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Stephanie A. Tellier

Nancy G. Calleja

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# Renegotiating Sexuality Following an Acquired Disability: Best Practices for Counselors

**Stephanie A. Tellier and Nancy G. Calleja**

*Acquired physical disabilities are a critical issue that confronts many adults today, and they are projected to continue to increase over the next several years. For many individuals with acquired physical disabilities, the disabilities affect sexuality, thus requiring a renegotiation of disability and sexuality. This article reviews the extant literature on physical disabilities and sexuality and provides best practices for counselors to effectively address the needs of this growing population.*

*Keywords*: disability, sexuality, adult development

Approximately 74.6 million individuals in the United States have some form of physical disability, making them the country's largest minority group (Centers for Disease Control and Prevention [CDC], 2015). A *physical disability* is defined as a limit to physical functioning, mobility, dexterity, or stamina (CDC, 2015) and is classified as either congenital or acquired. Whereas the effects of the disability are often similar among individuals with a congenital versus acquired disability, individual experiences related to the manner in which the disability occurred are often significantly different (Bogart, 2014; Bogart, Tickle-Degnen, & Ambady, 2012). Chief among these are the adaptive challenges and renegotiations at multiple levels that confront individuals with acquired disabilities, often resulting in the need to reestablish aspects of identity and to redefine functional abilities (Bogart, 2014; Bogart & Massumoto, 2010; Briegel, 2012; Ostrander, 2009). When the disability is acquired in adulthood, these challenges are that much greater, particularly as they relate to sexuality. Because sexuality is one of the most significant aspects of adulthood, changes in sexuality resulting

*Stephanie A. Tellier and Nancy G. Calleja, Counseling and Addiction Studies, University of Detroit Mercy. Correspondence concerning this article should be addressed to Stephanie A. Tellier, Department of Counseling and Addiction Studies, University of Detroit Mercy, 4001 West McNichols Road, Detroit, MI 48221-3038 (e-mail: telliesa@udmercy.edu).*

from an acquired physical disability can have wide-ranging implications for the individual—specifically for the individual's mental health and well-being. Therefore, counselors have a critical role to play in assisting individuals with acquired disabilities through these transitions and adaptations. Unfortunately, however, the topic of sexuality and acquired disability has been all but absent in the counseling literature. The purpose of this article is to address this gap in the literature by introducing the problem, reviewing the current literature from other health professions, and offering best practice guidelines for working with adults with acquired physical disabilities to renegotiate their sexuality.

## CONGENITAL VERSUS ACQUIRED DISABILITY

It has long been assumed that individuals with congenital disabilities are better adapted than individuals with acquired disabilities (e.g., Devins et al., 1983). However, few empirical studies have directly examined adaptation among individuals with congenital disabilities (Bogart & Massumoto, 2010; Briegel, 2012), and fewer have actually compared those with congenital disabilities with those with acquired disabilities (Bogart, 2014; Bogart et al., 2012; Li & Moore, 1998). This gap in the literature is largely due to a focus on understanding the process of adaptation to disability, and, as a result, researchers have often limited study to individuals with acquired disabilities. Unfortunately, this lack of research on congenital disability and adaptation may simply further reflect the implicit assumption that individuals born with disabilities do not have adaptive problems (Bogart, 2014) and therefore do not require study.

Despite the small body of extant research on congenital disabilities, however, findings have supported the notion that individuals with congenital disabilities are well adapted (Conley-Jung & Olkin, 2000) and do not experience increased psychological distress related to their disabilities (Bogart & Massumoto, 2010; Briegel, 2012). Similarly, a recent study comparing the two groups found that individuals who experienced congenital onset of a disability tended to experience higher satisfaction with life and have a higher disability self-concept than did those with an acquired disability (Bogart, 2014). Although these findings support long-held assumptions related to individuals with congenital disabilities, they may also be particularly useful to supporting assumptions regarding individuals with acquired disabilities. Therefore, the findings offer significant guidance to counselors regarding the importance of fostering a disability self-concept among individuals with acquired physical disabilities.

