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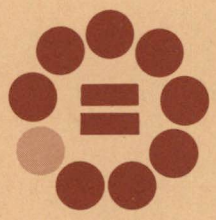
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WHO CARES?

A Handbook on Sex Education and Counseling Services for Disabled People



Sex & Disability Project
George Washington University

WHO CARES?

A Handbook on Sex Education and Counseling Services for Disabled People

By the Sex & Disability Project*

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Preface

The Sex and Disability Project, located at George Washington University, Washington, D.C., was awarded a one-year grant for the period September 1977-1978, by the Rehabilitation Services Adminstration, Department of Health, Education, and Welfare.

The major goals of the project have been: 1) to identify the needs of disabled persons for sex education/counseling services, 2) to examine the capabilities of existing sex education/counseling formats to meet these needs, 3) to identify discrepancies between services needed and those currently provided, 4) to suggest means by which these gaps can be filled, and 5) to disseminate this information to persons desiring these services and to persons capable of providing these services.

In order to achieve these objectives, our research has focused on the following populations: disabled individuals, rehabilitation counselors and other community service providers, trainers, and policy makers. For the sake of simplicity, we frequently use the term "clients" or "consumers" to indicate all disabled individuals who are potential recipients of sexuality-related services (e.g., people within residential facilities, patients in a medical setting, members of organizations for disabled people, and disabled persons seeking services within the community). We also occasionally use the term "counselors" to refer to all potential service providers (e.g., medical personnel, teachers, parents, peers, therapists, and clergy).

An extensive literature search has yielded considerable information on formats for the provision of sex education/counseling services and the training needs of potential providers. In addition, the needs of disabled people in general and within specific disability groups have been suggested by the literature.

The Sex & Disability Project staff also conducted anonymous surveys of possible recipients and providers of sex education/counseling services. These survey results indicated the needs of disabled people for specific services and the needs of potential providers for training and support in order to provide these services. In addition, valuable insight was gained into the willingness of both recipients and potential providers to participate in sex education/counseling. These surveys were designed to gather information, rather than to be part of a carefully controlled study. Therefore, the survey results suggest possible trends and attitudes, and support information gained from more scientifically valid sources.

The end result of this research is this handbook which presents a careful compilation of available information on the needs for and the provision of sex education/counseling services. We have also included recommendations, based on our research, for greater availability and increased applicability of these services to the particular needs of individuals who happen to be disabled.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Office of Human Development Services
Rehabilitation Services Administration
WASHINGTON, D.C. 20201

January 1979

To Members of the Rehabilitation Community:

The rehabilitation community has traditionally sought ways to meet the various needs of its clients. The comprehensive approach used includes addressing both the physical restoration and psychosocial services necessary to rehabilitate an individual. The inclusion of sexual adjustment counseling services in the past, however, has been at best uneven in its availability to disabled persons. The lack of, and need for, a body of knowledge and primer for rehabilitation professionals to use, was vividly brought to my attention during a visit to a comprehensive rehabilitation center. When I asked the chief rehabilitation counselor what procedure the center had for providing counseling on sexual matters, he replied, "If the counselor feels uncomfortable with the subject, he refers the client to the chaplain." In a subsequent RSA research planning conference with rehabilitation researchers, practitioners, and consumers, the participants identified the need to focus on this area as a priority.

In the fall of 1977, following national solicitation and competition, RSA awarded a grant to the George Washington University Sex & Disability Project (under the auspices of the Regional Rehabilitation Research Institute) to conduct research that would identify disabled client needs regarding sexual adjustment counseling, point out existing services, and develop models of sexual adjustment counseling services which could be used in a variety of rehabilitation settings. The project has been completed and the final report is this handbook which can be used by rehabilitation service providers, policy makers, trainers, and consumers. The handbook was not intended to answer all the questions, nor solve all the problems in the field of sexuality and disability. It does, however, bring together in an easy to follow sequence, the "how to" of developing elements of a sexual adjustment counseling program.

