Basic issues in sexual counseling of persons with physical disabilities*

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As part of the program at the Sex and Disability Unit of the University of California, San Francisco, counseling services have been provided to over 100 individuals and couples over the past 3 years. In addition, 28 disabled and nondisabled persons were trained in year-long programs that included supervised experience in a variety of rehabilitation and habilitation agencies. Based in part on these experiences, we would like to address some basic issues that we regard as significant in providing sexual education and counseling services to persons with physical disabilities, their families, their partners, and in consulting with health care providers.

The process of becoming comfortable with one's own sexuality before working with clients has been previously described in the literature. Working with disabled clients requires the additional step of exploring one's feelings and attitudes about disability, perhaps by seeking out disabled friends of whom to ask questions and share feelings. We consider these steps crucial in the training of sex educators and counselors.

Of equal importance in counseling is providing validation that each of us is a unique sexual being. Although the word "validation" itself may have been over used, we continue to be impressed with the potential for healing when a person's difficult life experiences are shared with and understood by another. We attempt to convey the spirit of the word "validation by emphasizing the importance of listening to our clients and asking them to describe their own experiences and feelings. Listening to a person describe his or her sexual concerns conveys a message of acknowledgment that the person is indeed a sexual being. Reassurance that it is natural and understandable at times to feel anxious about one's sexuality is also validating. This basic skill of providing validation and reassurance can be taught to potential counselors regardless of their level of professional training.

Some health care professionals feel secure talking with a disabled person about sexuality only after having had a thorough medical understanding of that person's disability from reading textbook descriptions of the disability and its ramifications for sexual functioning. Without negating the value of acquiring information about various disabilities or medical conditions as they relate to sexuality, we feel that such reading must be done cautiously, critically, and without generalizing the information to any particular individual. We are each uniquely sexual, and a
physical disability may or may not affect a person's sexuality or may affect it quite differently than the literature would lead one to believe. There is often a tendency to make assumptions about sexual functioning based on textbook or journal information that may discourage a particular person from exploring and experimenting to discover what he or she is able to enjoy sexually. Clearly, diagnosis does not dictate sexual functioning.

Most of the disabled clients we have seen do not ask complicated questions about the physiology of their disability when in sexual counseling. They often know more about their bodies than health professionals do and can answer some of their counselor's questions. In our experience, disabled clients also do not usually inquire about the mechanics of sex, how to's for pleasuring that may leave; the counselor feeling inadequate in his or her imaginative abilities. Usually they do ask for validation of feelings: "Will I ever find someone who will consider me attractive?" or "Is it really possible to be a sexual person if I can't feel my genitals?" Disabled counselors who are skilled in providing validation, reassurance, and encouragement for sexual exploration are often seen by such clients as role models who have dealt positively with such questions in their own lives. In considering sexuality and disability, problems that exist more often reflect attitudinal barriers set up by our culture and accepted by both disabled and nondisabled persons rather than actual physical limitations on sexual functioning. Many health professionals already have the basic skills needed to provide positive assistance to their disabled clients who have sexual concerns. With limited additional information about common myths, attitudes, or unrealistic expectations about sexuality or disability, they can be helpful to clients by listening rather than telling, by encouraging them to explore their sexual and sensual sensations, and by helping them discuss their discoveries. The addition of some simple suggestions, geared to a client's particular situation, is often very effective. These steps of validation, providing information, and offering simple suggestions can be taught in many settings and have widespread usefulness in dealing with a variety of sexual concerns. Knowing when to acknowledge ones limitation regarding information and/or ability to deal with a particular problem and recognizing when to refer to someone with greater expertise are also important.

The following examples of counseling situations highlight some of the previously discussed principles and other issues that we believe to be important. (Although we have changed the names and some of the identifying characteristics of the persons involved, the concepts remain the same.)

One of us and a co-counselor met with a man with an ileostomy who wanted sexual counseling. He was 35 years old and had apparently never spoken to anyone other than his physician about the ostomy. He had been sexual with a couple of women but had never mentioned it to them either; instead, he kept a bandage wrapped around his abdomen during sexual activities. The ostomy
was a secret that made it very difficult for him to relax and enjoy being sexual with a partner.

We guess that most people at one time or another have felt something negative about themselves and sought to keep those feelings a secret from others. It can be a very powerful and positive experience to finally entrust the information and feelings to someone and still be accepted. In this counseling situation the client eventually learned that the co-counselor also had an ileostomy. This enabled him to explore these issues even more openly; talking about his feelings about the ileostomy and having them validated was an important first step in his becoming more comfortable and accepting of himself. Having a co-counselor with a similar condition that was not a secret provided him with a role model, which helped him explore these issues. The counseling certainly didn’t solve all his problems, but it was an important start for him in dealing with his body image and its effect on his sexuality.