## PREVALENCE OF ACQUIRED PHYSICAL DISABILITIES

Acquired disabilities in adulthood typically result from chronic illnesses or accidents, and the number of individuals affected by acquired disabilities in the United States is staggering. In fact, 22.7 million adults (9.8% of the population)



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have limitation-causing arthritis, and arthritis has been the leading cause of acquired physical disability in the United States for the past 15 years (Barbour et al., 2013), accounting for 41% of physical disabilities today (CDC, 2015). Conversely, approximately 337,000 individuals in the United States are currently living with a spinal cord injury (National Spinal Cord Injury Statistical Center, 2015), and, in 2005, there were 1.6 million individuals with an amputation in the United States, with a projected increase to 3.6 million by 2050 (Ziegler-Graham, MacKenzie, Ephraim, Travison, & Brookmeyer, 2008). Whereas the primary cause of spinal cord injuries is vehicle-related accidents and the average age at which individuals are affected is 42 years, the majority of amputation cases result from dysvascular disease, with 64% occurring over the age of 65 years (Ziegler-Graham et al., 2008). Despite the differences in how the disability was acquired and the significant differences in prevalence, individuals with disabling arthritis and spinal cord injuries often share the same challenges related to adapting to the disability.

## ACQUIRED DISABILITIES AND SEXUALITY

Unfortunately, the sexuality of individuals with physical disabilities has been somewhat ignored and, at times, stigmatized by researchers (Esmail, Darry, Walter, & Knupp, 2010; Ostrander, 2009). In fact, individuals with disabilities have been considered asexual, or regarded as sexual beings solely in terms of reproduction and function (Dune, 2012; Esmail et al., 2010; Hess, Hough, & Tammaro, 2007). Therefore, a limited view of sexual health and well-being focused solely on the ability to achieve an erection/vaginal lubrication and orgasm may further contribute to the stigmatization of individuals with a physical disability (Dune, 2012; Esmail et al., 2010; Hough, Stone, & Buse, 2013). In particular, individuals with spinal cord injuries may experience this biased assumption if they are unable to maintain or achieve an erection or vaginal lubrication, or if they are void of tactile sensation that can promote orgasm (Hough et al., 2013). In fact, it has been assumed that these individuals cannot have a normal or healthy sexual lifestyle and that their sexual lives are destined to be inferior (Esmail et al., 2010; Ostrander 2009; Tiefer, 2006).

Similarly, the sexuality of individuals who experience chronic pain and/or a reduced sex drive as a result of their disability or medication is often ignored while the focus remains on other aspects of physical functioning and emotional well-being. As a result, rather than exploring the sexuality of individuals with acquired physical disabilities, mental health professionals may create social barriers for these individuals that may even be more disabling than the disabilities themselves (Esmail et al., 2010; Ostrander, 2009).

Unlike individuals with congenital disabilities who may have been able to develop a functional and meaningful sexuality with regard to their disabilities, individuals who have previously experienced an otherwise normal and healthy

sexuality often have a difficult time renegotiating their sexuality after injuries (Ostrander, 2009). Furthermore, they may fall into negative thinking patterns of what they have lost rather than examining their assets and channeling creativity toward a satisfying sexual life (Ostrander, 2009).

Conversely, although a disability can negatively affect one's sexuality, some individuals with acquired physical disabilities have also found sexual freedom and creativity as a result of their disabilities (Esmail et al., 2010). For example, individuals have reported new and creative ways to seek sexual pleasure, and many report pleasure in being able to shift their focus to their partner's sexual experience rather than their own (Esmail et al., 2010; Ostrander, 2009).

Effectively supporting an individual with an acquired physical disability requires a complex understanding of sexual development. In fact, it requires an understanding of the importance of sexual health and well-being to overall health and an understanding of the manner in which sexual health contributes to a variety of factors, such as life satisfaction, relationship satisfaction, and self-esteem (Esmail et al., 2010; Taylor & Davis, 2007). In addition, sexual development must be understood to include physical, emotional, and psychological needs and desires (Esmail et al., 2010; Fisher et al., 2002; Hess et al., 2007; Tiefer, 2006). Clearly highlighting this issue, Esmail, Munro, and Gibson (2007) found that adult men with spinal cord injuries rated intimacy and closeness as more important than the physical act of sex.

## CLINICAL ISSUES RELATED TO RENEGOTIATING SEXUALITY FOLLOWING AN ACQUIRED DISABILITY

One study found that individuals did not begin to deal with sexual renegotiation until 6 months after an injury (Fisher et al., 2002). The results highlighted the fact that individuals were not immediately concerned with issues related to sexuality—likely because other health-related issues took precedence. Therefore, these results provide essential information related to the timing of an intervention, particularly for individuals facing spontaneous life-changing events, such as spinal cord injury or amputation.

