right size" their disability and to assist them in viewing disability as an integrated part of who they are. Such a view is empowering as it provides people with the personal space to acknowledge and honor the presence of a disability as well as create room for other parts of their being and personhood (i.e., personal traits, familial roles, life experiences, career/employment; Stuntzner, 2012, p. 135).

From this perspective, people learn to see their disability as only piece of who they are rather than the sole focus of their identity (see Fig. 16.2; Stuntzner, 2012). People who view the disability as an integrated piece of themselves and their lives understand that they have more to themselves than the disability. Furthermore, many come to understand the importance and value of disability pride and the positive role such an identity has on their life (Dunn & Burcaw, 2013). People who identify with the concept "disability pride" are those individuals who accept themselves as they are and who do not feel a need to be "fixed" according to society's standards. Many such individuals describe the experience of living with a disability as something they would not change if given a choice because the disability has made them a better person and they fully embrace the person they are. Furthermore, people who subscribe to this way of life feel they do not need to eradicate the disability and that it is society that needs to change and to be more accepting, inclusive, and less stigmatizing and inaccessible.

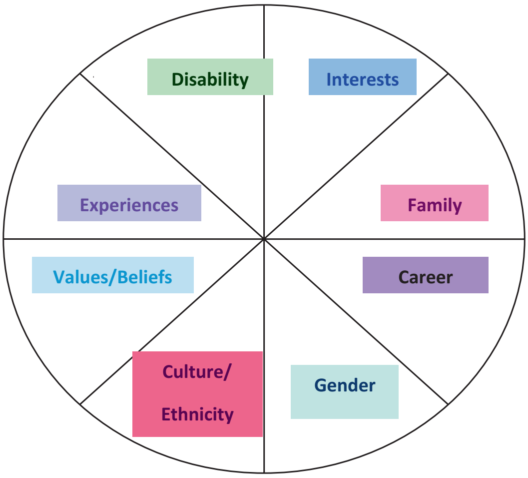

Fig. 16.2 Self-identification chart. (Source: Stuntzner 2012)

Related to positive self-concept is the role disability has in relation to personal growth. As previously indicated, several people with a disability positively adjust to the disability and its associated changes. Professionals seeking to understand how this can be the case may find it helpful to understand that people often describe disability as an experience that helped them learn and grow as a person and, in some instances, become a better and more evolved, caring, and compassionate person compared to who they were before the disability (Park, 2010). For many people, disability is an experience that helps them:

(a) transcend and rise above their disability (Vash, 2003);
(b) find a higher purpose in life;
(c) develop internal strength and resilience;
(d) make positive changes such as learning to forgive, improve coping skills, and become more compassionate and self-compassionate (Stuntzner & Hartley, 2014c);
(e) enhance their sense of spirituality and develop a closer relationship to God (Glover-Graf, Marini, Baker, & Buck, 2007);
(f) discover ways to use their situation to help others;
(g) develop a greater appreciation for life; and
(h) strengthen personal and familial relationships.

Personal and Societal Barriers Experienced by Persons with Disabilities

People with disabilities experience a number of personal and societal barriers. Numerous barriers accompany disability and have been a part of society and interpersonal interactions throughout the history of our nation and as an integrated part of cultures for a number of centuries. Such treatment and experiences are well-documented throughout the history of our nation as persons with disabilities have a long history of being mistreated, misunderstood, perceived as less than or as not capable, viewed differently, and being separated or socially isolated (see Rubin & Roessler, 2008). Despite this long lineage of misunderstanding and mistreatment, progress has been made to better understand disability and the needs of people with disabilities. However, society and the professionals who work with this group of people are not where they need to be in fully addressing and removing the barriers people encounter especially given the fact that such barriers are still heavily imbedded into our society and into the lives of people with disabilities.

Behavioral health professionals working with persons with disabilities can enhance their knowledge and effectiveness by understanding the complexity and multifaceted nature of disability-related barriers. Well-known barriers encountered by people with disabilities include those that can be categorized as societal, attitudinal (i.e., stigma, perceptions as a second-class citizen), architectural, environmental (i.e., lack of access to a building), medical, poor health insurance coverage, employment (i.e., employer's beliefs about disability), lack of access to services and community activities, and personal, just to name a few (Stuntzner & Hartley, 2014a). Of particular importance are societal and attitudinal barriers as these are the number 1 offensive and most difficult barriers to deal with as reported by persons with disabilities (Vash, 2003). Attitudinal barriers are difficult because people may not be able to prove they happened. Similarly, attitudinal barriers appear ambiguous to the person who is trying to help others see the offense that is taking place. Some attitudinal barriers may seem trite and often take the form a microaggression. Common microaggressions experienced by persons with disabilities may include being told how bad their situation is or looks, that someone could never deal with the situation like they do, or by being belittled or mimicked by another person (Lu, 2016).

