EXPANDING THE KNOWLEDGE OF MENTAL HEALTH PROFESSIONALS ON
SEXUALITY AND PHYSICAL DISABILITY

A Project

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by
Amber K. Berens

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Department of Psychology
Abstract

of

EXPANDING THE KNOWLEDGE OF MENTAL HEALTH PROFESSIONALS ON SEXUALITY AND PHYSICAL DISABILITY

by

Amber K. Berens

The objective of this thesis project was to develop educational materials aimed at improving mental health professionals’ knowledge of sexuality and physical disability. The materials were developed based on a thorough literature review and needs assessment performed on a convenience sample of students from the Marriage and Family Therapist Master’s program at California State University, Sacramento. Both the literature review and needs assessment confirmed the lack of knowledge mental health professionals have on this topic as well as their interest in gaining additional knowledge. Once developed, the educational materials were reviewed by experts in the field of sexuality and physical disability for correctness and completeness as well as theorized effectiveness. After review, suggestions for revision were incorporated into the training materials as summarized and reported in the discussion.

__________________________________________
Rebecca Cameron, Ph.D.

__________________________________________
Date

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Chapter 1

HISTORY AND OVERVIEW OF SEXUALITY AND PHYSICAL DISABILITY

The field of sexuality and disability began to develop rather recently. Prior to the 1970’s, little or no research was conducted on the sexuality of people with disabilities. Western culture has traditionally viewed people with disabilities as asexual or as sexual deviants (Milligan & Neufeldt, 2001). Sexual behaviors involving people with disabilities are generally viewed more negatively than the same sexual behaviors among non-disabled people (Milligan & Neufeldt, 2001). The resulting isolation and marginalization have been shown to be associated with internalization of negative attitudes and beliefs by people with disabilities themselves (Di Giulio, 2003). The presumption of asexuality perpetuated by society has also been shown to act as a self-fulfilling prophecy which leads people with disabilities away from intimacy and sexual fulfillment (Milligan & Neufeldt, 2001).

Statement of the Problem

Many researchers in the fields of disability and sexuality have stressed the importance of education on these topics due to the current lack of a knowledge base for both students and practicing mental health professionals (MHPs) (Ballan, 2008; Caruso et al., 1997). The knowledge mental health professionals lack in these areas, initially pointed out by Glasgow (1981), has experienced little growth over the last several decades (McCabe, Cummins, & Deeks, 2000). As suggested by Ballan (2008), additional educational materials should be implemented in graduate school curricula. Concurrently, educational materials should also be made easily available to practicing mental health
professionals so that they may increase their knowledge base and ability to serve diverse populations.

**Purpose**

The purpose of this project was to develop training materials on sexuality and physical disability by first identifying the existing knowledge and needs of an accessible group of mental health professionals. Data surrounding sexual education suggests that the average mental health professional may know less about the sexual concerns of their clients than expected (Ridley, 2009). In order to increase MHP awareness of sexuality among people with disabilities, training materials were developed using a four step process. First, MHPs were assessed on knowledge, interests, and attitudes about disability and sexuality. Training materials were then developed utilizing the available literature and guided by the results of the needs assessment. These training materials were submitted to experts for review and feedback. The feedback was then incorporated and the training materials were revised. The developed educational materials will be available for future self-directed learning or use in instructor-led training efforts for mental health professionals. Ballan (2008) showed that exposure to training materials such as those developed here was related to higher levels of knowledge in this area among a sample of Canadian social work students.
Chapter 2

LITERATURE REVIEW OF SEXUALITY AND PHYSICAL DISABILITY

Circulation of educational materials for mental health professionals on the topic of sexual health has begun to increase (Esmail et al., 2001). Yet, educational materials that place an emphasis on disability or the cross-section of disability and sexuality are sparse. These findings are alarming since clients with disabilities do approach mental health professionals for support and have expectations that they will be knowledgeable in this field.

Disability Culture and Diversity

Disability culture is a term that has been used to describe the shared meaning and experiences faced by individuals with disabilities (Greenwell & Hough, 2008). In 2006, Greenwell and Hough found that approximately 20% of residents of the United States had a “disabling condition,” making up the largest minority group in the country at the time (p. 189). In this article, “disabling condition” included all forms of disability such as physical, sensory, intellectual, and so forth. Due to the size and differing characteristics of this population, there is an inherently large amount of within-group variation. Consequently, people in this field have debated whether or not there was a distinct disability cultural group (Greenwell & Hough, 2008; Shakespeare, 2000). This debate centered largely around whether or not there was enough shared experience to unite the people in this population into their own distinct culture.

Since this time, four common factors that represent progress “for those striving to unify and strengthen the collective voice of individuals with disabilities” have been
identified (Greenwell & Hough, 2008, p. 190). Namely, these factors are: fortification which offers “endurance against oppression”, unification which “encourages mutual support and underscores common values”, communication through “developing art, language, symbols, and rituals” that signal distinctness to each other and the world, and recruitment through expression of disability culture as “a positive and defiant conversion of social marginalization into celebration of distinctness” (Gill, 1991, p. 2).

Further discussion of the culture of disability by Gill (1991) illuminates a list of core values that are seen in political struggles, art, conversations, goals, and behaviors of disability culture. These are: First, “an acceptance of human differences (e.g., physical, functional, racial, intellectual, economic/class)”, second, “a matter-of-fact orientation toward helping; an acceptance of human vulnerability and interdependence as part of life”, third, “a tolerance for lack of resolution, for dealing with the unpredictable and living with unknowns or less-than-desired outcomes”, fourth, “disability humor- the ability to laugh at the oppressor and our own situations, to find something absurdly hilarious in almost anything, however dire”, fifth, “skill in managing multiple problems, systems, technology and assistants”, sixth, “a sophisticated future orientation; an ability to construct complex plans taking into account multiple contingencies and realistically anticipated obstacles”, seventh, “a carefully honed capacity for closure in interpersonal communication; the ability to read others’ attitudes and conflicts in order to sort out, fill in the gaps and grasp the latent meaning in contradictory social messages”, eighth, “a flexible, adaptive approach to tasks; a creativity stimulated by both limited resources and experience with untraditional modes of operating.” (Gill, 1991, p. 3)
However, the identification of unifying factors, functions, and values by scholars in this field also addresses the finding that variation does exist in this population. Multiculturalism in the culture of disability is now a recognized central facet. Disability culture is not limited to one specific ethnicity, sexual orientation, age group, socioeconomic status, education level, etc. but rather encompasses an endless multitude of other intersecting cultural designations.

**General Concerns of People Living with Physical Disabilities**

People with congenital versus acquired physical disabilities may experience different emotions and beliefs about their sexuality. In one study by McCabe, Cummins, and Deeks (2000), “people with congenital physical disabilities experienced low levels of sexual knowledge, held negative feelings about sexuality, and experienced high levels of sexual needs” in addition to having lower levels of experience with sex (p. 55). Conversely, adjustment patterns for people who experience an acquired disability vary. Some adjust quickly, while for others, adjustment may be a life-long process. People who acquire a physical disability may compare themselves to their previous sexual experiences and sexual performance (pre-injury), and some literature shows that they may be concerned with being sexual in a culturally-normative way (Tepper, 2000).

Sexual esteem, defined as “positive regard for and confidence in an individual’s capacity to experience his or her sexuality in a satisfying and enjoyable way,” has been found to be negatively affected by disability (Taleporos & McCabe, 2001, p. 131). Sexual esteem can be affected by many factors among people living with disabilities. For example, Mona, Gardos, and Brown (1994) found that the age of physical disability onset
was related to sexual esteem. These authors found that the later in life people acquired their physical disability, the more negatively sexual esteem was affected. Since sexual esteem is an important part of an individual’s identity and self-esteem, the importance of offering knowledgeable support for individuals with physical disabilities who may have questions regarding their sexuality cannot be overstated. Based on such previous studies, mental health providers (MHPs) should be educated about factors that affect sexual esteem among people with disabilities (Mona, Gardos, & Brown, 1994; Taleporos & McCabe, 2001).

As addressed in Di Giulio (2003), people with physical disabilities often experience common, systemic barriers to sexual health. One of these barriers is a lack of general personal privacy because people with physical disabilities often utilize assistance from others to help them with an array of daily tasks. As a result of decreased privacy, they also often have less access to social interaction and, consequently, sexual partners. This has been found to be particularly common among women with disabilities. Women have been shown to have different patterns of socialization than men; for instance, women are generally more passive in dating interactions. As such, men are traditionally looked at as the pursuer, while women are pursued (Di Giulio, 2003).

People with physical disabilities have an increased vulnerability to HIV, AIDS, and other sexually transmitted diseases (Di Giulio, 2003). Certain risk factors are present within this population, including disadvantages in negotiating for safe sex, social marginalization that can result in unstable relationships, and a lack of interventions to promote safe sex. Additionally, there is the increased vulnerability of this population to
sexual exploitation and abuse. Since many people living with physical disabilities often depend on caregivers for their well-being, feelings of powerlessness may accompany real vulnerability. Perpetrators of sexual exploitation and abuse may also have awareness about the physical vulnerability of people living with physical disabilities. Finally, as stated before, the lack of sexual education for people with disabilities also may make them more susceptible to being taking advantage of sexually.