Other findings have also highlighted the importance of clinicians working with the individual's sexual partner as part of the renegotiation (Dune, 2012; Ostrander, 2009; Tiefer, 2006), because he or she, too, often requires a transitory stage of adjustment (Fisher et al., 2002; Hess et al., 2007). Inclusion of the individual's partner is particularly important given that preexisting relationships are much less likely to succeed than relationships that began postinjury (Hess et al., 2007).

In terms of theoretical approaches, cognitive behavior therapy (CBT) and humanistic approaches have been shown to be effective in increasing an individual's coping and adjustment following an acquired disability (Hough et al., 2013; Mehta et al., 2011, Tiefer, 2006). More specifically, interventions such as cognitive restructuring, the use of problem-solving strategies, and the

development of coping skills have assisted individuals in adopting a new understanding of who they are postdisability (Mehta et al., 2011). In addition, cognitive restructuring may shift the comparative focus to an asset frame of reference and change the sexual discourse between couples from making negative comments to making positive requests, which can aid in engaging in sexual exploration and thinking outside the box in terms of problem solving (Esmail et al., 2007). CBT can also be useful in challenging faulty beliefs, such as the belief that individuals with acquired disabilities cannot achieve or are not deserving of sexual satisfaction (Mehta et al., 2011).

As a further demonstration of the effectiveness of CBT, the ability to effectively problem solve has been associated with lower levels of depression and distress for individuals with spinal cord injuries (Mehta et al., 2011). In addition, a positive correlation has been found between the use of cognitive restructuring, effective coping skills, and adjustment (Hough et al., 2013; Mehta et al., 2011). Thus, CBT has helped individuals regain a sense of control over their lives and has been found to be effective in improving one's adaptation to the disability and increasing overall life satisfaction (Mehta et al., 2011).

Humanistic therapy has long been an effective method of sex therapy that emphasizes emotional authenticity and genuine awareness of one's body and feelings (Tiefer, 2006). In this way, humanistic therapy can offer support and strength in the process of self-(re)discovery, and it encourages an atmosphere of collaboration and creativity toward sexuality with a partner. The humanistic approach emphasizes the phenomenological experience of both sexuality and disability (Tiefer, 2006). Through this lens, the counselor can help clients examine values, intentions, and meanings in the dual context of their sexuality and disability. A humanistic approach can help clients focus on creativity and growth in their sexual development, and it can help counselors view clients holistically as individuals with unique needs. In addition, the counselors' unconditional positive regard reinforces human sexuality as normal and healthy (Tiefer, 2006).

## THE ALLOW AND PLISSIT MODELS

Although sparse, the extant research on sexual renegotiation following an acquired disability has been useful in the development of specific models to assist mental health and primary health professionals in addressing this issue. These include the ALLOW and the PLISSIT models.

The ALLOW model is based on the premise that discussions of disability and sexuality both can be embarrassing and can involve a highly emotional process. Therefore, candid discussions about disability and sexuality are specifically addressed as part of the sexual renegotiation process. Specifically, the ALLOW model posits that clinicians should *ask* directly about the individual's sexual activity and functions, *legitimize* the client's concerns by recognizing them as

important, address *limitations* from the lack of knowledge and comfort, *openly* discuss sexual issues for assessment and arrangement of specialist referrals, and *work* collectively to develop a treatment plan (Dune, 2012). The model emphasizes a collaborative and educational approach toward sex and disability, which is presumed to be useful between treatment providers and clients and also between sexual partners.

Establishing and maintaining open communication can allow individuals to learn more about themselves and their desires, as well as their partners, and contribute to creative learning and problem-solving strategies (Dune, 2012; Taylor & Davis, 2007). It is also important for partners to discuss limitations, lack of knowledge or any discomfort—physical or cognitive—related to their own sexuality and that of their partners, and the disability (Dune, 2012; Taylor & Davis, 2007). Finally, a collaborative approach that includes not only the counselor and client, but also the client and partner is necessary (when applicable) to ensure that everyone's needs are being effectively met (Dune, 2012; Ostrander, 2009; Tiefer, 2006).