Earlier, we discussed the importance of language, expectations, and personal/professional beliefs about the capabilities of people with disabilities. This topic, although challenging for some professionals to examine and honestly evaluate, is imperative as it is these actions and beliefs that contribute to the issue of societal and attitudinal barriers when left unchecked and uncorrected. Furthermore, the phenomenon of societal and attitudinal barriers are real and valid even if professionals cannot see them or have not witnessed them throughout their own life (Stuntzner & Hartley, 2014a). Understanding the power all of these barriers have on people with disabilities is essential as they can affect how people view themselves, their worth, and their ability to cope and adapt to the disability and its associated changes.

Personal barriers are another area of importance for behavioral health professionals to address. Personal barriers can be understood as those related to a person's self-concept, beliefs about oneself and the disability, negative thoughts and feelings (i.e., depression, anxiety), locus of control and feelings of empowerment, level of independence, family support or lack thereof, changes in relationships and friendships, and ability to self-advocate.

Adjustment Is a Multifaceted Process

Adjustment to disability is an area of importance and relevance to persons with disabilities that encompasses many facets. Clinicians striving to understand adjustment and its relationship to disability are encouraged to learn about the numerous issues people face related to coping and adaptation (i.e., unemployment, attitudinal barriers, self-identity), beyond what is covered in this chapter, as well as those that extend beyond the disability. While some of these are mentioned as a part of this chapter, the sheer volume and complexity of these issues are more extensive than what can be covered in a chapter. Thus, clinicians are also encouraged to familiarize themselves with the various factors that are associated with positive coping and adaptation and variations in the needs of individuals living with a disability versus those of family members. Understanding all of these pieces of adjustment are vital as they can assist clinicians in understanding the experience of disability within a broader context, conceptualizing the process of adjustment, and implementing therapeutic approaches and techniques to meet the needs of the people they serve.

Adjustment to Disability

Adjustment to disability is often viewed as a person's ability to positively cope with the disability and its associated disability-related changes (i.e., physical functioning, relationship changes, social support, self-concept, negative societal attitudes) (Marini & Stebnicki, 2012). Such a perception is understood; however, this view resembles only one goal of adjustment. In reality, adjustment is more inclusive than the thoughts, feelings, and behaviors people experience while learning to cope with the disability and the changes it brings. A review of the literature helps us understand that people who adjust to disability experience a reduction of negative outcomes as well as an increase in more positive ones. More specifically, the better adjusted people are the less likely to be self-critical and experience negative feelings, stress, depression, anxiety, or social isolation and often report a less negative view of self (Marini & Stebnicki, 2012; Stuntzner, 2008). As far as positive attributes, adjustment to disability can help people be more self-compassionate, develop a better self-image, forgive oneself and others, become more resilient, access coping skills, possibly improve their health and functioning, have a better outlook on life, and find purpose and meaning, just to name a few.

Beyond the mental, emotional, and changes in coping aspects are those related to people's daily functioning and overall quality of life. Within this context, adjustment can be understood as the ability to navigate the physical environment, be mobile and function as independently as possible, become employed or engaged with important personal life goals, and achieve a well-sustained quality of life. In short, successful adjustment to disability is about learning to cope with the disability and any associated changes in functioning and being an individual who is well integrated into society and who is pursuing meaningful life goals (Livneh & Antonak, 1997). Achieving these goals may seem simplistic and realistic, but for many reaching such dreams and aspirations is challenging due to the continued existence of societal barriers, attitudes, and inadequate resources available to help them do so. The last point is of utmost importance because some people need additional external resources and services to overcome such barriers, to be fully integrated, and to complete the goals and dreams they aspire to achieve.

Factors Associated with Adjustment to Disability

Numerous factors, well known by many rehabilitation scholars and practitioners, are associated with coping and adjustment to disability and discussed extensively throughout the literature. Factors associated with adjustment to disability include those related to a person's thoughts, feelings, perceptions, self-identity, personal experiences, disability and the situations surrounding the disability, supports or lack thereof, culture, resources, and the external environment. Specific examples of these areas can be understood and categorized as listed below (de Roon-Casssini, de St. Aubin, Valvano, Hasting, & Horn, 2009; Enright, 2015; Johnstone & Yoon, 2009; Livneh, 2000; Livneh & Antonak, 1997; Martz & Livneh, 2007; Nosek & Hughes, 2003; Smart, 2009; Stuntzner, 2008; Trieschmann, 1988; Vash, 2003; Webb, Toussaint, Kalpakjian, & Tate, 2010; White, Driver, & Warren, 2008, 2010; Willmering, 1999; Wright, 1983):