I believe many rehabilitation professionals will find it of value in developing programs on the subject.

Mark E Shoob

Mark E. Shoob
Project Officer
Rehabilitation Services Administration

HOW TO USE THIS HANDBOOK

This handbook is organized into sections, providing you with foundation information first, more specific information for particular populations next, and finally supplemental material and resource listings. Section I: *Sexuality & Disability* is the foundation of the handbook and should be read first. It provides you with the current state of the art and research results.

Sections II through V assume that you are familiar with the information presented in Section I. They provide more specialized information which applies to disabled consumers, counselors and other service providers, trainers, and policy makers. Included in these sections are discussions of specific issues which are relevant to the above populations.

Appendices A through H provide you with resource listings, survey reports, bibliographies, and other supplemental material. These sections are intended to be used as reference guides to additional information in the area of sexuality and disability.

Chapter 1

Myths, Attitudes & Rights

DEFINITIONS

Sexuality. Ask ten people what this word means, and you will probably receive ten very different responses. Answers may include:

- a method of procreation
- a way to reduce tension
- a form of communication and merging in which tenderness, mutual concern, love, and affection are expressed
- activity of autonomic muscles culminating in orgasm
- gender identity
- a means to control and manipulate another person
- a form of recreation
- a way to bolster one's ego
- a spiritual union
- an integral part of one's personality affecting all aspects of one's life; the expression of one's maleness or femaleness.

In order to clarify issues related to sexuality, it is essential to differentiate among the many meanings associated with the term. Often "sexual intercourse," "sex act," and "sex" are used synonymously with "sexuality." Sexuality, however, encompasses a great deal more than the physical aspects of sexual expression. For the purposes of this handbook, **sexuality can be defined as the integration of physical, emotional, intellectual, and social aspects of an individual's personality which express maleness or femaleness**.

People do not express their maleness or femaleness only in the bedroom. Sexuality is a part of all the activities in which a person engages: work, socialization, decoration of one's home, telephone conversations, political discussions, expressions of affection, arguments, eating a meal, child rearing, walking down a street, watching a movie, etc. Sexuality, then, is an expression of one's personality and is evident in everyday interactions.

Mention of disability can also give rise to ambivalent and uncomfortable reactions. Negative stereotypes of disabled persons abound, and there is often a tendency to emphasize the differences rather than the similarities existing between disabled and nondisabled people. The greatest handicap is not the disability itself, but rather, the negative attitudes and behavior directed toward a disabled person.

> Society creates handicaps. While most disabilities are products of birth and accident, the debilitating impact on a person's life often results not so

> much from the "disability" as from the manner in which others define or treat the person. (Gordon, 1974)

A combination of the topics of sexuality and disability can be anxiety-producing. Because of misconceptions and discomfort, the sexual concerns of disabled individuals may be avoided, ignored, actively discouraged, or distorted.

MYTHS ABOUT SEXUALITY AND DISABILITY

Myths concerning sexuality and disability can drastically and unnecessarily curtail the sexual expression of disabled people. Other areas of a person's life can also be affected negatively; these include self-concept, vocational performance, and motivation to live as independently as possible. Some common myths are examined below:

■ MYTH: Disabled people are asexual.

This misconception usually stems from the belief that if a person is disabled in one way, he or she is disabled in all ways. For instance, because a person is unable to see, it is assumed—according to this myth—that he or she lacks sexual interest and capability as well. In essence, the disabled person is regarded as a neuter who does not have the same needs, desires, and capabilities as the nondisabled individual.

■ MYTH: Disabled people are over-sexed and have uncontrollable urges.

Although this myth appears to be in direct contradiction to the first one, they are sometimes mentioned together as reasons *not* to provide sex education for disabled people. Mentally retarded adolescents, for example, may be treated by the staff of a residential institution as though they have no sexual needs at all ("They don't know the difference"). At the same time, this same staff may resist efforts to incorporate sex education in the program because they believe it would result in wild, promiscuous behavior. Winifred Kempton (1977) states that there is a:

> ...conviction in most people that unless sexuality of the retarded youth is rigidly repressed, the girls will be prolific in the production of unwanted children, and the sexual impulses of the boys will emerge in uncontrollable spurts of violence.