Similar to the ALLOW model, the PLISSIT model emphasizes openness and direct exploration of issues related to disability and sexuality. Specifically, the PLISSIT model involves *permission* to be sexual, *limited information* about sexual matters, *specific suggestions* about ways to address sexual problems, and *intensive therapy*. Ultimately, the PLISSIT model is based on the belief that individuals experiencing sexual problems can resolve them if they are given the permission to be sexual. This can be a particularly powerful notion because social stigma often prevents individuals from considering that sexuality and disability can coexist, especially because negative thinking patterns often prohibit individuals with acquired disabilities from having healthy and fulfilling sexual lives (Dune, 2012; Taylor & Davis, 2007).

When using the PLISSIT model, counselors should give ongoing and explicit permission. This practice directly counters the misguided notions that giving permission once is enough or that if clients are interested in being sexual or have questions they will simply ask (Taylor & Davis, 2007). Because the PLISSIT model was designed for use with couples, inherent in the model is the understanding that it is important for partners to recognize that they are each sexual beings with desires and that permission should be given freely to respect their ideas, questions, and experiences, as well as to learn and grow together to renegotiate sexuality after an acquired physical disability.

In addition, the model is based on the notion that providing specific limited information directed toward each individual's concerns about how the disability affects his or her sexuality (Taylor & Davis, 2007) is essential to renegotiation. Sexually focused communication therapy is recommended as part of the PLISSIT model for individuals who desire it, and specific activities are suggested as part of the renegotiation process. These activities may include homework assignments to increase communication or self-awareness,

sexual needs/desires assessments, or the use of specific suggestions about sexual positions or stimulation to accommodate one's disability. Furthermore, facilitated discussion in a sexual context between partners is also believed to be an important part of the model, particularly as it relates to the new process of discovery about what feels good, what does not feel good, and where and when there is a lack of feeling or stimulation. Thus, these discussions are believed to aid in identifying needs as part of the renegotiation process (Taylor & Davis, 2007).

The PLISSIT model has been used in addressing the sexual well-being of individuals with chronic illness and acquired disabilities (Dyer, Aubeeluck, Yates, & Das Nair, 2015). Additionally, it has been adapted as a framework for sexual education and to be used in various situations by mental and physical health professionals (Dyer et al., 2015; Farnam, Janghorbani, Raisi, & Merghati-Khoei, 2014; Pillai-Friedman & Ashline, 2014).

Both the ALLOW and PLISSIT models encourage a holistic, phenomenological, and collaborative approach to understanding sex and disability that aims to assist individuals in becoming autonomous and to successfully renegotiate their sexuality. Chief among the two models is their emphasis on promoting open communication regarding sexuality and disability, and, as such, they each provide a basic framework for health practitioners to promote healthy sexual renegotiation following disability. However, each model is limited by its inability to address the broader clinical issues associated with identity development and the experience of significant transitions.

## IMPLICATIONS FOR COUNSELORS

Collectively, the small body of research developed to date provides important information for use by counselors, and the ALLOW and PLISSIT models of communication offer a starting place for counselors to engage clients. In fact, the extant knowledge may offer essential guidance to counselors as they work with individuals with acquired disabilities in renegotiating their sexuality. Because the topic of sexual renegotiation following acquired disability is not one currently discussed in the counseling literature, the first step in equipping counselors with the knowledge needed to effectively work with these individuals involves increased awareness. Counselors must appreciate the increasing prominence of acquired disabilities, especially as the United States continues to confront an ever-expanding aging population and engage in armed conflicts. Therefore, it is likely that counselors will confront a growing number of individuals with acquired disabilities.

In addition to increased awareness about individuals with acquired disabilities, counselors will need to actively work to eliminate any stigma associated with sexuality and disability. In contrast to more overt forms of marginalization, the sexuality of individuals with disabilities is often ignored by professionals, not

consciously, but rather because the sexuality of the individual is often simply not considered. As a result, the individual's sexuality may remain invisible to the counselor, thereby prohibiting any acknowledgment or exploration of sexuality. Therefore, counselors may first need to resolve any of their own issues related to sexuality. Counselors must be aware of their own biases and discomfort surrounding sexuality and disability. Because counselors must be able to directly and openly discuss sexuality, they must be not only comfortable with sexuality but also knowledgeable and competent in facilitating such discussion. In addition, counselors need to be effectively competent not only in treating individuals through their renegotiated transitions, but also in engaging in broader advocacy efforts.