(a) *Thoughts and beliefs*—locus of control, self-blame or cause of disability, perception of disability as positive or negative
(b) *Feelings*—negative feelings, anger, depression, anxiety, self-empowerment
(c) *Self-identity*—self-esteem, self-concept
(d) *Personal experiences*—gender, familial expectations
(e) *Disability and associated situations*—age of onset, type of disability, cause of disability, stability of the disability, visibility of the disability, amount of stigma associated with the disability, perceived meaning of disability
(f) *Supports*—spirituality, familial support, friendships and relationships, social support
(g) *Culture*—cultural views within family or ethnic heritage
(h) *Resources*—employment, education, socioeconomic status, financial well-being, health insurance, coping skills (i.e., forgiveness, resilience)
(i) *External environment*—societal attitudes (i.e., strangers, employers), low expectations of persons with disabilities, environmental barriers

Specific factors most relevant to the people we serve are likely to vary from person to person and situation to situation due to the fact that adjustment to disability is an individualized process (Livneh & Antonak, 1997). Similarly, it is the fact that no two individuals with disabilities, even those with the same disability, diagnosis, or level of functioning will adjust to the disability and their set of circumstances the same, nor will they necessary rely on the same identified factors to help them adjust to the disability. For this reason, it is essential that clinicians familiarize themselves with as many of these factors as possible and to consider them on an individualized case-by-case basis through a holistic lens of what is most relevant to the person.

Individual Versus Family Coping

Disability is an experience that forever changes the life of the person and family members. Following the advent or diagnosis of disability, behavioral health services become geared towards the needs of the individual and sometimes at the expense of the family. Focusing on the specific needs of persons with disabilities is important and necessary; however, consideration of the family and how the presence of a disability affects the family is also of value.

Because disability is an experience that affects both parties, it is plausible that the person with the disability and the family have different needs and priorities as well as coping and adaptation responses to the disability. Ultimately, it is our hope that both the person with a disability and the family learn to accept the disability and its associated changes. Sometimes this happens, but sometimes it does not. One example of this coping disparity is when the person living with a disability learns to cope and adjust to the disability and its associated changes but the family does not. As clinicians, we may see this when the individual is moving forward with one's life in positive ways while the family is still dealing with feelings of grief and loss or is still living in the past and can only see the family member with a disability as the way he or she used to be. Another possible scenario is evident in situations where the family member with a disability views him- or herself as a lovable individual and as an acceptable child of God or as a member of a spiritual and religious organization while the family views the person's disability as a curse, or some sort of punishment. Negative views as such work their way into family interactions and can have a harmful impact on the person's self-concept and coping process.

Due to the varying needs and coping processes which are separate but somewhat intertwined, clinicians working with persons with disabilities may find it helpful to consider and reflect on the needs of the person versus those of the family and ways the two may influence one another and the coping process. Figure 16.3 depicts a process model of coping with the initial advent or discovery of disability for both the person with a disability and the family or individual family members (Stuntzner, 2015b).