**Physical Disability, Gender, Maturation, and Sexuality**

As discussed previously, there is great variation within the population of people who identify as disabled. In terms of female sexuality, Nosek and colleagues (2001) found that, when compared to a population of able-bodied women, the sample of women with physical disabilities differed in many ways. The findings of this study from a large national sample in the United States suggest that women with disabilities have limited opportunities to establish romantic relationships when compared to able-bodied women. Women with disabilities were less satisfied with the frequency of dates and felt that they had more constraints on their ability to attract partners. They also found that friendships were less likely to evolve into romantic relationships and that only 38% of women with disabilities had borne children. However, despite these challenges, the large majority of women with disabilities had been married or in at least one serious relationship.

Women with physical disabilities appear to have as much sexual desire as women without disabilities; however, they also appear to have less opportunity for sexual encounters. In 2001, Nosek and colleagues found that approximately 94% of women with disabilities had experienced sexual activity during their lifetime. At the time of the study,
61% of able-bodied women were currently sexually active compared to 49% of women with physical disabilities. Furthermore, 41% of women believed they did not have enough information about how their particular disability affected their sexual abilities and overall, women with disabilities reported significantly lower levels of sexual activity, response, and satisfaction, despite their aforementioned interest in sex. The level of sexual activity was not significantly related to the severity of the woman’s disability (Nosek et al., 2001).

A serious problem that is common for women with disabilities is abuse. Nosek et al. (2001) found that the same percentage of women with and without physical disabilities had experienced emotional, physical, or sexual abuse, but women with disabilities had experienced the abuse for longer periods of time. Women with disabilities also face serious barriers to reproductive health care. In the same study, women reported difficulty locating a physician who was knowledgeable enough about their condition to help them manage their pregnancy appropriately. Women in this group reported chronic health conditions such as urinary-tract infections much more often and at younger ages than the group without disabilities.

When learning about sex, women with physical disabilities reported being educated on the physical aspects of sexual intercourse at approximately the same age as women without physical disabilities (age 13). On average, women with physical disabilities had their first date at a later age than women without physical disabilities (ages 16.6 and 14.9, respectively) (Walter, Nosek, & Langdon, 2001). The sources from which women learn about sex appear to be similar for women with and without
disabilities. Women with disabilities also learned more frequently from certain sources (other women with disabilities, counselors, and college courses) than women without a physical disability (Walter, Nosek, & Langdon, 2001).

Studies examining the sexuality of men with physical disabilities have yielded interesting results in terms of their sexuality. Tepper (1999) discussed the idea that “boys learn that their manhood is tied to their penis, and having and using erections has something to do with masculinity… boys learn a fantasy model of sex… because we [men] don’t have any realistic models or standards in sex, we tend to measure ourselves against these fantasies” (p. 44). For a man with a physical disability, who consequently may have impaired erectile functioning, the realization that he does not match up to the fantasized model of sexuality may be painful. MHPs can play an important role in helping men to deconstruct sexual myths, critically evaluate the sexual fantasy model, and then construct a more personally-relevant version of male sexuality (Tepper, 1999).

Some other treatment concerns surrounding sexuality for men with physical disabilities discussed by Tepper (1999) include: physiological changes in sexual function, inability to express fear and despair, denial, repression, anger and misinformation around sexual issues, the wish not to burden loved ones and/or partners, and the potential for using substance abuse to cope with sexual trauma. MHPs can help men with physical disabilities personalize their view of sexuality by (Tepper, 1999, p. 49):

- “Helping men to unlearn sexual myths- facilitate a critical examination of what men learn about sex and manhood” in our society
• “Helping men to learn facts about human sexuality that are accurate”
• “Helping men to understand the physiological effects of disability on their sexual functioning”
• Offering possible “solutions to impaired sexual function” and alternative “options for sexual expression”
• “Helping men to improve their communication skills around sexual issues”
• “Reacting constructively to anger” and helping “guide men to explore the underlying causes of such anger”
• “Encouraging men to take control of their own rehabilitation process as much as possible”
• Discussing the “benefits of adapting to a more flexible gender role”
• Educating men on how to “focus on pleasure and intimacy” with sex as opposed to “performance and orgasm”
• Paying attention to possible substance abuse

Adolescents with physical disabilities are another group with specific sexual concerns. Gordon and colleagues (2004) suggested that adolescents with physical disabilities may possess negative self-views and may struggle to create friendships and intimate relationships. Due to limited dating experience, adolescents with disabilities may rely heavily on media portrayals of romance and relationships which further distort their views and expectations (Howland & Rintala, 2001). Adolescents with disabilities also often know little about the way that their physical disability affects their sexual functioning and whether their disability has genetic or reproductive implications (Gordon
et al., 2004). Adolescents may also be particularly sensitive to the “myth of bodily perfection” which establishes physical standards that are impossible for individuals to meet. MHPs can help to educate adolescent’s about general sexuality, safe sex, pregnancy, and the effect their disability may have on their sexual functioning and may work on age-appropriate social and relationship skills using role-play as needed (Gordon et al., 2004).

Parents of children with physical disabilities may also have little knowledge about their adolescent’s sexuality concerns. The process of separation and individuation that naturally occurs during adolescence can become especially difficult for people with disabilities (Olkin, 1999). Socialization is an important factor in adolescent sexual identity formation. Parents who have a difficult time supporting age-appropriate activities where sexual knowledge may be gained can limit their adolescent’s ability to develop and learn about sex (Di Giulio, 2003). It is important for MHPs to work with parents to identify what their concerns are and help them to have positive expectations about their social interactions and potential for long-term relationships later in life. Helping parents to identify realistic concerns and to evaluate or challenge distorted beliefs may be a goal for MHPs working with adolescents with physical disabilities (Gordon et al., 2004).

**Sexual Counseling by Mental Health Professionals**

There are various intervention strategies that have been shown to be effective for the general population, including what is known as the P-LI-SS-IT model (Annon, 1974). The P-LI-SS-IT model is one way for mental health professionals to conceptualize the goals of sexual counseling. This model provides a helpful framework for assessment not
only of the client/s needs, but also for the MHPs level of comfort and ability to adequately address those needs. The model helps to identify appropriate treatment goals for generalists as well as guidance for when the average mental health will need to refer a client to a sex therapist or other specialist (Di Giulio, 2003). All mental health professionals should develop competence in basic assessment of sexual well-being and in making appropriate referrals to sexual health specialists. The goals of this project were to document beginning therapists’ knowledge and comfort in the area of sexuality among people with physical disabilities and to develop a training tool to assist mental health providers in expanding their knowledge of this important topic.

The Sexual Response Cycle identified by Masters and Johnson (1966) provides a basis for diagnosis of sexual dysfunction, but may have limited utility for people with physical disabilities. Many people with physical disabilities may feel content in their sexual experiences, despite differences in their own “sexual response cycles” (Di Giulio, 2003). Furthermore, Tepper (2000) states that “traditional models of sexual response provide a genitally-focused and performance-oriented conception of sexuality that presents a conceptual challenge to optimizing sexual potential for people with disabilities” (p. 44). MHPs can play an important role in helping individuals to deconstruct sexual myths, critically evaluate the sexual fantasy and/or sexual response cycles, and then construct a more personally-relevant version of sexuality (Tepper, 2000).

**Relationship Counseling for Couples with Physical Disability**

Previous findings support the need for awareness and education of mental health professionals working with couples in which one or more person(s) has a physical
disability. Whether one partner identifies as an individual with physical disability or both do, the subjective health of a relationship has been found to be strongly related to sexual wellbeing (Taleporos & McCabe, 2003). One study found that sex could be the largest problem in marriages involving at least one person with a disability (Esmail et al., 2001). The frequency of long-term relationships is lower and the rates of divorce are higher among people with disabilities versus people without disabilities. Estimates of divorce in populations with physical disability are as high as 85% for couples in which one partner acquires a disability after marriage (Esmail et al., 2001; Taleporos & McCabe, 2003). In couples who formed their relationships before a partner acquired a physical disability, the non-disabled partner was more likely to be in a caregiver role and strength and commitment could be seen in the relationship alongside “noticeable areas of loss and regret” (Crewe, 1993, p. 146). Findings also indicate that people who form long-term relationships after acquiring a physical disability report greater overall satisfaction in their lives, including their sex lives (Esmail et al., 2001).

Researchers have found that characteristics associated with successful marriages are the same for most couples, regardless of physical disability status. However, some differences in relationships do appear to exist. Esmail and colleagues (2001) discuss these potential differences and provide suggestions for interventions by MHPs in their article entitled, Sexuality and disability: The role of health care professionals in providing options and alternatives for couples. These authors highlight three major points pertaining to intimacy. First, intimacy is a key ingredient in relationships. MHPs should avoid a narrow focus on physicality as the only way to regain closeness. Emotional
closeness, mutual concern, and willingness to take part in a variety of sexual activities have been reported as most important for sexual satisfaction (Esmail et al., 2001).

Second, non-disabled partners often report greater difficulty adjusting cognitively to a disability-related loss in sexual functioning than learning to work around the physical impairment to sexual functioning. Finally, couples who are able to define and/or redefine intimacy in terms of a “mutually caring and companionate relationship with shared interests and pleasurable activities” instead of focusing on the physical act of sex have a greater likelihood of continuing on with satisfying sexuality in their relationship (Esmail et al., 2001, p. 272).