The major tenets of the ALLOW and PLISSIT models stress actively permitting clients to be sexual and the importance of openness, honesty, and nonjudgment, all of which can be useful to informing counseling practice. Drawing from these tenets, counselors can begin a dialogue with clients about sexual renegotiation following disability. Using the basic framework of the models, counselors may be able to ease the transition for individuals by providing an effectively open therapeutic space in which sexuality can be freely explored. However, although the framework provides a starting place, specific and individualized interventions and considerations must guide counseling practice.

## BEST PRACTICES FOR COUNSELORS

In addition to the prerequisites of increased awareness, knowledge, and understanding of sexuality and disability, several best practices should guide counselors in their work with this population. Best practices result from the current body of knowledge that counselors have about individuals with disabilities and from research on theoretical approaches, and include practices related to initial assessment, collaboration, exploration, and theoretical approaches, as well as general best practices to promote clinical competence.

### Initial Assessment

Once basic rapport has been established, an initial assessment of the client's medical history and origin of the disability in conjunction with a sexual history is necessary to both create an atmosphere of openness and gather important information. The assessment should include the role and nature of the client's current or past relationships; changes that have occurred since the injury; and the impact, if any, that the changes have had on the individual's sexual identity, sexuality, and quality of life. Care should be taken to explore the interplay of gender, culture, religion, and sexual orientation with disability with the client, and explore how these views affect the client's values and perceptions of disability and sexuality.

## Collaboration

There are two important types of collaboration to consider when working with individuals with acquired disabilities—that of medical professionals and that related to intimate partners. Medical professionals, including the individual's primary care physician, physical therapist, or other health professional, should be consulted as part of the counselor's initial activities, if the client consents. The very act of discussing the need for collaboration with medical professionals and requesting the client's authorization for disclosure of information may effectively resolve stigma and promote open communication about sexuality and physical health. In this way, the counselor is able to create an effective therapeutic environment in which to discuss sexuality. Potential areas for discussion with medical personnel include, but are not limited to, types of prescribed medication and any side effects on mood and libido, physical limitations and weight restrictions, use and limitations of prosthetics, and chronic pain and illness.

The second form of collaboration involves the individual's partner. If the individual has a sexual partner and both individuals consent, couples counseling should be offered. This type of counseling is especially important to promote an effective transition for the individual and partner as they together work to renegotiate their relationship. Including the partner early in the treatment process also signals that there is mutual responsibility for the partnership, thus easing the burden on the individual with the disability while promoting ownership for the partner. The couple can then collaboratively engage in education, open communication, and counseling toward healthy sexual renegotiation.

## Exploration

After an acquired disability, the individual's perception of sexual identity may dramatically change, or, in some cases, the individual's identity related to disability may take precedence over or even negate the individual's sexual identity. Counselors should assist individuals in fully exploring both their disability-related identity and sexual identity, and the interplay between the two (Dune, 2012). Whereas some individuals may have difficulty exploring sexuality in the context of their disabilities, counselors should also be aware that some individuals or their partners may find the body modifications or limitations of the disability erotic (Sullivan, 2008), thus creating another change for the individual and/or couple.

When engaging in discussions of sexual exploration, counselors should address intimacy and love. As individuals explore their identities, counselors can offer support and guidance to them as they work through the process of redefining their thoughts, feelings, relationship roles, and sexual roles to be more adaptive and fulfilling. In addition, educating individuals in sensate focus assignments can assist individuals in exploring old and new feelings of sensuality in both mind and body (Brotto, 2013). Counselors should also be aware of various

sexual aids, such as massagers and lotions, which may be helpful in assisting the self-exploration process.

Finally, counselors must be concerned with consent and safety when encouraging sexual exploration. This issue is particularly important because an acquired disability may affect the manner in which individuals are able to negotiate safety and consent. To effectively address this concern, counselors must explore individuals' vulnerabilities before educating individuals about consent, sexually transmitted infections, sexual practices, and other individualized issues.