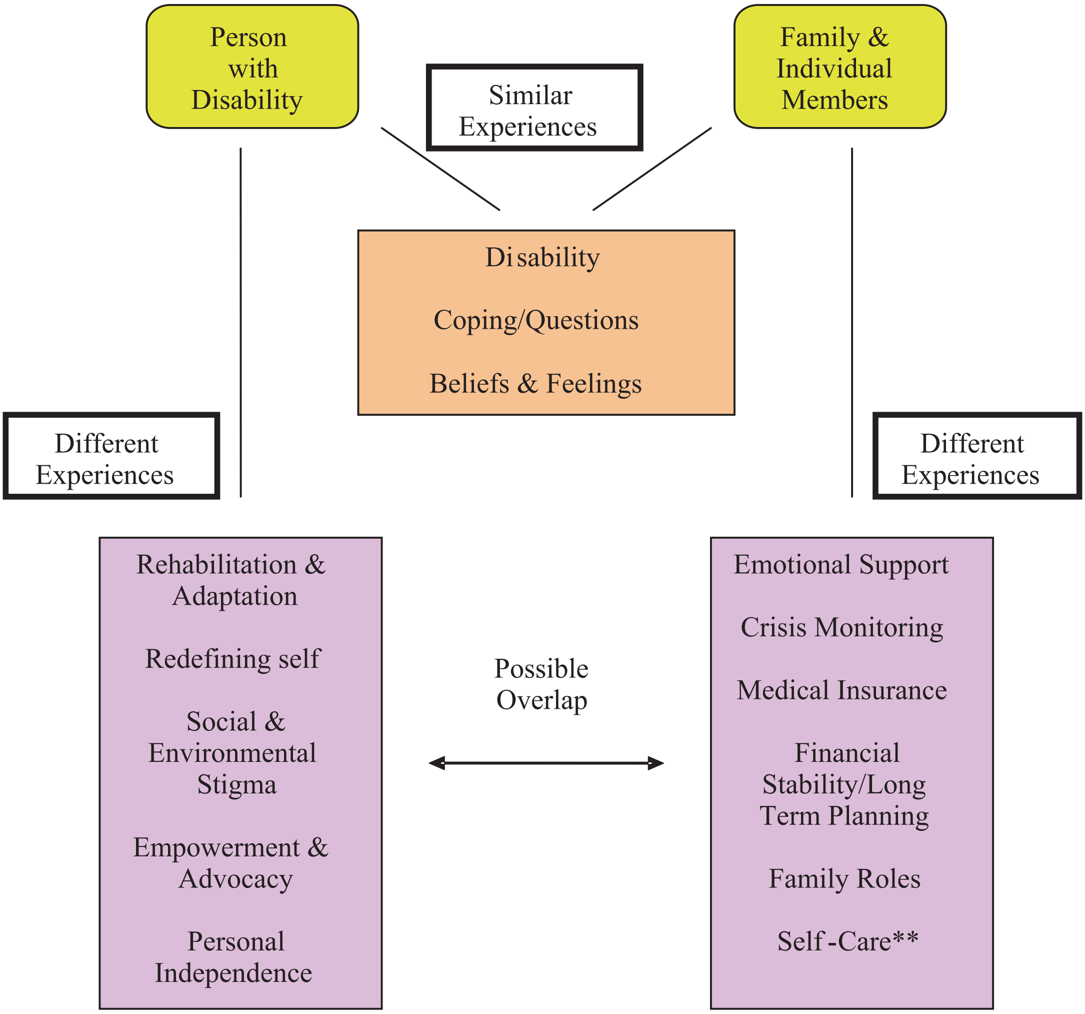

Fig. 16.3 Process model: the individual versus the family. (Source: Stuntzner 2015b)

The process model illustrates that both parties may have similar concerns and issues they are working through, initially, while also trying to address separate ones as a part of the coping process. According to this model, both the person with a disability and the family may have questions, concerns, and personal beliefs or reactions to the disability they are trying to deal with as a part of the adjustment process. Having said that, the ways both parties respond to the disability may differ the same as varying issues may be of primary importance to either group at any given time. More specifically, the person with disability may be trying to understand and cope with the disability, participate in therapy or rehabilitation, develop a new self-concept and self-identity, work on strategies to deal with societal and environmental bias and stigma, learn how to self-advocate, and explore levels of improved functioning and independence. While these may not be the only areas the person is trying to address, it gives us some idea of the complexity of issues that may be taking place simultaneously or as a part of the adjustment process.

While the individual with a disability is trying to make sense of the disability and his or her new set of experiences, the family and individual family members are also going through their own coping process. Examples of their coping process might include (a) seeking out resources for emotional support and coping, (b) managing the existence of a disability which may include crisis management, (c) issues concerning finances and payment of medical/treatment services, (d) financial and bill planning, (e) changes in family roles, and (f) access to self-care support. Because the family is often involved with activities pertaining to keeping the family afloat emotionally, functionally, and financially, issues such as learning to positively cope and adjust to the disability or practicing good self-care are often relegated to the bottom of the priority list. As a result, families and individual family members may not be getting the support and assistance they need to accept and move past the disability. When this happens, the family's negative coping style may inadvertently affect the coping process of the person with a disability. Helping the family access behavioral health services is important as some may need support to deal with their own feelings of loss or change. For instance, some families experience (Stuntzner, 2015b) the following:

(a) loss of the person they used to know;
(b) grief and loss tied to presence of a disability;
(c) changes in familial and personal relationships;
(d) stress and difficulties associated with caregiving;
(e) alteration or loss of intimacy and companionship;
(f) changes in social support due to having a family member with a disability;
(g) changed or lowered expectations of the family member with a disability; and
(h) alteration of personal hopes and dreams for their loved one and family.

Family support is vital to successful coping and adjustment. Families that receive the necessary support and services are in a position to better help themselves heal, learn ways to reorganize their lives and perceptions of disability so they are positive and more affirming, and assist the family member with a disability in moving forward in a positive fashion. For these reasons, clinicians working with persons with disabilities are encouraged to consider both the individual's view and experience with a disability as well as the family's particularly given the fact that either one has the potential to positively and negatively influence the other.

Therapeutic Techniques to Help People Move Forward

Given the complexity of living and coping with a disability, it is imperative for behavioral health clinicians to have a number of therapeutic techniques at their disposal. Some of the approaches clinicians use may be tied to specific theoretical approaches while others may not. Many of the counseling theories taught as a part of counseling, psychology, or social work programs can be used to help people with disabilities.

Theories that help people get in touch with their thoughts, feelings, and behaviors and that can help people find meaning in their experience are of particular value. For example, the use of person-centered therapy, behavioral therapy, cognitive behavioral therapy, rational emotive therapy, reality therapy, and existential therapy are relevant to the needs and issues experienced by persons with disabilities (Chan, Berven, & Thomas, 2004, 2015). In addition, the possibilities offered under the third wave of behavior therapy [i.e., dialectical behavioral therapy (DBT), mindfulness-based stress reduction (MBSR), mindfulness-based cognitive therapy (MBCT), acceptance commitment therapy (ACT)] are particularly exciting (Corey, 2009). Such approaches help us understand how newer therapeutic approaches such as mindfulness and self-compassion can be incorporated into the therapeutic relationship. Clinicians conducting work around the family may want to consider Adlerian therapy or family systemic therapies as frameworks to help conceptualize what is taking place.