The article also focuses on the possible changes that occur in roles and expectations for these couples, which are generally not limited to the partner with the physical disability. First, it has been found that the longer a non-disabled person takes on the role of caretaker for their partner, the harder it is to return to the level of intimacy that the couple experienced pre-disability. Also, gender roles and socialization should be taken into account when analyzing how the couple copes with the disability. Each gender often has different strengths and/or skills affecting how they adjust to the disability.

Third, couples will often need assistance to “clearly outline what self-care activities can be done independently, which activities require assistance from the partner and which require professional help” (Esmail et al., 2001, p. 272).

According to Esmail and colleagues (2001), non-disabled partners should be involved in caring for and educating the disabled individual since they are also highly affected by the disability. These authors suggest using language that helps clients reframe
their disability-related experience as a shared challenge rather than a problem belonging to only one member of the couple. This gives each member of the couple permission to examine their own attitudes toward disability. For couples to function at the highest level, both partners must view the disability experience as involving mutual responsibility in order to work together toward intimacy, including sexual adjustment (Esmail et al., 2001). Such assumption of mutual responsibility allows the couple to face their challenges through unity and togetherness.

Facilitating communication within the couple is an important intervention that includes healthy verbal and non-verbal communication. These forms of communication are seen as essential to maintaining the relationship and overcoming sexual changes and challenges due to physical disability (Esmail et al., 2001). Partners should be encouraged to express their sexual needs and desires openly in a safe environment. Such discussions can include: how the couple defines intimacy, hindrances to open communication of sexual experience, and how the physical disability affects intimacy both positively and negatively (Esmail et al., 2001).

Attitudinal and behavioral changes are often necessary to dispel the societal myths that can create inhibitions and undermine a couple’s ability to satisfy their own sexual needs and desires. Using open communication, definitions of sexuality should be explored, with the goal of broadening these definitions to include an affirmative conceptualization of sexuality in the context of the disability. For instance, Esmail and colleagues (2001) suggest defining sexuality as “any activity that is mutually stimulating and pleasurable for the couple” (p. 275). Sexual boundaries, roles, and expectations
should be discussed as part of the couple’s definition of sexuality; these need to be comfortable for both partners. Once a broader definition of sexuality has been explored and established, couples can discuss with their MHP intimate and sexual activities that they might be open to trying.

Educating couples with accurate information is also a key aspect of counseling. Clearly explaining and defining disability can be very helpful. Some studies have found that the more information and awareness the spouse of the person with a physical disability has, the fewer negative effects disability has on the relationship (Esmail et al., 2001; Williams, 1993). Esmail and colleagues (2001) suggest that the education of the couple should include: “an understanding of the disability itself, prognosis and complications, specific information on sexual anatomy, physiology, and function, fertility, pregnancy, contraception, and bowel and bladder management” (p. 274).

A final approach discussed by Esmail and colleagues (2001) that may be helpful for couples affected by a physical disability includes prescription of aids, prostheses, and resources. The use of orthotic and assistive devices can aid in positioning, overcoming functional limitations, and enhancing physiological sexual pleasure. In addition to external aids, it is very important that MHPs have a list of resources available to clients in the form of literature and competent referrals to local MHPs with greater expertise in assisting couples affected by physical disabilities.

**Using Effective Education Practices**

Research in the area of education and learning illustrates the effectiveness of certain types of needs assessment and training for professionals. Hauer and Quill (2011)
discuss needs assessment as a process that includes the following aspects: defining the purposes, identifying the audience and pertinent issues, utilizing resources, carrying out data collection, and then analyzing the data. This project followed the guidelines suggested by Hauer and Quill in the following ways: defining purposes and issues by stating the problem clearly, identifying the audience as MHPs, utilizing the proper resources found in peer-reviewed journal articles and texts, carrying out data collection with a multi-faceted needs assessment, and finally, analyzing the data according to current behavioral research standards.

Tannenbaum and Yuki (1992) have also suggested an academic model for developing training materials in their article *Training and Development in Work Organizations*, which was used as a guideline when creating the educational materials for this project. They state that the “design of training should take into account learning objectives, trainee characteristics, current knowledge about learning processes, and practical considerations such as constraints and cost in relation to benefits” (p. 403).

When the educational materials were developed for this project, learning objectives were clearly stated in the project proposal and revised based on the results of the needs assessment and expert feedback. Furthermore, characteristics of the trainee population (MHPs) were taken into account. Current knowledge regarding the learning processes of MHPs suggests that the use of PowerPoint presentations and other interactive media technology can be very effective in educating participants who commonly work in professional settings (Rosenfield & Humphrey, 2012). The use of a PowerPoint presentation is also inexpensive. This is in accordance with the budgetary constraints of
many university degree programs, non-profit agencies and other community organizations that will be most likely to utilize such materials.
Chapter 3

METHOD

The Knowledge of Sexuality and Physical Disability Project (KSPDP) was completed in four major phases. First, a needs assessment was developed to be used with a student population of Marriage and Family Therapist Trainees. This assessment was developed in conjunction with a literature review of sexuality and disability literature. Second, the results of the needs assessment and literature review guided the development of educational materials that would theoretically increase the knowledge of MHPs on the topic of sexuality and physical disability. Once these were developed, the third phase involved evaluating the PowerPoint materials by obtaining expert reviews. Finally, the expert critique was incorporated into the final revision of the sexuality and physical disability educational materials.

Phase 1:

Needs Assessment Administration

The content of the needs assessment was developed based on a thorough literature review the topic of sexuality and physical disability. The objective of the needs assessment was to provide qualitative and quantitative information, using a three-part survey (See Appendix A). The qualitative portion included six open-ended questions, one located at the end of the questionnaire, and the quantitative portions included the Attitudes Scale, Knowledge Scale, and Comfort Scale. These scales were developed by the researcher since no viable needs assessment scales could be found during the literature review.
The first portion of the survey was designed to gather qualitative information via open-ended questions. This included several open-ended questions that were administered to participants prior to the other questionnaires so that the specific, closed-ended items administered later would not influence their responses. For example, one item asked, “Is there anything particular about sexuality and physical disability that you would like to know more about?”

The initial portion of the quantitative section, the *Attitudes Scale*, addressed participant attitudes about physical disability. There were six items, and participants were asked to “read each item carefully and consider how it applies to you.” They then rated the personal applicability of each item based on a Likert-type response scale from 1 to 5, with “1” being “not likely”, and “5” being “extremely likely.” The scale includes questions such as “How likely are you to see a client’s physical disability as a positive influence on their life?”

The third part then used a Likert-type scale to allow participants to rate their comfort with and knowledge of specific aspects of sexuality and physical disability. It was decided that rather than directly testing the knowledge of students in an area that research has shown most mental health professionals to be lacking in, it would be better to ask about perceived knowledge. This approach encouraged self-reflection by the participants as they assessed their own knowledge and comfort.

Participants were asked to evaluate their perceived knowledge and comfort levels on 36 items assessing both broad (e.g., “overall knowledge of how living with a physical disability can affect sexuality” and “knowledge of families in which one or more people
have a physical disability”) and specific (e.g., “knowledge of the effect Rheumatoid Arthritis can have on sexuality” and “knowledge of sexual esteem and people with physical disabilities”) topics. Response options were on a scale of 1 to 5, with “1” being “very little or no knowledge and/or comfort”, and “5” being “extremely knowledgeable or comfortable.”

Finally, one open-ended question was administered to participants last to serve as a final catch-all prior to their completion the needs assessment. This question asked, “Is there anything else you’d like to add with regard to sexuality and physical disability?”

The needs assessment was developed with the assistance and expertise of Psychology department faculty members at California State University, Sacramento. The assessment was edited and revised by experts in the fields of tests and measurement and cultural studies before the final version (Appendix A). Overall, the assessment was designed to take one hour or less and be administered to a group using paper and pencil format rather than interview.

The needs assessment was given to a small convenience sample of six Marriage and Family Therapist Trainee student participants. All of these participants were advanced Counseling Psychology Master’s degree students at California State University, Sacramento, within the Psychology department. All ten current students in this population were sent an email inviting them to take part in the needs assessment. Eight people responded with interest, of whom six were available to take part at one of the two times offered. Both times were on weekdays, one in the afternoon and one in the evening. Student participation was voluntary and individuals invited to participate included men
and women of a range of ages and ethnicities. Participants were offered refreshments, such as bottled water, but they did not receive any other tangible incentives to participate.

After reviewing and signing informed consent forms, participants were given short instructions on how to fill out the needs assessment, while being supplied with the materials (questionnaire forms and pens). The instructions were simply that they “complete the assessment to the best of their ability and may leave upon completion.” The assessment took less time than originally planned; all participants finished within 30 minutes. Participants were debriefed upon leaving and informed that a final copy of the educational materials would be made available electronically within the year. They were also directed to an email address should they have questions or more interest in the study.