Comparison of various approaches, however, reveals that irresponsible or inappropriate behavior results from segregation of the sexes, isolation, ineffective sex education, and ignorance about sexuality. Experiences in Scandinavia support the view that the more accurate information and social skills training disabled people receive, the more likely that their sexual behavior will approximate the cultural norm.

■ MYTH: Disabled people are dependent and child-like, and, thus, need to be protected.

The Eternal Child myth is especially insidious because the people who view themselves as "protectors" and "guardians" believe that they are acting in the best interest of their "charges." On a deeper level, however, the desire to keep disabled persons in a child-like role suggests feelings of fear on the part of nondisabled individuals. This fear may stem from insecurities about one's own sexuality, negative attitudes toward disability, or a combination of both. Viewing disabled people from a paternalistic (protector) stance, the believer of this "Peter Pan" myth can avoid confronting his or her own fears. Unfortunately, however, many disabled individuals are prevented from exploring their own sexuality because of this denial and avoidance. Not only is sexual expression curtailed, but the disabled person may also be regarded as incapable of forming an intimate relationship which may lead to marriage and child rearing. The child-like myth is perhaps most obvious with individuals who are mentally retarded: at age 30, for instance, they may still be referred to as "kids" by staff members of sheltered workshops. Persons with other disabilities, however, also experience this paternalistic attitude. Dependency and helplessness are often encouraged—not only by family members, acquaintances, and society in general—but also by rehabilitation and medical professionals.

■ MYTH: Disability breeds disability.

This myth stems from a movement in the early part of the century which envisioned a scenario of "defectives" outbreeding "normals." As a result of this belief, drastic measures were taken to prevent child-bearing by disabled persons. Segregation of the sexes was common; involuntary sterilization occurred.

Medical research indicates that some disabilities can be inherited; other findings are still unclear. Current advances in genetic research, however, have resulted in more accurate predictions of genetically-linked disabilities. Many disabilities, however, are not related to heredity at all. A spinal cord injured woman, for example, has no greater chance of producing a disabled child than a nondisabled woman.

■ MYTH: Disabled people should stay with and marry their own kind.

This myth emphasizes the differences rather than the similarities between disabled and nondisabled people. Forced segregation of disabled children from their nondisabled peers, for instance, creates an artificial barrier which makes both groups uncomfortable and hesitant to interact. As a result, handicapped children may grow up experiencing satisfying peer relationships only with other disabled children. Similarly, nondisabled children may never experience informal contact with their disabled peers.

As adults, these two groups may have difficulty relating to each other because of their early socialization experiences. Due to this unfamiliarity and discomfort, personal contact between the two groups may be avoided. This situation, however, is based on fear and anxiety, and unnecessarily limits relationship possibilities for both disabled and nondisabled people.

The implication of this myth is that a handicapped person's most important characteristic is his or her disability. Yet people form relationships on the basis of shared interests, personality traits, feelings, empathy, etc. The presence or absence of a disability does not determine a relationship. Two people who both happen to be deaf may have nothing in common; their mutual lack of hearing is not the basis of a relationship any more than a shared trait such as tallness. However, two people who both love literature, New York City, and Chinese restaurants have the basis for at least a casual friendship; the fact that one of them is in a wheelchair does not alter the satisfactions gained from sharing their common interests.

■ MYTH: Parents of handicapped children don't want sex education for their children.

Some parents do, in fact, disapprove of sex education. However, this applies to parents of both disabled *and* nondisabled children. Many parents welcome sex education for their disabled children. Sol Gordon (1974), in his pamphlet, "Sexual Rights for the People...Who Happen to be Handicapped," notes that,

> ...it has been our experience that parents are among the first to demand knowledge about how information on sexuality can be imparted to their sons and daughters.