### Theoretical Approaches

CBT is an evidence-based practice that is effective in working with sexuality and disabilities (Mehta et al., 2011), and, as a result, it provides the necessary theoretical framework for clinical practice with this population. Because CBT focuses on the present, it can be especially helpful in assisting individuals who may be stuck in past references of how their bodies and sexuality were before the disability. Similarly, because it may be difficult or impossible for some individuals to regain what they previously considered their "normal" sexuality, CBT may also be useful in helping individuals reassess current desires and abilities and begin the process of identifying and pursuing new desires, abilities, and goals. In addition, CBT may be particularly helpful in effectively assisting individuals to work through the grieving process and, more specifically, to deal with disenfranchised grief. According to Pillai-Friedman and Ashline (2014), *disenfranchised grief* is "a grief that is precipitated by a loss that cannot be socially sanctioned, openly acknowledged, or publicly mourned" (p. 440).

CBT may also be useful in promoting healthy thinking related to sexual misperceptions of individuals with disabilities. Targeting faulty thinking patterns is pivotal when working with individuals who may believe in common misconceptions of sex and disability—namely, that individuals with disabilities are not deserving of sexual satisfaction and that they cannot be sexual. Furthermore, brainstorming, using problem-solving strategies, shifting to positive thoughts and assets, and developing healthy adjustment and coping skills can be highly effective when working with clients with disabilities (Mehta et al., 2011).

In addition to CBT, humanistic approaches have been discussed as potentially effective in assisting individuals in sexual renegotiation (Tiefer, 2006). Because humanistic approaches emphasize clinician openness, nonjudgment, and authenticity, they may be particularly helpful in facilitating clients' exploration of their needs, desires, goals, and expectations. Moreover, humanistic practices may encourage a healthier identity that allows individuals to maintain and/or redevelop a diverse and fulfilling view of sexuality. Doing so may effectively counter an otherwise disembodied medicalized view of "functional" sex. A humanistic approach could also prove effective in promoting an exploration of individual values and meanings attributed to disability and sexuality, thus facilitating the process of redefining meanings attributed to disability and sexuality.

Furthermore, it is pivotal to understand how the client's medical health and psychological health are linked. Because of the nature of the injury, the client may be in chronic pain, which can adversely affect his or her sexuality and mental well-being. It may be necessary to closely collaborate with a medical health professional when addressing the physical mechanics of sex, along with how medications affect the mind, body, and libido.

### Other Best Practices

In addition to best practices related to assessment, collaboration, exploration, and theory, best practices that further take into account the complexities of issues related to individuals dealing with sexual renegotiation following disability are equally important. These include both rights-based and holistic approaches; the need for basic knowledge of physiology, particularly sexual physiology; and the use of assessment in the treatment process.

When working with individuals through the sexual renegotiation process, counselors must maintain a rights-based approach focused on advocacy for equality, empowerment, safety, and accessibility. Recognizing that all individuals are unique and have exclusive needs allows for thorough, comprehensive, and individualized treatment planning. A holistic approach is necessary to address the physical and emotional aspects of sexuality, along with the individual's self-concept, body image, sexuality, and any changes in relationship roles.

Counselors must also be familiar with basic sexual anatomy and physiology, as well as correct terminology, to promote education, understanding, and ease of communication with individuals about their sexual needs. This knowledge is essential to counselors for both effectively guiding individuals through the treatment process and promoting effective collaboration with medical health professionals.

Finally, counselors must be aware of the interplay of physical and psychological health and any existing comorbidities. It is necessary to critically assess the need for reliable and valid assessments when needed to examine potential physical or psychological barriers.

## SUMMARY

Individuals with acquired physical disabilities are one of the fastest growing subpopulations in the United States today, and these individuals often face specific challenges related to renegotiating their sexuality following acquiring disabilities. Because successful renegotiation involves an understanding of the complexity of issues related to disability, sexuality, and identity, counselors have a unique opportunity and responsibility to effectively treat these individuals. Doing so, however, first requires counselors to reject limited definitions of sexuality (e.g., penetration, reproduction) and adopt an expansive view of sexuality. Counselors must be diligent in addressing clients holistically by examining sensuality, relationship and gender roles and identities, and issues related to

safety and consent. Counselors must promote open and direct communication and exploration to effectively work with clients, their partners, and medical professionals. In addition, counselors must create an effectively open and safe therapeutic environment through a nonjudgmental stance and encouragement of growth and exploration toward renegotiating sexuality.

Counselors should be guided by the small, but growing, body of knowledge related to sexuality and disability. However, most important, counselors must actively work to ensure that the issue of sexual renegotiation following disability is not ignored. This requires counselors to become competent in treating individuals in need while engaging in necessary professional advocacy to create greater awareness of this critical issue.

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