**Phase 2:**

**Development of the Educational Materials**

PowerPoint educational materials on sexuality and physical disability were developed after the needs assessment was carried out with the Marriage and Family Therapist Trainee student sample (Appendix B). These educational materials were developed with the intention of creating readily usable materials that could serve to increase the knowledge of mental health professionals in the area of sexuality and physical disability. Using the academic model developed by Tannenbaum and Yuki (1992) as a framework, these materials were based on the theoretical current knowledge that the Marriage and Family Therapist Trainees appear to have given the results of the needs assessment and literature review.
The educational materials focused in part on topics the Marriage and Family Therapist Trainees rated low in the quantitative portions of the needs assessment, but more importantly, on what they expressed in their own words during the qualitative portion. Additionally, a thorough literature review of sexuality and disability yielded a number of journal articles that provide an empirical foundation for knowledge of sexuality and disability. Due to the information gained from both the needs assessment and literature review, it was decided that the training materials should reflect a broad range of topics in order to effectively serve the training needs of mental health generalists rather than sex therapists or other sexual health specialists.

The developed materials are written in easily accessible language for the target population. They are meant to be given in oral presentation form over the course of approximately one and one-half hour. The materials may also be utilized as educational reading, however self-administration is not the intended use and is not viewed as the most effective form of learning with the PowerPoint. In particular, the portions of the educational materials that highlight self-examination of cultural experience are likely to function better when delivered by a trained speaker as part of a face-to-face training rather than through self-directed reading for educational purposes.

**Phase 3: Expert Feedback Questionnaires**

Three expert consultants were asked to give their feedback on the materials so they could be refined. These reviewers were qualified as experts based on their experience in clinical and scholarly work on sexuality and disability, including extensive,
peer-reviewed presentations and publications in this field. The experts were recruited through the use of referral or “snowball” sampling and were asked to provide feedback via a brief questionnaire. The feedback form included four open-ended questions (Appendix C): “Do you feel that the educational materials on sexuality and physical disability will increase knowledge of the subject for mental health providers? Is there anything additional that you would have liked the materials to have covered? Overall, how would you describe the quality, correctness, and thoroughness of the educational materials? Use the following space for any additional comments, questions, and/or concerns.” The goal of this assessment by experts in the field of sexuality and disability was to check for the accessibility, thoroughness, and correctness of the educational materials. The feedback given by the experts was then incorporated into the revision of the educational materials.

Phase 4:
Revision of the Educational Materials

Based on the expert feedback, the educational materials were revised twice. The materials were revised once utilizing the feedback from two expert reviewers, and then again with the feedback from a final expert reviewer. Thus, the final reviewer was given an interim version of the educational materials, with feedback from the initial two expert reviewers already incorporated. Once this expert’s feedback was received, the materials were revised one final time. In an effort to provide supplemental information for MHPs on sexuality and physical disability, a reference slide providing additional sources of information was included in the final version of the educational materials (Appendix D).
This includes references highlighting the importance of competence, multicultural awareness, disability-affirmative theory, and advocacy.
Chapter 4

RESULTS

Results of the Needs Assessment

Overall, the assessment indicated that further training on sexuality and physical disability is needed for this sample of Marriage and Family Therapist Trainees. Although this sample of trainees had low perceived levels of knowledge, they did express high levels of interest in learning more about sexuality among people with physical disabilities.

The population was predominantly female, multi-ethnic, and included both United States-born individuals and immigrants to the United States. Ages of individuals ranged from mid-20’s to 50’s. The sample was generally representative of the population. A total of six Marriage and Family Therapist Trainees completed the needs assessment questionnaires. All six participants were female and in their final year of the Master of Arts counseling program located within the Psychology Department of California State University, Sacramento.

The data compiled from the questionnaires was both quantitative and qualitative in nature. Question 14 on the Knowledge and Comfort scales was not completed by one participant and therefore that data point could not be included in the results. Quantitative data from the needs assessment questionnaires is presented in Table 1 and a copy of the entire questionnaire is found in Appendix A.

The needs assessment included six open-ended questions, five of which were located at the start of the questionnaire. Responses to each question were coded into
categories. Question One: *Is there anything particular about sexuality and/or physical disability that you would like to know more about?* As a group, participants responded to this question with one of the following categorical answers: “no”, “interested in general knowledge”, “interested in specific knowledge”, or “interested in a combination of both general and specific knowledge.” Of the six participants, one expressed no interest, while one expressed interest in general knowledge. Two participants expressed a desire to know more about specific aspects of sexuality and physical disability and two others expressed a desire to learn a combination of both general and specific knowledge on these topics.

Question Two: *Please describe your interest level in the topic of sexuality and physical disability and why.* Participant responses were coded into one of three interest levels: high, moderate, and low. Most respondents stated that they had high or moderate interest levels in the subject (n = 5), while only one reported a low interest level which they stated was due to the participants’ own current “able-bodiedness.”

Question Three: *How do you think you have gained most of your knowledge regarding sexuality and physical disability?* Responses to this question varied amongst sources, including reading and research such as journal articles and books, graduate coursework, popular culture such as movies and television, and a combination of multiple sources. No participants reported gaining knowledge via conferences or seminars on the subject.

Question Four: *What are a few of the clinical concerns that you would address involving sexuality if you had a client with a physical disability?* Respondents wrote about a variety of clinical concerns including history and current sex life status, general
wants and needs concerning sex, pertinent medical information about their physical disability, and issues of sexual abuse and discrimination due to disability. Two participants also mentioned their lack of knowledge of this subject and worried that they might “offend them.”

Question Five: Please describe some of your own training needs on the topics of sexuality, disability, or the intersection of both. All six participants responded to this question by stating that they need more training on either both of these topics separately or the intersection of the two.

Question Six: Is there anything else you’d like to add with regard to sexuality and physical disability? This question was asked separate from the other five open-ended questions, following the closed-ended portion of the needs assessment. Half of the participants requested more training and research on this topic (n = 3), while half also stated that the questionnaire helped them to realize their lack of knowledge and preparation to help clients with physical disabilities regarding sexual concerns (n = 3).

One final important finding from the overall qualitative section of the needs assessment again highlights the importance of training for mental health professionals on the intersection of sexuality and physical disability. Several of the needs assessment participants cited having already worked with a client or clients living with physical disabilities in their limited amount of experience as Marriage and Family Therapist Trainees. Participants also stated that these same clients wanted to discuss sexual concerns. Given that Marriage and Family Therapist Trainees are commonly in their initial 500 hours of experience as a therapist or counselor, this shows the imminent need
for more training materials to be developed on this topic, not only for Trainees but all mental health professionals.

The Grand Mean for the Attitudes Scale was middling (M = 3.50) and individual items with their corresponding means can be found in Table 1. The specific subject matter of the items on the Attitudes Scale included not only attitudes, but also expectancies and cultural awareness. Item means ranged from 2.67 to 4.33. The lowest rated item asked participants to identify “how likely they were to see a client’s physical disability as a positive influence on their life” (M = 2.67) and the highest rated item asked participants to identify “how likely it is that they will see a client with a physical disability” (M = 4.33).

Interest in learning more on the field of sexuality and physical disability appears to be high (M = 4.17), and participants appeared to believe that it was highly likely they would see a client with a physical disability during their career (M = 4.33). The data also indicated that the sample was not overly concerned about their ability to adequately meet a client’s needs around sexuality and physical disability (M = 2.83). They expressed some awareness of a distinct disability culture (M = 3.83). Awareness that people with disabilities might view their disability in a positive way (M = 3.17) and participants’ own ability to view disability in a positive way (M = 2.67) fell in the middle of the scale (3 = “somewhat likely”).
Table 1

_Data for the Attitudes Scale_

<table>
<thead>
<tr>
<th>Item #</th>
<th>Description</th>
<th>Item Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>How likely would you be to attend a Continuing Education class or conference presentation on sexuality and physical disability?</td>
<td>4.17</td>
</tr>
<tr>
<td>2</td>
<td>How likely do you think it is that you will see a client with a physical disability?</td>
<td>4.33</td>
</tr>
<tr>
<td>3</td>
<td>How likely is it that you will not be able to adequately meet a client’s needs regarding sexuality and physical disability?</td>
<td>2.83</td>
</tr>
<tr>
<td>4</td>
<td>How likely do you think it is that people living with disabilities are a part of their own distinct culture?</td>
<td>3.83</td>
</tr>
<tr>
<td>5</td>
<td>How likely do you think it is that people living with disabilities see their disability in a positive way?</td>
<td>3.17</td>
</tr>
<tr>
<td>6</td>
<td>How likely are you to see a client’s physical disability as a positive influence on their life?</td>
<td>2.67</td>
</tr>
</tbody>
</table>

The mean score across respondents and items on the *Comfort Scale* (*M* = 2.85) was higher than the mean scores for the *Knowledge Scale* (*M* = 2.09). This suggests that despite their relatively low level of knowledge on the subject, mental health professionals have some openness and may be comfortable discussing sexuality and physical disability concerns with their clients.

For the *Knowledge Scale*, individual item means ranged from approximately 1.33 to 4.17. Participants generally rated higher perceived knowledge on broader sub-topics in
the field of sexuality and disability, such as “overall knowledge of human sexuality” (M = 4.17) and “overall knowledge of individuals with physical disabilities” (M = 3.17). Participants generally rated lower perceived knowledge on more specific sub-topics such as “knowledge of Spastic Syndrome and its effect on sexuality” (M = 1.33) and “knowledge of Parkinsonism and its effect on sexuality” (M = 1.33). This indicates that participants may believe they have less knowledge on specific medical diagnoses affecting disability.