Quite frequently, people who have been in some form of counseling or psychotherapy report that sexuality was never really discussed. One young woman with a congenital hip deformity came to our clinic after several years of psychotherapy. She was anxious and felt very uncomfortable talking about her "problem": she hadn’t been able to have intercourse and felt quite badly; in her own eyes she was a failure and believed that it wasn’t possible to be truly sexual without being able to have intercourse. When we spoke with her about other kinds of sexual pleasure, she; reported that she; had experienced and enjoyed manual and oral stimulation and was orgasmic. When we questioned her assumption that only intercourse "qualified" as the "real thing," she began to cry and said that she had never considered otherwise. We spoke with her about women who are able to have intercourse yet aren’t orgasmic, and how they also sometimes feel that they are lacking sexually. Even though our culture stresses that "sex is intercourse" we don’t have to abide by such narrow definitions of sexuality. She returned one more time to report that she felt tremendously relieved that she wasn’t so strange (validation and reassurance) and that her disability didn’t make her so different from other women.

The skills of intensive sex counseling obviously require extensive training. However, in our experience, simple suggestions can also have a positive impact on people; with sexual concerns, for example, in the following situation.

A couple that we saw reported that they had not had intercourse for 10 years since the man had had a surgical procedure for cancer. The woman had had a physical disability since birth, and they described having an active and enjoyable sex life with frequent intercourse prior to the man’s surgery. When the couple consulted the physician involved regarding the man’s lack of erections following the treatment for cancer, the reply was, "Well, you should just be grateful you’re alive."
That was the only time the couple had discussed their concern with a professional person. Now at our clinic they were understandably hesitant to discuss their worry. Obviously at ease with each other, they described their relationship as "good in every way" except for their frustration about sex. Even that was not a major concern because they had adjusted to limiting their relationship. When asked why they had decided to come for counseling at this particular time, the man described having attended a workshop on sexuality and disability in which one of our former trainees had given a talk (role modeling). The positive messages they heard in that workshop—that there are many ways to enjoy being sexual—prompted them to come and explore further their own possibilities. After listening to the man talk about and then discount his morning erections, we suggested that they go home and try some exercises such as taking a bath together, and that they not attempt intercourse for the next week, even if he happened to get an erection. Three days later, we received a telephone call from the couple reporting their successful attempt at intercourse: "Guess what? We ignored your orders, and it was great!"

Another couple who had congenital physical disabilities complained in counseling that they had one position for sexual intercourse that worked well for them but that it wasn't the right position. We asked, "What do you mean, not the right one?" They then described a position in which the man had entry from behind the woman; for physical reasons, it wasn't convenient or comfortable for them to have the man on top. We told them that many couples come in for counseling to explore how to have other positions because they were tired of the classical man on top one; we also mentioned that it sounded as if they had an enjoyable way to pleasure each other with intercourse that worked well for them (validation). They looked at each other and said, "You mean, that's an O.K. way to do it?" Our response was that many people thought that the way this couple had intercourse was a great position!

Since they had come a long distance, we asked if there were other issues they wanted to discuss. For example, as sex counselors, we often find that people who have concerns about sex eventually stop touching each other—whether sexually or nonsexually. They replied, however, that they had been trying to get married for several years, and now that they finally were married, no one could keep them apart! They were certainly right about that; in our office they had shown that they enjoyed touching and cuddling, so that certainly wasn't a problem area for them.

They then told us that they had only been married 3 months. We let lliim know that many people take a lot longer than 3 months to get used to each other sexually (validation and reassurance). That was news to them, and they felt better after hearing that. One concern did appear briefly when the woman said that she knew more than her husband about sex and had to teach him. Before we could validate anything, he supported himself by saying: "Look, I didn't have
the opportunity to go out on dates in high school and to have other social experiences because I was out earning money to be able to live independently. It's taken me awhile but I'm a good learner now at the age of 30! " We asked her if it was really so bad, "teaching" him about her sexual likes and dislikes. She giggled that, in a way, she really enjoyed it. Later, feedback from the person who had referred lliein to us from their home community—where they hadn't talked to anyone about the specifics of their concerns—was as follows: "You know, they came back and we asked them how the counseling session went and they said, 'Well, we met two really nice people, but you know, we know as much about sex as they do! We think that letting people be their own sex experts is another key issue. None of us can be experts about anyone's sexuality but our own, but we can help people develop a better sense of what they want and like.

We want to assure you that we do not always have success stories. Sometimes a client's situation appears impossible. One client who was living in a board and care facility wanted to become sexually active. She spent her lime in counseling being frustrated and angry. In her view, to even choose her own clothes was a threat to the people who were managing the facility. She had been institutionalized for several years prior to board and care home placement and was afraid to risk being sent back to such a setting if she became sexually active. Solutions for her were not easy to come by.

In conclusion, we would like to oiler the following observations:

1. Validation, reassurance, provision of information, and ollering of simple suggestions are useful approaches in counseling disabled clients with sexual concerns.

2. The sexual problems that exist for disabled clients are more often related to culturally established attitudinal barriers rather than physical limitations.

3. Although there is much we have yet to discover about sexuality and disability, we can be of real service to clients by encouraging them to fully explore their sexual and sensual potential. The mind is one's greatest erogenous zone, and sexual pleasure is restricted only by the imagination.

4. Many disabled clients continue to struggle with complex issues of sexual freedom as experienced in institutions such as hospitals, board and care facilities, and nursing homes. We need to devote a great deal more attention to these neglected areas.

REFERENCE
RECOMMENDED READINGS