Beyond the theoretical approaches are concepts and techniques that can be used as a part of a counseling framework or as a standalone process. Those covered as a part of this section (i.e., forgiveness, self-compassion, resilience) have a strong history of empirical evidence to support their value as healing agents and are definitely relevant to the needs of people with disabilities. Each of these can be used as a set of skills, a process learned, or as an integrated component of another strategy. Furthermore, each one is effective in helping people "reduce thoughts (e.g., mental rumination, self-judgment, critical thinking) and feelings (i.e., anger, anxiety, depression), and decrease fears as well as negative psychological reactions to disability" (Stuntzner et al., 2018, p. 49). The authors further explain that forgiveness, self-compassion, and resilience can help people feel less socially isolated, be more connected to others, emotionally heal, increase self-esteem, become more hopeful, learn to be kinder and more accepting of themselves, and in the end be more resilient—all of which are important when learning to deal with and move past a disability.

Having specific tools and techniques is one area of consideration, but perhaps larger questions and ones that are not always clear is that of where to start or which area is most relevant to the person's particular needs. Does a clinician begin with forgiveness, self-compassion, or resilience? Which of these three is most relevant given the person's presenting issues and specific needs? Or how does a clinician start in one area and transition to another? (Stuntzner et al., 2018).

Clinicians wanting to better understand the therapeutic value and interconnectivity of these three skills are encouraged to try to conceptualize them according to model called, "therapeutic triad of disability" developed by Stuntzner, Dalton, and MacDonald (2017). The therapeutic triad of disability is a model comprised of three components: forgiveness, self-compassion, and resilience. Each of these areas is viewed as distinct skills and processes by themselves but also as portals to the other two. In other words, therapeutic work in one area may lead to work in another as these three areas often overlap and are intersected (see Fig. 16.4). Similarly, each of these areas are likely to overlap and serve as portals or gateways to the other two. While some professionals may want exact answers about where to start, our recommendation is to work with each person individually and to explore with them on a case-by-case basis about which area they are most open to or feel is most relevant. All three areas are typically a learning and educational process and require work to become familiar with the practice of each skill within a person's life; therefore, it is essential for clinicians to get a feel for the amount of readiness and willingness a person has to complete work in each of these areas.

Fig. 16.4 Interconnection of forgiveness, self-compassion, and resilience. (Source: Diagram from Stuntzner, Dalton, et al. 2017)

Clinicians wanting to learn more about each of these components are encouraged to learn as much as they can about each one, what each term means, and how they relate to people with disabilities and the issues they encounter as well as become familiar with resources that are available. One such resource is a two-part counseling podcast produced by Mike Shook for The Thoughtful Counselor. This two-part podcast is entitled, "The Therapeutic Triad: Forgiveness, Self-compassion, and Resilience." Throughout, clinicians are exposed to information pertaining to the definition of disability; the interconnection between forgiveness, self-compassion, resilience, and disability; and an overview of forgiveness, self-compassion, and resilience and their interconnection to one another. Clinicians are also educated about some of the barriers and benefits on skill cultivation when working with people with disabilities as well as an understanding of how each of these are related and relevant to persons with disabilities and their specific needs (Shook, 2018a, 2018b, February 17 and 21). Having a full understanding of the meaning of each term, their associated benefits and barriers as well as potential resources and interventions is helpful as it is our belief that the more familiar professionals are with each one, the more comfortable they will be in applying them to their own life and in their work with the people they serve.

Proceeding forward, it is important to recognize that many excellent trainings, models, and resources exist but most of them do not directly apply the concept or process to the experience of living with a disability. Stuntzner and colleagues recognize this void and have worked to change this trend and to provide behavioral health clinicians and persons with disabilities resources and interventions (i.e., see Stuntzner, 2014, 2015c, 2016b, 2017; Stuntzner et al., 2018, 2019; Stuntzner & Hartley, 2014b, 2014c; Stuntzner & MacDonald, 2016) that are specifically tailored to meet and address this population's needs. In an effort to assist clinicians in being able to access some of the available resources pertaining to forgiveness, self-compassion, and resilience, a brief definition and summary of each is provided.

Forgiveness

Forgiveness is a term defined somewhat differently among forgiveness scholars. However, many of these definitions converge and are in alignment with one another to understand that forgiveness is an individualized and personal process that is not necessarily linear or a one-time event. Forgiveness is also a process that occurs over time and requires intentional effort when a deep hurt or offense has been committed (Freedman, 2011). People who pursue and practice forgiveness find they experience less frequent negative thoughts, feelings, and behaviors and replace them with more positive qualities such as tolerance, patience, compassion, and benevolence (Enright, 2015). Furthermore, forgiveness is a means that allows people to confront their emotional and psychological pain and, in many instances, injustices followed by a period of learning to reframe the event(s) and to view them in a more constructive and balanced manner (Berecz, 2001).