For the Comfort Scale, individual item means ranged from approximately 2.00 to 4.33. Participants generally rated higher comfort discussing broad sub-topics in the field of sexuality and disability with their clients, such as “comfort discussing human sexuality” (M = 4.33) and “comfort discussing physical disabilities” (M = 3.67). As was found with the Knowledge Scale, participants generally rated lower comfort on more specific sub-topics such as “comfort discussing cranial trauma and its effect on sexuality” (M = 2.00) and “comfort discussing bladder and bowel-related sexual problems for people with physical disabilities” (M = 2.00). These findings may indicate that participants have less comfort discussing the more specific aspects of sexuality and physical disability, particularly those concerning specific knowledge of medical diagnoses.

Results of the Expert Feedback

In order to evaluate the theoretical effectiveness of the educational materials, expert feedback of the proposed materials was solicited. Experts responded to the four open-ended questions in the Sexuality and Physical Disability Training Materials
Feedback Questionnaire (Appendix C) with helpful comments and suggestions. Overall, the feedback pertaining to the quality, correctness, and thoroughness of the educational materials was positive, as summarized below.

Question One: Do you feel that the educational materials on sexuality and physical disability will increase knowledge of this subject for mental health providers? In general, experts responded “yes” to this question and commented on the lack of training for MHPs on working with persons with physical disabilities and/or sexual concerns. The sex-positive approach was highlighted by one expert as a strength of the educational materials, as well as the expansion of the definition of sex “away from a performance and penetration focused act.”

Question Two: Is there anything additional that you would have liked the materials to have covered? One expert responded that the self-assessments within the materials may not be helpful, but that this would be based on whether or not the educational materials are meant “to be stand-alone, or be delivered.” If delivered, this person believed that the self-assessments could be facilitated more clearly. As discussed previously, the materials were designed to be presented in PowerPoint form, either by the researcher or another trainer who is competent in these fields. Therefore the self-assessments should still serve as a useful tool to help MHPs examine their own beliefs and misconceptions about sexuality and physical disability. Another expert responded to question two by suggesting an additional slide placed near the PLISSIT discussion that offers further questions which can be used for clinical interviewing. This suggestion was implemented into the final version of the educational materials (Appendix D).
Question Three: Overall, how would you describe the quality, correctness, and thoroughness of the educational materials? As a group, the experts responded to this question positively. Their feedback indicated that the materials were of high quality, covering important areas of research with relevant and current citations. They also reported that the materials appeared to be correct as a whole and that the major parts of the fields of sexuality and physical disability were discussed. One expert suggested some expansion on the discussion of the culture of disability, as well as research that would complete this discussion. This suggestion was integrated into the final version of the educational materials found in Appendix D.

Question Four: Use the following space for any additional comments, questions, and/or concerns. As a whole, expert respondents suggested that the original layout of the slides was not visually pleasing and found them hard to follow. It was suggested that too much information was on some of the slides and that the density of this style of educational materials could be simplified by breaking up some of the individual slides into two or more slides. These suggestions were taken into consideration when the final version of the materials was completed. The new slides are in a PowerPoint format that is easier to follow, as suggested by the experts, with each slide containing less information so as to make them less dense while utilizing a simpler slide layout design.
Chapter 5
DISCUSSION

Research confirms the need for further education in the areas of sexuality, physical disability and the intersection of both (Di Giulio, 2003; Milligan & Neufeldt, 2001). Researchers have also documented the specific sexual health and counseling needs of clients with disabilities (Di Giulio, 2003; McCabe, Cummins, & Deeks, 2000; Tepper, 2000). Establishing thorough educational materials of high quality that address the lack of training and need for competent treatment options for this population was the target of this project. The materials were designed to be presented in easily accessible language and content for people working in the mental health field.

The needs assessments conducted with the Marriage and Family Therapist Trainee sample confirms the lack of education that current MHPs receive in the average Master’s degree training program. However, the results of the needs assessment also highlight the interest that this group has in learning more about sexuality and physical disability in order to become more competent in their ability to help clients. Analysis of the expert feedback questionnaires supports the theorized effectiveness and accuracy of the proposed educational materials, particularly once the recommended revisions were incorporated.

One of the limitations of this project was the inability to test the educational materials on a diverse population of MHPs to ensure their effectiveness. The revised educational materials are not meant to be an exhaustive representation of all current knowledge pertaining to sexuality and physical disability, but to serve as a starting point
for further research and training. More in-depth materials could be developed for those seeking to cultivate higher-level expertise. The materials will need to be refined over time as the literature base for sexuality and disability expands and treatment strategies evolve.

Additional topics that should be covered in future educational materials within this field include specific issues related to body image for women living with physical disabilities. As suggested by the expert reviewers, some studies have shown that sexual self-esteem is closely related to body image for women in this population (Mona, Gardos, & Brown, 1994; Taleporos & McCabe, 2001). Further research and discussion of this relationship as well as interventions that MHPs can use to help this group could be added to expand the coverage of the educational materials. For instance, current body image interventions, such as Cognitive-Behavioral Therapy, might be useful for people with disabilities, although empirical research would need to validate this possibility.

Additional testing should be conducted in order to further improve, develop, and legitimize the *Sexuality and Physical Disability Educational Materials*. Needs assessments from a broader range of MHP participants could help with efforts to refine the materials or to develop additional modules or specialized trainings for MHPs whose knowledge base is different from those sampled in this study. Furthermore, the effectiveness of the training materials could be assessed using a pre-post design.

This project has attempted to meet the training needs of MHPs based on the field of sexuality and physical disability. Disability-affirmative interventions and the recognition of disability culture should be highlighted to a greater extent in the education of MHPs. Able-ism among therapists should continue to be addressed in order for the
materials to have maximum effectiveness. Since there is a high likelihood that MHPs will
see a client with a physical disability during their career and the data suggest that they
may not be able to strongly endorse disability as a positive part of identity, attitudes may
be a limiting factor in therapist effectiveness. Knowledge alone is not enough and the
process of addressing internalized cultural attitudes should be ongoing. With a better
understanding of the educational needs of MHPs and the effectiveness of developed
materials, the importance of addressing sexuality concerns among clients with physical
disabilities can be better recognized and the unique needs of clients affected by physical
disability can be successfully met.
Sexuality and Physical Disability

Questionnaire

Part 1: Please answer the following questions in as much detail as possible. Use the back of the sheet if you need additional space for your answers.

1. Is there anything particular about sexuality and/or physical disability that you would like to know more about?

2. Please describe your interest level in the topic of sexuality and physical disability and why.

3. How do you think you have gained most of your knowledge regarding sexuality and physical disability?

4. What are a few of the clinical concerns that you would address involving sexuality if you had a client with a physical disability?

5. Please describe some of your own training needs on the topics of sexuality, disability, or the intersection of both.
Part 2: The following items describe different attitudes toward sexuality and/or physical disability. Please read each item carefully and consider how it applies to you. Fill in the blank next to each item by choosing a number from the scale below:

1 = Not likely
2 = Slightly likely
3 = Somewhat likely
4 = Very likely
5  = Extremely likely

1. _____ How likely would you be to attend a Continuing Education class or conference presentation on sexuality and physical disability?

2. _____ How likely do you think it is that you will see a client with a physical disability?

3. _____ How likely is it that you will not be able to adequately meet a client’s needs regarding sexuality and physical disability?

4. _____ How likely do you think it is that people living with disabilities are a part of their own distinct culture?

5. _____ How likely do you think it is that people living with disabilities see their disability in a positive way?

6. _____ How likely are you to see a client’s physical disability as a positive influence on their life?
Part 3: Please rate both your knowledge level and comfort level on the following topics. Fill in both of the blanks on each item by choosing a number from the scale below:

- 1 = Very little or no knowledge or comfort
- 2 = Slight knowledge or comfort
- 3 = Moderate knowledge or comfort
- 4 = Very knowledgeable or comfortable
- 5 = Extremely knowledgeable or comfortable

1. _____ Overall knowledge of human sexuality
   _____ Comfort discussing human sexuality

2. _____ Overall knowledge of individuals with physical disabilities
   _____ Comfort discussing physical disabilities

3. _____ Overall knowledge of how living with a physical disability can affect sexuality
   _____ Comfort discussing how living with a physical disability can affect sexuality
4. _____ Knowledge of couples in which one or both people have a physical disability
   _____ Comfort having discussions with couples in which one or both people have a physical disability

5. _____ Knowledge of families in which one or more people have a physical disability
   _____ Comfort having discussions with families in which one or more people have a physical disability

6. _____ Knowledge of the effect spinal cord injuries can have on sexuality
   _____ Comfort discussing the effect spinal cord injuries can have on sexuality

7. _____ Knowledge of the effect Rheumatoid Arthritis can have on sexuality
   _____ Comfort discussing the effect Rheumatoid Arthritis can have on sexuality

8. _____ Knowledge of the effect blindness can have on sexuality
   _____ Comfort discussing the effect blindness can have on sexuality

9. _____ Knowledge of the effect loss of hearing can have on sexuality
   _____ Comfort discussing the effect loss of hearing can have on sexuality
10. _____ Knowledge of sexuality among adolescents with physical disabilities
   _____ Comfort discussing sexuality among adolescents with physical disabilities

11. _____ Knowledge of sexual abuse of people with physical disabilities
    _____ Comfort discussing sexual abuse of people with physical disabilities

12. _____ Knowledge of sexual functioning of people with physical disabilities
    _____ Comfort discussing the sexual functioning of people with physical disabilities