Lack of information about how their child's disability affects sexuality may cause parents to shy away from the subject. Often, however, these same parents respond very favorably to sex education which alleviates this confusion. In fact, parent groups have frequently been the first to advocate for adequate sex education for their children.

■ MYTH: Sexual intercourse culminating in orgasm is essential for sexual satisfaction.

This myth has plagued not only persons with disabilities, but nondisabled people as well. The emphasis on penile-vaginal contact, traditional positions, and achievement of orgasms has substantially limited the sexual potential of many persons. Believers of this myth spend a great deal of time and energy worrying about their "ratings": "Did I *perform* well?" "How well?" "Did I have enough orgasms?" "What's wrong with me?" etc. Instead of enjoying the many varieties of sexual expression and allowing themselves to move with the flow, these people narrowly define "acceptable" sex, and rarely explore other options. When a person with this attitude encounters an individual who, due to a disability such as spinal cord injury or arthritis, is unable to "perform" according to the rules, the conclusion drawn is that the disabled person cannot possibly have a satisfying sex life. This limiting attitude can be so strong that disabled people themselves might also believe it. As a result, exploration and experimentation are stymied.

Sexual expression encompasses a wide variety of activities and feelings. There is no one way to "do it." There need not be any arbitrary standards of measurement. Sexual expression includes: kissing, hugging, flirting, caressing, mutual masturbation, oral-genital sex, anal stimulation, body massage, etc. Once the pressure to "measure up" sexually disappears, people—disabled and nondisabled—are free to explore and enjoy their sexual experiences.

■ MYTH: If a disabled person has a sexual problem, it is almost always the result of the disability.

The presence of a disability does not automatically indicate that a sexual dysfunction is disability-linked. Sexual difficulties occur in both disabled and nondisabled people. Although a sexual problem or concern *may* be related to a disabling condition, it frequently has other causes. These causes are usually the same ones that appear in the nondisabled population.

Many of the sexual problems confronted by disabled individuals are related less to actual impairment than they are to the negative and stereotyping attitudes of other people. Increased socialization opportunities and appropriate sex education would greatly alleviate these particular areas of concern.

■ MYTH: If a nondisabled person has a sexual relationship with a disabled individual, it's because (s)he can't attract anyone else.

As with the other myths, this one assumes that disabled individuals are somehow inferior and devalued in comparison to "normals." The implication here is that inferior status is contagious. If a nondisabled person associates intimately with a disabled person, it is interpreted as an indication of failure. People believing this myth cannot fathom why a "normal" person would *choose* to have a relationship with an individual who has a disability. This myth can be summed up as "devaluation by association."

REACTIONS TO THE SEXUALITY OF DISABLED PEOPLE

The reactions of nondisabled people to the sexual concerns of disabled individuals vary widely. The presence or absence of fear and/or ignorance determines these reactions.

1. *Disbelief:* "But he isn't interested in sex. He's blind." This statement reflects a complete inability to see the disabled person as a sexual being. The disability is viewed as the predominant characteristic.

2. *Revulsion/Disgust:* "Ugh! That's perverted." Disability is seen as a perversion of the "normal"; sexuality may also be considered "dirty." A disabled person engaging in sexual activity is viewed as doubly disgusting.

3. *Active Suppression:* "We don't allow that kind of thing here." Methods of actively suppressing sexual behavior and discussion include: segregation of sexes in residential institutions; punishment for being "caught" holding hands, kissing, engaging in sexual intercourse; allowing no privacy in bedrooms and/or bathrooms, etc. Suppressing masturbatory activity is often viewed as an important goal.