Clinicians wanting to learn more about the forgiveness process, interventions, and resources have a number of options from which to choose. Those who are new to the concept of forgiveness as a therapeutic tool and process are encouraged to become familiar with the work of Dr. Robert Enright, forgiveness scholar, at the University of Wisconsin–Madison. Enright, Freedman, and Rique (1998) developed a forgiveness process model comprised of 4 phases and 20 units. People working through forgiveness according to this framework are guided through the forgiveness process and are exposed to the *Uncovering Phase*, the *Decision Phase*, the *Working Phase*, and the *Outcome/Deepening Phase.* Throughout this process, people learn to recognize their own negative thoughts, feelings, behaviors, and obstacles to forgiveness. Following this recognition, many proceed to the *Decision Phase* where a decision is made to forgive. Once a commitment is made to forgive, people begin to address the hurt and to work through it until they reach a place of peace and healing. Such a model is not intended to be linear or a quick fix as these scholars understand that forgiveness exists on a continuum ebbs and flows and, in many instances, takes time to occur.

Clinicians interested in learning more about how forgiveness as a process is relevant to persons with disabilities may want to consider a forgiveness model developed by Stuntzner et al. (2019). These scholars expand the information known about forgiveness and adjustment to disability and integrate the two into a 6-phase, 23-unit forgiveness model. From this perspective, forgiveness is also viewed as an educational process, one in which people have the opportunity to: (a) examine their hurts and offense, (b) review their existing coping skills, (c) explore the use of forgiveness and other therapeutic options to aid in healing, (d) address any barriers or obstacles that inhibit their ability to forgive, (e) learn about forgiveness and its relevance to peoples' lives, and (f) cultivate and integrate forgiveness skills. Similar to Enright's model, forgiveness is viewed as a process and as one that is not necessarily linear. Additionally, due to the nature of forgiveness being difficult and not easy for some to consider, it is anticipated that a certain amount of forgiveness education and learning regarding the ways forgiveness can help people heal and move forward can be of help.

Knowing where to start or what resources to use can be a daunting process, particularly for clinicians who are unfamiliar with the use and integration of forgiveness as a part of professional practice. As previously mentioned, there are a number of resources clinicians can use to assist them with forgiveness work among the people they serve. Applied resources and interventions that may be of use to consider include the work of Enright (2001), Stuntzner (2014), and Tutu and Tutu (2014). Enright's (2001) process model is displayed in a book entitled, "Forgiveness is a Choice: A Step-by-Step Process for Resolving Anger and Restoring Hope." Throughout this book, readers are guided through the forgiveness process in a step-by-step fashion. Stuntzner (2014) offers clinicians exposure to a forgiveness intervention that is specifically geared towards people with disabilities and to the experience of disability. In this intervention, people proceed through seven modules. People learn about forgiveness, its applicability to disability, barriers to forgiveness cultivation, forgiveness and disability in relation to gender, impact of forgiving versus not forgiving, being ready to forgive, strategies to promote forgiveness, and ways to continue the forgiveness work started. Finally, Tutu and Tutu (2014) wrote a book entitled, "The Book of Forgiving," which also covers many important concepts related and relevant to the forgiveness process. Tutu and Tutu help the reader understand why forgiveness is important, differentiate between what forgiveness is and is not, and get in touch with the importance of telling one's story and in understanding the hurt. These authors also help us understand the importance of needing forgiveness, forgiving ourselves, and applying forgiveness to our external world.

Self-Compassion

Self-compassion is a relatively new concept within our Westernized culture and as an integrated component of behavioral health practices. Thanks to the founding efforts of self-compassion research scholar, Dr. Kristin Neff at the University of Texas–Austin, and other self-compassion experts (i.e., Christopher Germer, Paul Gilbert), self-compassion has emerged as an essential therapeutic tool within the counseling, psychology, and allied helping professions.

Self-compassion is often described as the ability to accept oneself, fully, despite a person's imperfections and flaws and to treat oneself with kindness, gentleness, and warmth the same was we would offer such traits to another person (Neff, 2012) especially towards a person experiencing pain or hurt. While such a behavior may appear simplistic, the opposite is often true. Some of this is related to the fact that self-compassion is an Eastern, Buddhist philosophy and way of life, not a traditional Westernized value. Instead, many of us may have been reared to value the extension of compassion towards others but not towards ourselves. Those that do have sometimes been described as *weak* or *lazy* because they are perceived by outsiders—people who do not understand the value of self-compassion—as individuals who are somehow not owning their pain.