13. _____ Knowledge of pregnancy for women with physical disabilities
    _____ Comfort discussing pregnancy for women with physical disabilities

14. _____ Knowledge of sexually transmitted diseases among people with physical disabilities
    _____ Comfort discussing sexually transmitted diseases among people with physical disabilities

15. _____ Knowledge of Osteoporosis and its effect on sexuality
    _____ Comfort discussing Osteoporosis and its effect on sexuality
16. _____ Knowledge of birth control for people with physical disabilities
   _____ Comfort discussing birth control for people with physical disabilities

17. _____ Knowledge of health care utilization and people with physical disabilities
   _____ Comfort discussing health care utilization and people with physical disabilities

18. _____ Knowledge of sexual esteem and people with physical disabilities
   _____ Comfort discussing sexual esteem and people with physical disabilities

19. _____ Knowledge of Spastic Syndrome and its effect on sexuality
   _____ Comfort discussing Spastic Syndrome and its effect on sexuality

20. _____ Knowledge of Multiple Sclerosis and its effect on sexuality
    _____ Comfort discussing Multiple Sclerosis and its effects on sexuality

21. _____ Knowledge of muscle diseases and their effects on sexuality
    _____ Comfort discussing muscle diseases and their effects on sexuality

22. _____ Knowledge of amputation and its effect on sexuality
    _____ Comfort discussing amputation and its effect on sexuality
23. _____ Knowledge of post-Polio physical disabilities and their effects on sexuality
   _____ Comfort discussing post-Polio physical disabilities and their effects on sexuality

24. _____ Knowledge of cranial trauma and its effect on sexuality
   _____ Comfort discussing cranial trauma and its effect on sexuality

25. _____ Knowledge of barriers to sexual health for people with physical disabilities
   _____ Comfort discussing barriers to sexual health for people with physical disabilities

26. _____ Knowledge of lifelong versus acquired disabilities and their effects on sexuality
   _____ Comfort discussing lifelong versus acquired disabilities and their effects on sexuality

27. _____ Knowledge of Chronic Fatigue Syndrome and its effect on sexuality
   _____ Comfort discussing Chronic Fatigue Syndrome and its effect on sexuality

28. _____ Knowledge of Cerebral Palsy and its effect on sexuality
   _____ Comfort discussing Cerebral Palsy and its effect on sexuality
29. _____ Knowledge of the effect physical disability has on finding sexual partners
   _____ Comfort discussing the effect physical disability has on finding sexual partners

30. _____ Knowledge of the use of sexual positions for people with physical disabilities
   _____ Comfort discussing the use of sexual positions for people with physical disabilities

31. _____ Knowledge of the use of sexual aids for people with physical disabilities
   _____ Comfort discussing sexual aids for people with physical disabilities

32. _____ Knowledge of bladder and bowel-related sexual problems for people with physical disabilities
   _____ Comfort discussing bladder and bowel-related sexual problems for people with physical disabilities

33. _____ Knowledge of preparations for sexual activity for people with physical disabilities
   _____ Comfort discussing preparations for sexual activity for people with physical disabilities
34. _____ Knowledge of Parkinsonism and its effect on sexuality
    _____ Comfort discussing Parkinsonism and its effect on sexuality

35. _____ Knowledge of female sexuality for women with physical disabilities
    _____ Comfort discussing female sexuality for women with physical disabilities

36. _____ Knowledge of male sexuality for men with physical disabilities
    _____ Comfort discussing male sexuality for men with physical disabilities

4. Is there anything else you’d like to add with regard to sexuality and physical
disability? Feel free to provide comments or feedback on this form and use the back of
the sheet if you need additional space.
APPENDIX B

Original Sexuality and Physical Disability Educational Materials
Disability culture is a term that has been used to describe the shared meanings and experiences related to disabilities.

In 2006, an estimated 20% of all residents in a growing condition, making it the largest minority in the country. Scholars debated for many years whether or not there was a distinct disability culture, given the diversity of individuals with disabilities and the need for more research on the topic.

Some, four common factors have been identified which define the disability culture:
- Identification
- Alienation
- Separation
- Exclusion

These four factors represent symptoms of the disempowerment that people experience when they live with a disability and how they feel their culture is not valued.

The culture of Disability

Cultural Diversity within Disability and Sexuality

A suggested Model of Cultural Diversity within Disability and Sexuality

Ask yourself

- What is my overall knowledge of human sexuality?
- What is my knowledge of individuals living with physical disabilities?
- What is my knowledge of people living with a disability? Can I answer the following questions?
  - What is my knowledge of people living with disabilities?
  - What is my knowledge of people living with disabilities in the community?
  - What is my knowledge of people living with disabilities in their community?

Self test: What is your level of knowledge?

Sexual esteem can be defined as “positive regard for and confidence in an individual’s capacity to experience his or her sexuality in a satisfying and enjoyable way.”

Research shows that people with disabilities experience lower levels of sexual esteem compared to their non-disabled counterparts. However, there is evidence that people with disabilities can and do engage in sexual activity and that they may experience positive sexual experiences.

Physical Disability and Sexual Esteem

Gender may affect the relations among physical disability status, general self-esteem, and sexual esteem. For example:

In their 2006 study, Greenlaw and Ruff conducted a methodological and interview study of persons with disabilities and their experiences within society. Findings include:
- The most common type of disability represented was Motor impairment, which included spinal cord injury, loss of limb, or paralysis in the United States.
- 97% of the sample represented same-sex culture groups in the United States, including women, African-American, and older participants.
- 83% of studies reported the type of disability represented was Motor impairment in the United States.
- 27% of studies reported the type of disability represented was Motor impairment in the world.
- 38% of studies reported the type of disability represented was Motor impairment in the world.
- 36% of studies reported the type of disability represented was Motor impairment in the world.
- 36% of studies reported the type of disability represented was Motor impairment in the world.

Physical Disability and Sexual Esteem

Research shows that people with disabilities experience lower levels of sexual esteem compared to their non-disabled counterparts. However, there is evidence that people with disabilities can and do engage in sexual activity and that they may experience positive sexual experiences.

Physical Disability and Sexual Esteem

Research shows that people with disabilities experience lower levels of sexual esteem compared to their non-disabled counterparts. However, there is evidence that people with disabilities can and do engage in sexual activity and that they may experience positive sexual experiences.
Women with physical disabilities have much sexual desire as men in general, however they have expectations for sexual outcomes.

- Men with disabilities who are able to engage in sexual activity report higher levels of sexual desire than those who are not able to engage in sexual activity.
- Physical disability and female sexuality can be linked to general and reproductive health issues.
- Women with disabilities have been shown to have a lower incidence of sexual activity, sexual expression, and satisfaction when compared to the general population.
- Women’s life experiences and perceptions related to physical disability can be influenced by their individual experiences.
- Women with disabilities face barriers to general and reproductive health care.

(Walter, Novak, & Langston, 2001)

Physical Disability and Female Sexuality

- Women with physical disabilities have a lower incidence of sexual activity, sexual expression, and satisfaction when compared to the general population.
- Physical disability and female sexuality can be linked to general and reproductive health issues.
- Women with disabilities face barriers to general and reproductive health care.

(Walter, Novak, & Langston, 2001)

Physical Disability and Male Sexuality

- Physical disability and male sexuality can be linked to general and reproductive health issues.
- Men with physical disabilities have a lower incidence of sexual activity, sexual expression, and satisfaction when compared to the general population.
- Men’s life experiences and perceptions related to physical disability can be influenced by their individual experiences.

(Walter, Novak, & Langston, 2001)

Physical Disability and Adolescent Sexuality

- Adolescents with physical disabilities may possess negative self-images and may struggle to create friendships and intimate relationships.
- Inadequate information about sexuality and reproductive health issues may contribute to these feelings.
- Physical disability and male sexuality can be linked to general and reproductive health issues.
- Men with physical disabilities have a lower incidence of sexual activity, sexual expression, and satisfaction when compared to the general population.

(Walter, Novak, & Langston, 2001)

Intimacy as a Key Ingredient in Relationships

- Some couples report difficulty in the use of physical intimacy as it relates to the physical process of establishing intimate, physical, and emotional connections.
- Emotional closeness, mutual support, and willingness to take part in a variety of sexual activities have been reported as most important for sexual satisfaction, more so than physical aspects.
- Furthermore, non-disabled partners often report greater difficulty in adjusting cognitively to a disability-related topic than learning to adjust physically to the physical impairment to sexual functioning itself.
- Couples who are able to define and create intimacy without it being a matter of concern or concern, and are able to overcome the physical implications of their sexual dysfunction, are more likely to report higher levels of satisfaction in their relationships.

(Erazma et al., 2001)
Changes in Roles and Expectations

- According to Emsai and colleagues (2001), non-disabled partners should be involved in caring for and educating the disabled individual since they are also highly affected by the disability.
- One thing highlighted in the literature are the issues of “our problem” or, more positively, “our challenge.” This gives the couple permission to examine their own attitudes toward the disability.
- For couples to function at the highest level, both partners must assume responsibility for the disability, seeing it as a joint experience in order to work together.
- Furthermore, both members of the couple must assume responsibility for the challenges inherent in sexual adjustment. This way of assuming mutual responsibility allows the couple to face their challenges through unity and togetherness.