4. *Avoidance:* There are several different manifestations of this response. Some examples are:

a) "If we don't talk about it, maybe nothing will ever happen." This approach usually accompanies the Eternal Child myth. Staff members of residential institutions, parents, and rehabilitation/medical professionals sometimes try to deceive themselves and others into believing that sexuality will remain latent as long as the topic is not mentioned. Needless to say, this approach has met with almost complete failure. Results of this avoidance tactic may include: confusion, irresponsible behavior, unwanted pregnancy, unhappiness, venereal disease, and sexual exploitation.

b) "It's not my job." Many medical and rehabilitation professionals flock to this banner. The usual rationale given for this response is that sexuality is not related to "rehabilitation goals." Although much time, energy, and money is spent strengthening muscles, fitting a prosthesis, or providing vocational training, sexual concerns are ignored. This narrow view of rehabilitation promotes increased compartmentalization, confusion, and unnecessary

suffering on the part of the disabled person. One aspect of one's life can affect many other aspects; there are no clearly defined boundaries. The main problem with this avoidance response is that all professionals providing services to a disabled person may consider sexuality as "not their job." As a result, the disabled person may be referred to many professionals, but still receive no services in this area.

c) "It's private." Although sexual expression is private, the subject itself is not. Topics such as bladder control and dressing are also private activities, but are considered appropriate to discuss in a rehabilitation or medical setting. This response reflects an unwillingness to discuss the subject of sexuality. This reluctance may stem from the service provider's discomfort rather than concerns for a client's privacy.

5. *Resigned Tolerance:* "We don't really like it, but there's not much we can do." This response often masks a negative attitude toward the expression of sexuality by disabled persons. Although there are no active attempts to eliminate sexual behavior, the underlying message is that sexual expression is not considered socially acceptable for disabled individuals. Resigned tolerance, however, does allow sexual activity to some extent.

6. *Acceptance:* "It's OK." Those who respond with acceptance to the sexuality of disabled people usually perceive the similarities between the disabled and nondisabled populations as being greater than the differences. If sexual expression is considered "normal" and natural for nondisabled individuals, the same holds true for persons with disabilities. Acceptance implies a positive attitude, as contrasted with resigned tolerance which may connote a negative attitude.

7. *Active Encouragement:* "It's OK, and we need to make it better." The person who has an active encouragement response not only accepts the sexuality of disabled persons, but also seeks to enhance sexual expression and fulfillment through direct intervention. Examples of intervention include: setting up a sex education curriculum, providing opportunities for socialization with the opposite sex, referring a disabled client/patient to a Planned Parenthood within the community, providing contraceptives to interested disabled adolescents and adults, showing a film concerned with sexuality, suggesting sexual options, etc.

In evaluating the responses of people and organizations, it is important to differentiate among: attitudes toward sexuality in general, attitudes toward disability in general, and attitudes toward disability *and* sexuality. It is possible, for example, for a person to regard sexual expression by anyone—disabled or nondisabled—as something to be tolerated, but not really accepted or encouraged. Another individual may believe that disabled persons are handicapped in every way, and may simply consider sexuality inappropriate along with work, independent living, and participation in community activities. In order to change negative attitudes into positive ones, it is essential to identify clearly the basis of those attitudes.



RIGHTS AND RESPONSIBILITIES

The basic sexual rights and responsibilities of disabled people are identical to those of all people. In keeping with the United Nations Declaration of Human Rights, every citizen has the same basic rights as every other citizen of the same country and age. No person can be denied a right because of a perceived difference, e.g., race, sex, economic class, presence of a disability, political opinion, etc. This basic concept is still not a reality for all members of our society. Yet, in order to consider ourselves truly just and civilized, we must strive toward this goal.

All people, including disabled people, have the following sexual rights and responsibilities:

1. **The right to sexual expression**. Sol Gordon (1972) sums up this right:

> ...sexual behavior among consenting adults, regardless of mental age and whether it is homosexuality or heterosexuality, should be nobody elses *[sic]* business, providing there is little risk of bringing an unwanted child into this world.

No one has the right to limit the sexual expression of another person unless coercion, sexual use of children, or the high probability of an unwanted child (unwanted by the individual, not by society) are involved. The right to sexual expression includes the opportunity to experiment and discover what is sexually satisfying, e.g., masturbation, use of sex aids, various positions, etc.