Despite these historical negative views, society and helping professions are beginning to understand the power and value of self-compassion (Neff, 2018a; Neff & Germer, 2018). More specifically, self-compassion research helps us clearly see that self-compassion is a healthy, personal skill that holds many healing qualities and can be used to help improve our life and our relationship with ourselves. In short, it is through the practice and integration of self-compassion that people are able to decrease negative thoughts and feelings (i.e., anxiety, depression; Leary, Tate, Adams, Allen, & Hancock, 2007; Neff, 2003; Neff, Kirkpatrick, & Rude, 2007), stress, self-criticism (Neff, 2003; Neff, Kirkpatrick, et al., 2007), and self-blame (Terry & Leary, 2011). Furthermore, self-compassion has the ability to promote positive qualities, some of which include greater life satisfaction (Neff, 2003), feeling more socially connected (Neff, 2003), optimistic outlook on life (Neff, Rude, & Kirkpatrick, 2007), feeling more motivated (Neff, Rude, et al., 2007), becoming more resilient (Leary et al., 2007; Neff, Hsieh, & Djitterat, 2005), and forgiveness (Neff & Pommier, 2012), just to name a few.

Similar to forgiveness, learning to be self-compassionate is an active and intentional process. While some people may be born with a higher ability to be kind and loving towards oneself, self-compassion is a skill that ebbs and flows throughout a person's life and is strengthened with intentional practice. Clinicians wanting to learn more about self-compassion have a number of resources at their disposal.

Resources include active workshops and self-compassion trainings some of which can be accessed and viewed on Dr. Neff's self-compassion website (i.e., http://self-compassion.org/). Self-compassion workshops offered include both those that are short and more time intensive. Specific trainings that may be of interest to some clinicians are the Mindful Self-Compassion (MSC) Intensive trainings and the MSC Teacher trainings. A second helpful feature from both a research and a practical standpoint is Neff's (2018b) self-compassion scale (see http://self-compassion.org/test-how-self-compassionate-you-are/) that measures how self-compassionate a person is. Such a tool can be instrumental in helping people recognize their current level of self-compassion or lack thereof and can be integrated into the therapeutic relationship as a means to begin the discussion and exploration of self-compassion.

Knowledge and understanding of self-compassion and its role in therapy can be understood by accessing the number of books and resources that are beginning to emerge. Resources that appear to have an applied context and may be of interest to clinicians include the following: (a) *One Minute Mindfulness* (Altman, 2011), (b) *The Self-Compassion Skills Workbook: A 14-day Plan to Transform Your Relationship with Yourself* (Desmond, 2017), (c) *Self-compassion: Stop Beating Yourself Up and Leave Insecurity Behind* (Neff, 2011), (d) *The Clinician's Guide to Teaching Mindfulness: The Comprehensive Session-by-Session Program for Mental health Professionals and Health Care Providers* (Wolf & Serpa, 2015), and (e) *The Power of Self-compassion* (Welford, 2013).

Resilience

Resilience is another term that is not consistently defined. Perhaps, the most common description of resilience are those that refer to a person's ability to "bounce back or overcome some sort of difficult life event or adversity despite the odds" (Edhe, 2009) which may include the presence or advent of a disability. Some scholars describe resilience as a trait that once acquired helps people to grow exponentially and to become stronger or better at dealing with the challenges life throws at them (Neenan & Dryden, 2012). In recent years, several scholars stress the fact that people do not have to be born resilient to succeed in overcoming difficult life events; instead, many believe that resilience can be taught, enhanced, and further developed with purposeful intention and effort (Deshields, Heiland, Kracen, & Dua, 2016; White et al., 2008, 2010). Recognizing this fact is good news and provides people with much hope as they move forward. For many, resilience and resilience skill cultivation becomes a gateway to healing and a portal to other areas of change, previously unseen (Stuntzner & MacDonald, 2014a, 2014b).

Resilience is a concept relevant to the needs and experiences of persons with disabilities. As mentioned earlier, when disability occurs people are faced with a number of changes. In short, disability is an experience where people have to learn about the disability and the associated changes that accompany it along with the multiple barriers and obstacles that often accompany it (i.e., low expectations, poor and inadequate societal attitudes, unemployment, bias). Some people may not be aware or prepared for these changes and experiences, particularly given the fact that many parts of living with a disability are still not openly discussed (Stuntzner et al., 2018).

With the growing awareness of resilience and the role it plays in peoples' lives is an increase in resources, education, and training pertaining to this topic. Yet, resilience and resilience cultivation is an area that remains minimally recognized and applied to persons with disabilities. In an effort to address this void and need within the helping professions, Stuntzner and colleagues developed an online course for counselors and allied helping professionals (Stuntzner, 2016a, 2016b), a ten-module resilience intervention for persons with disabilities (Stuntzner & Hartley, 2014a, 2014b), and provide trainings to professionals (Stuntzner, MacDonald, & Dalton, 2017) on this subject matter.