Interventions: Mutual Responsibility

- Emsai et al. (2001)

Interventions: Education and Information

- Also according to Emsai and colleagues (2001), sexual and non-sexual communication are essential to maintaining the relationship and overcoming sexual changes and challenges during a physical disability.
- This can serve as an area of external difficulty for the MHP working in the couple. Partners should be encouraged to discuss their sexual needs and desires honestly, and make sure they discuss the issues that are shared.
- Some of the difficulties that should be included:
  - “Issued of intimacy” such as the couple defines intimacy (p. 274)
  - What should be avoided in the communication of sexual preference
  - How physical disability affects intimacy, both positively and negatively, and how the couple can overcome any challenges

Interventions: Facilitating Communication

- Emsai et al. (2001)

Interventions: Attitudes and Behavior Changes

- An approach that may be helpful for the couple to consider when challenged by a physical disability is the use of orthotic and assistive devices.
- Such devices can aid in positioning, overcoming functional limitations, and enhancing psychological sexual pleasure.
- In addition to external aids, it is very important that MHPs have a list of resources available to clients in the form of literature and competent referrals to local MHPs better trained in counseling couples affected by physical disabilities.

Interventions: Prescription of Aids, Prostheses, and Resources

- Emsai et al. (2001)

Questions and Discussion

- Is there anything particular about sexuality and physical disability that you would like to know more about?
- What are some of your own continued training needs on the topics of sexuality, disability, or the intersection of both?
- Is there anything else you’d like to add with regard to sexuality and physical disability?
- Further questions???
References


APPENDIX C

Sexuality and Physical Disability Training Feedback Questionnaire
Sexuality and Physical Disability

Training Materials

Feedback Questionnaire

Please answer the following questions in as much detail as possible. Type your answers and use as much space as is needed.

1. Do you feel that the educational materials on sexuality and physical disability will increase knowledge of this subject for mental health providers? If so, why? If not, why not?

2. Is there anything additional that you would have liked the materials to have covered? Please list and explain.

3. Overall, how would you describe the quality, correctness, and thoroughness of the educational materials? Please explain.

4. Use the following space for any additional comments, questions, and/or concerns.
APPENDIX D

Final Sexuality and Physical Disability Educational Materials
Expanding the Knowledge of Mental Health Professionals on Sexuality and Physical Disability

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Introduction to Physical Disability and Sexuality Topics

- Introduction and History of the Topic
- The Culture of Disability
- P-LI-SS-IT Model for Sexual Counseling
- Physical Disability and Sexual Experiences
- Physical Disability and Male Sexuality
- Physical Disability and Adolescent Sexuality

Relationship Aspects of Sexuality and Physical Disability

- Pre/Post Disability: Relationships
- Successful Adjustment
- Intimacy as a Key Ingredient
- Changes in Roles and Expectations
  - Mutual Responsibility
  - Education and Information
  - Facilitating Communication
  - Attitude and Behavior Changes
  - Prescription of Aids, Prostheses, Resources, Referrals

Introduction and History of the Topic

- The Sexual Response Cycle identified by Masters and Johnson (1966) provides a basis for diagnosing sexual dysfunctions.
- Three phases identified by Masters and Johnson are: excitement, plateau, orgasm, and resolution.
- However, people living with physical disabilities may not necessarily follow the same four stages of the sexual cycle as their able-bodied counterparts.
- Many people with physical disabilities may feel comfortable with their sexual experiences, despite differences in their own "sexual response cycle" (K.G. Guido, 2003).
- "Traditional models of sexual response provide a gender-focused and performance-oriented conception of sexuality that precludes a conceptual challenge to optimizing sexual potential for people with disabilities" (Topper, 2003, p. 44).

Introduction and History of the Topic

- People with congenital versus acquired physical disabilities may experience different reactions and beliefs about sexuality.
- In one study, "people with congenital physical disabilities experienced low levels of sexual knowledge, held negative feelings about sexuality and experienced high levels of sexual stress," in addition to experiencing "a lower level of sexual experience" (McCabe, Cummans, & Dues, 2000, p. 35).
- Adjustment patterns for people who experience an acquired disability vary. Some adjust quickly, while for others, adjustment may be a life-long task.
- People who acquire a physical disability often compare themselves to their previous sexual experiences and performance abilities (pre-injury), and some estimate that they may be concerned with being sexual in the culturally relevant "normal way" (Topper, 2000).

Introduction and History of the Topic

- People with physical disabilities often experience common, systemic barriers to sexual health (K.G. Guido, 2003). These include:
  - Lack of privacy due to the need for personal assistance or care-giving from others
  - Decreased access to sexual partners
  - Physical or sexual disabilities: based on their different socialization patterns (passivity)
  - Increased vulnerability to HIV/AIDS
  - Presence of risk factors such as drug use in negotiating safe sex, social marginalization resulting in unstable relationships, lack of interventions to promote safe sex, etc.

Introduction and History of the Topic

- Common, systemic barriers to sexual health, continued (K.G. Guido, 2003):
  - Increased vulnerability to sexual exploitation and abuse
  - Due to the need for personal assistance or care-giving, feelings of helplessness, prevention perceptions of people with disabilities, lack of sexual education, physical vulnerability, and so forth.
  - Reduced access to sexual health information and health care resulting in inability to avoid aforementioned issues of sexual health.
Disability from a Cultural Lens of Practice

Cultural Competence Self-Assessment Exercise

Ask yourself:
- What does it mean to me to have a disability?
- How do I feel about it?
- How have I participated in removing barriers?
- How do I feel about it?
- How do I feel about it?
- How do I feel about it?
- How do I feel about it?

These factors represent progress toward understanding individuals with disabilities (p. 199).

(Greenwell & Hues, 2000)

The Culture of Disability

Disability culture is a term that has been used to describe the shared meanings and experiences faced by individuals with disabilities.

In 2006, an estimated 20% of US residents had a disability, making up the largest minority group in the country.

Scholars debated for many years whether or not there was a distinct disability cultural group, given the amount of within-group variation and whether or not there is enough shared experience to unite people with disabilities into their own cultural group.

(Greenwell & Hues, 2000)

The Culture of Disability

Since four common factors have been identified which delineate the disability culture:
- Incapacity against suppression
- Subjugation
- Communication
- Recruit

These factors represent progress for those striving to unify and strengthen the collective voice of individuals with disabilities.

(Greenwell & Hues, 2000)

Cultural Diversity within Disability and Sexuality

In their 2008 study, Greenwell & Hues conducted a methodological and content review of sexuality and disability studies from four journals that focus on the topic. The articles dated from 2002 to 2006, and the purpose was to examine multiculturalism within the culture of disability. Findings include:
- The most common type of disability represented was “multiple impairment” (e.g., spinal cord injury, loss of limb, Central Pain, etc.)
- 17% of the studies indicated a specific cultural group in their title (e.g., women, African-American, etc.)
- 33.3% of studies reported participant age, with a mean around 32% of 37.6 years.

(Greenwell & Hues, 2000)

Cultural Diversity within Disability and Sexuality

- 83.4% of studies reported gender information, with 42% of participants being female and 58% male.
- 30.4% of all studies reported ethnic and/or racial status, and the majority, 15.7% of participants, identified themselves as Caucasian White.
- Approximately half of the studies reported educational level.
- Approximately two out of three studies reported a sexual orientation data, but the authors did not report percentages for LGBT populations or discuss the statistic any further.
- 93.4% of studies reported socioeconomic status of their participants.
- None (out of 34 studies) provided religious affiliation designations.

(Greenwell & Hues, 2000)

Cultural Diversity within Disability and Sexuality

Overall, the data from Greenwell & Hues (2008) suggest that ethnic and racial minorities, among other minority designations, are highly underrepresented in studies on individuals with disabilities.

Disabilities do not impact all demographic groups, including people who identify with other minority designations, but this heterogeneity has not been represented in research samples of participants with disabilities.

There is evidence to suggest that cultural differences, including race, gender, and socioeconomic status, could affect one’s experience as an individual living with a physical disability.

In the future, greater attention to the varied cultural identities of people with disabilities will be valuable in increasing understanding of the needs and concerns of this population.

(Greenwell & Hues, 2000)

The P-LI-SS-IT Model for Sexual Counseling


- Permission: involvement with sexual issues
  - Identify the problem (e.g., sexual dysfunction, communication, relationship issues, etc.)
  - Review the client's concerns and desires
  - Explore the client's sex life in a non-judgmental manner
  - Establish a sexual behavior goal and treatment plan

- Imminent Therapy: (tailored to the client's needs)
  - Identify the problem (e.g., sexual dysfunction, communication, relationship issues, etc.)
  - Develop a treatment plan
  - Implement the treatment plan
  - Evaluate the outcome
  - Adjust the treatment plan as necessary

(Greenwell & Hues, 2000)
Self-test:
What Is Your Level of Knowledge?

Ask yourself:
• What is your overall knowledge of human sexuality?
• What is your knowledge of individuals living with physical disabilities?
• What is your knowledge of how living with a physical disability can affect sexuality?
• What is your knowledge of couples in which one or both partners have a physical disability?
• What is your knowledge of families in which one or more people have a physical disability?
• What is your knowledge of pregnancy, STDs, and sexual abuse of people living with physical disabilities?
• What do you know about the sexual esteem of people living with physical disabilities?
• What is your knowledge of the use of sexual positions, aids, and formulas for people with physical disabilities?

Physical Disability and Sexual Esteem

• Sexual esteem can be defined as “positive regard for and confidence in an individual’s capacity to experience his or her sexuality in a satisfying and enjoyable way” (Talpes & McCube, 2001, p. 131).
• People with disabilities vary on levels of sexual esteem, and mental health professionals (MHPs) should assume that a person with a disability will have low sexual esteem.
• Researchers have found that many people with physical disabilities struggle with social and sexual involvement, increased feelings of negativity about their sexuality are often present.
• Some of these negative effects may include the idea that they are less sexually desirable than a non-disabled person, or the idea that having a physical impairment significantly limits their sexual expression.

Physical Disability and Female Sexuality

Noek et al. (2001) found that women with disabilities had reduced female sexual desire compared to women without disabilities.
• Women with disabilities experience lower levels of sexual activity, sexual arousal, and satisfaction with their sex life.
• Finally, levels of sexual activity were not significantly related to the severity of the woman’s given disability.

Physical Disability and Male Sexuality

• Tepper (1999) states that “boys learn that their maleness is tied to their penis, and the way they use and express it is something they need to do with themselves.”
• They also state that “the fantasy model of sex is... because we don’t have any realistic models or standards in sex, we tend to assume ourselves against these fantasies.”
• For a man with a physical disability, who consequently may have impaired erectile functioning, the realization that he does not match up to the fantasized model of sexuality may be painful.
• MHPs can play an important role in helping men to deconstruct sexual myths, critically evaluate the sexual fantasy model, and then construct a more personally relevant version of male sexuality.
Physical Disability and Male Sexuality

- Potential treatment concerns that men with disabilities may present with (Tropp, 1999).
  - Childlike feelings of dependency
  - Physiological changes in sexual function
  - Inability to express fear and desire
  - Denial, repression, anger, and misinformation around sexual issues
  - The wish not to burden loved ones and/or partners
  - The potential for substance abuse to soften sexual trauma

Physical Disability and Male Sexuality

- Suggested treatment interventions (Tropp, 1999, p. 49).
  - "Help men to unlearn sexual myths - facilitates a critical examination of what men learn about sex and masculinity in our society"
  - "Help men to learn facts about human sexuality that are accurate"
  - "Help men to understand the physiological effects of disability on their sexual functioning"
  - Offer possible "solutions to impaired sexual function" and alternative "options for sexual expression"
  - "Help men to improve their communication skills around sexual issues"

Physical Disability and Adolescent Sexuality

- Adolescents with physical disabilities may possess negative self-views and may struggle to create friendships and intimate relationships (Gordon et al., 2004).
- It has been suggested that, due to limited dating and experience, adolescent with disabilities may rely heavily on media portrayals of romance and relationships - further distorting their views and expectations (Howland & Raina, 2003).
- Adolescents also often know little about the way that their physical disability affects their sexual functioning and whether their disability has genetic or reproductive implications (Gordon et al., 2004).

Physical Disability and Adolescent Sexuality

- Parent of children with physical disabilities may also have little knowledge about their adolescent's sexuality concerns. The process of separation and individuation that naturally occurs during adolescence can become especially difficult (Okin, 1999).
- Adolescents with physical disabilities may also be particularly sensitive to the "myth of bodily perfection" which establishes impossible standards of physical appearance for individuals to accept (Gordon et al., 2000).
- Relationship is an important factor in adolescent sexual identity formation. Parents who have a difficult time supporting age-appropriate activities, such as dating and other peer activities, where social knowledge is gained, may limit their adolescent's ability to develop and learn about sex (De Giuli, 2000).

Pre and Post Disability Relationships

- The frequency of long-term relationships is lower and the rates of divorce are higher among disabled versus non-disabled people. Some estimates of divorce in populations with physical disability are up to 57% (Essmail et al., 2001; Tellegen & McClain, 2003).
- For couples who formed their relationship before a partner acquired a physical disability, the non-disabled partner was more likely to be a caregiver as well and strength and commitment could be seen as well as notable areas of stress and regret" (Creeve, 1993, p. 148).
- Findings indicate that people who form long-term relationships after acquiring a physical disability report greater overall satisfactions in their lives, including their sex lives (Essmail et al., 2001).

Successful Sexual Adjustment

- Many researchers have found that most characteristics associated with successful marriages are the same for couples, regardless of if they are affected by a physical disability or not.
- However, some differences in relationships do appear to exist. Essmail, Esmaill and Mauro (2001) discuss these potential differences and provide suggestions for interventions by MHPs in their article entitled, "Sexuality and disability: The role of health care professionals in providing options and alternatives for couples." The following seven ideas summarize their major points.
Intimacy as a Key Ingredient in Relationships

- Some sexuality research focuses on the physical mechanics of sex during rehabilitation rather than the important process of establishing or regaining intimacy. MDPs should avoid a narrow focus on physicality as the only way to regain closeness.
- Emotional closeness, mutual concern, and willingness to take part in a variety of sexual activities have been reported as most important for sexual satisfaction, more so than physiological aspects.
(Essall et al., 2001)

Intimacy as a Key Ingredient in Relationships

- Furthermore, non-disabled partners often report greater difficulty adjusting cognitively to a disability-related loss in functioning than learning to work around the physical impairment to sexual functioning itself.
- Couples who are able to define and/or redefine intimacy in terms of a “mutually caring and compassionate relationship with shared interests and pleasurable activities” instead of focusing on the physical act of sex may have a greater likelihood of continuing with satisfying sexuality in their relationship (p. 272).
(Essall et al., 2001)

Changes in Roles and Expectations

- Changes that take place after one acquires a disability are not limited to the affected partner. It has been found that the longer a non-disabled person takes on the role of carer for their partner, the harder it is to return to the level of intimacy that the couple experienced pre-disability.
- Gender roles and socialization should be taken into account when analyzing how the couple copes with the disability. Each gender often has different strengths and weaknesses affecting how they adjust to the disability.
- Couples will often need assistance to “clearly outline what self-care activities can be done independently, which activities require assistance from the partner and which require professional help” (p. 272).
(Essall et al., 2001)

Interventions: Mutual Responsibility

- According to Essall and colleagues (2001), non-disabled partners should be involved in caring for and educating the disabled individual since they are also highly affected by the disability.
- One thing MDPs can do is to introduce the issue as “our problem” and work positively, “we face challenges.” This gives the couple permission to maintain their own attitudes toward disability.
- For couples to function at the highest level, both partners must assume responsibility for the disability, seeing it as a joint experience in order to work together.
- Furthermore, both members of the couple must also take responsibility for the challenges inherent in sexual adjustment. This way of assuming mutual responsibility allows the couple to face their challenges openly and together.
(Essall et al., 2001)

Interventions: Education and Information

- Clearly explaining and defining disability can be very helpful. Some studies have found that the more information and awareness the spouse of the person with a physical disability may have, the less negative the impact of the disability was on the relationship (Williams, 1999; Essall, Essall, & Mauro, 2001).
- Essall and colleagues (2001) suggest that education should include (p. 274):
  - Understanding the disability itself
  - Progression and complications
  - Specific information on sexual anatomy, physiology, and function
  - Reproductive concerns such as “amenorrhea, pregnancy and contraception”
  - “Growth and bladder management”

Interventions: Facilitating Communication

- Also according to Essall and colleagues (2001), healthy verbal and non-verbal communication are essential to maintaining the relationship and overcoming sexual changes and challenges due to a physical disability.
- This can also be seen as a major challenge for the MDP living with the couple. Partners should encourage the couple to discuss their sexual needs and fears openly, and a safe environment for discussion should always be maintained.
- Some of these discussions should include:
  - “Issues of intimacy” such as how the couple defines intimacy (p. 274)
  - What might hinder the open communication of sexual experiences
  - How physical disability affects intimacy, both positively and negatively, and how the couple can overcome any challenges
(Essall et al., 2001)

Interventions: Attitudes and Behavior Changes

- As discussed previously, societal myths and attitudes can often create situations that challenge a couple’s ability to satisfy their own sexual needs and desires.
- Using open communication, definitions of sexuality should be explored and broadened for the couple. For instance, Essall and colleagues (2001) suggest defining sexuality as “any activity that is mutually stimulating and pleasurable for the couple” (p. 275).
- Included in the couple’s definition of sexuality, sexual boundaries, rules, and expectations should be discussed and established according to the couple’s subjective comfort levels.
- Once a broader definition of sexuality is established, couples can discuss with their MDP intimate and sexual activities that they might be open to trying.
(Essall et al., 2001)

Interventions: Prescription of Aids, Prostheses, and Resources

- An approach that may be helpful for the couple to consider when challenged by a physical disability is the use of orthotic and assistive devices.
- Such devices can aid in positioning, overcoming functional limitations, and enhancing physiological sexual pleasure.
- In addition to external aids, it is very important that MDPs have a list of resources available to their clients in the form of literature and competent referrals to local MDPs better trained in assisting couples affected by physical disabilities.
(Essall et al., 2001)
Suggested Reading for
Mental Health Professionals


Questions and Discussion

- Is there anything particular about sexuality and/or physical disability that you would like to know more about?
- What are some of your own experiences or observations in this area?
- Is there anything else you'd like to add with regard to sexuality and physical disability?
- Further questions???

References

References