The online resilience course is entitled, *Resilience and Disability: Enhancing Rehabilitation Professionals' Understanding and Application of Resilience to Rehabilitation Counseling*, and is a part of the Commission of Rehabilitation Counselor Certification e-university program. Professionals who take the course are afforded the opportunity to learn about resilience and its applicability to persons with disabilities (Unit 1), benefits and barriers of resilience cultivation (Unit 2), and factors associated with resilience and examples of how these are applicable and relevant to persons with disabilities (Units 3–6). In Unit 7, the final unit, professionals have an extended opportunity to apply the information learned and reflect on how they would integrate the content learned into their professional practice. Clinicians completing the program receive 13 CEUs.

According to the data collected by the Commission on Rehabilitation Counselor Certification e-university program, professionals who completed the aforementioned resilience course were asked to evaluate the course's strength, applicability, and relevance to their role as professionals and to the work they do with individuals with disabilities. Preliminary data is comprised of feedback from 100 rehabilitation counseling professionals who completed the course. Course participants to date range from the new counselor to those who are more seasoned (i.e., 0–35 years of experience). Among these 100 participants, majority reported that the resilience course had practical and relevant content which could be used in the work they do. More specifically, 97% found the explanations of resilience, self-compassion, and forgiveness of value, 91% reported the applied learning activities to be useful, and 93% reported the learning activities as appropriate and helpful in learning and applying the various concepts. Furthermore, the data gathered by CRCC supported the fact that the activities and content delivered throughout the course helped professionals construct various strategies they could use to cultivate and enhance resilience among themselves and the people they serve.

A second available resource that is specifically geared towards the needs and issues of persons with disabilities is Stuntzner and Hartley's (2014a, 2014b) resilience intervention. The resilience intervention is comprised of ten modules, each consisting of resilience-based skills and delivered in a format so that each module builds upon the other. Resilience skills covered include: an overview of resilience and its applicability to persons with disabilities, attitude and outlook on life, locus of control, regulation of thoughts and feelings, coping skills, spirituality and forgiveness, compassion and self-compassion, growth and transcendence, and social and family support. The intervention concludes with a review of the skills learned and opportunities for reflection about how people may continue to use and enhance the skills learned in their journey to become more resilient and how these may be used and further enhanced.

Furthermore, as a part of the intervention, Stuntzner and MacDonald (2014a, 2014b) conducted two pilot studies among persons with various disabilities. Findings from these studies demonstrated a significant decrease in participants' anxiety and depression, an increase in forgiveness and resilience, and changes in various phases of adjustment to disability.

A third option for clinicians to expand their knowledge and understanding of resilience is that of self-exploration which may include increasing one's knowledge through reading or professional trainings. Some suggested resources that can be accessed to help professionals include the following books: (a) *The Resilience Break-Through: 27 Tools for Turning Adversity into Action* (Moore, 2014), (b) *Chronic Resilience: 10 Sanity-Saving Strategies for Women Coping with the Stress of Illness* (Horn, 2013), (c) *The Woman's Book of Resilience: 12 Qualities to Cultivate Resilience* (Miller, 2005), (d) *Reflections from the Past: Life Lessons for Better Living* (Stuntzner, 2014), and (e) *The Resilience Factor: 7 Keys to Finding Your Inner Strength and Overcoming Life's Hurdles* (Reivich & Shatte, 2002).

Concluding Thoughts

Disability is an experience that forever changes a person's life and that of one's family. While many people learn to cope with the disability and its associated changes, adjustment and moving past the disability is a process: one that takes time and support. Clinicians working with this population are in a position to assist people with this process and in creating the life they seek. Furthermore, disability is a life situation that affects many of us over the lifespan whether we consciously recognize this or not, from birth to death.

Disability statistics consistently support that approximately one in five people (20%) live with a disability (US Census, 2010), making it the largest minority group in the USA. However, it is a group of individuals that perhaps remains the least understood. In an effort to help change this phenomenon, information has been provided to assist clinicians in learning more about this diverse group of individuals and some of the issues they encounter. Key points covered throughout this chapter include:

- The way professionals talk about and conceptualize living with a disability is important and can positively or negatively influence the therapeutic relationship.
- Labels can negatively impact persons with disabilities (Smart, 2009).
- Clinicians have a professional responsibility to be aware of their own beliefs and expectations about persons with disabilities.
- Clinicians can enhance their therapeutic effectiveness by learning to view a person with disabilities in a holistic manner, not as the disability (Stuntzner, 2012).
- Most people with a disability do not view themselves as the disability.
- No two people view a disability the same, nor do they cope the same based on similar disabilities (Livneh & Antonak, 1997).
- Adjustment to disability is complex and is about much more than adjusting to the disability; adjustment is comprised of many components and influenced by several factors.
- Disability is an experience that influences the individual as well as the family.
- Emerging techniques such as forgiveness, self-compassion, and resilience are important components of helping people move forward following a disability.

Content covered throughout is intended to serve as a starting basis in learning about disability and the needs of persons with disabilities. Clinicians desiring to learn more about this group of individuals are encouraged to continue their education and understanding as there is a lot to know about the experience of disability and ways to enhance the services offered to and received by persons with a disability.

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