2. **The right to privacy**. The privacy issue is not confined to the sexual realm. All people need privacy in their daily lives, yet disabled individuals are not always accorded the same rights that nondisabled people often take for granted. Privacy during activities such as going to the bathroom, undressing, having sex, and simply being alone may be difficult to arrange. Individuals living in institutions, for instance, may sleep in dormitories with no adequate partitions, go to the bathroom on toilets that are in the open, and socialize under the watchful eyes of the staff. In order to engage in sexual activities with some degree of privacy, disabled people living under such circumstances may find it necessary to resort to the bushes and broom closets.

Lack of privacy can also be a problem outside of the institutional environment. Overprotective parents of a disabled adolescent, for instance, may not realize that, although their child is handicapped, he or she is also approaching adulthood and needs more privacy. The common tendency to treat a disabled teenager or adult like a dependent child limits the individual's opportunity for growth. As a result, all areas of life suffer, including sexuality.

The key in terms of privacy and other issues is: Would you want to live under these conditions? If the answer is "no," then why should other people be forced to live this way?

3. **The right to be informed**. All people need the opportunity to talk and learn about matters related to sexuality. Accurate information is essential for the healthy development of one's sexuality; the opportunity to put this information into practice is also important. The lack of social skills (e.g., how to start a conversation with another person) has frequently been cited as creating difficulties for disabled adolescents and adults. They know what to do *when* they get there, but they don't know *how* to get there.

A knowledge of social norms, i.e., what is generally considered socially acceptable, is also necessary to enhance sexual development. Although an individual may *choose* a sexual option which is not culturally typical, he or she should at least be aware of the current social norms.

4. **Access to needed services**. Although special services may sometimes be appropriate, disabled individuals should also have access to services used by the general community whenever possible. This normalized approach to services may require modifications by the service organizations such as building a ramp, providing an interpreter, etc.

Easy access to sexuality-related services is a right of all individuals. Examples of such services are:

- contraceptive counseling
- medical care (e.g., examination by a gynecologist)
- genetic counseling
- legal aid (related to matters such as competence to handle own affairs, marriage laws, etc.)

5. **The right to choose marital status**. Arbitrary restriction of marriages involving disabled persons is a violation of human rights. No one has the right to decide for other adults whether or not they will be permitted to marry. Many nondisabled people lack the maturity and commitment to make a marriage work; these people, however, are not prevented from getting married. Yet some disabled people have encountered resistance to their plans for marriage strictly on the basis of their disability. This form of discrimination is most often experienced by individuals with severe physical impairments or mental retardation. Disabled people are generally the best judges of their own limitations *and* capabilities. Although some counseling and training may be necessary so that marital responsibilities are clearly understood, the final decision must rest with the couple.

People also have the right *not* to marry. Children and adolescents should not be conditioned to believe that marriage is the only acceptable option available. Some people do not want to marry, and should not be made to feel "abnormal."

6. **The right to have or not have children**. In our society, the decision to have or not have children is made by the potential parents. Disabled people are also entitled to this right. Information regarding genetic factors should be readily available to all people to determine the possibilities of passing on a genetic characteristic.

Realistic assessment of one's limitations and capabilities is an essential component in making a responsible decision regarding parenthood. Modifications and supportive services may need to be considered, e.g., an attendant to help a person with limited use of their hands take care of a newborn infant.

Information about the responsibilities, as well as the joys, of childbirth and childrearing may need to be communicated. A mentally retarded young woman, for example, may not realize all the responsibilities involved in caring for a child. Education and training should be available so that the decision whether or not to have a child is based on a realistic foundation.

As with marriage, no person should be conditioned to believe that being a mother or father is equated with maturity and adulthood. If an individual does not wish to be a parent, that is his or her choice.

7. **The right to make decisions which affect one's life**. Feelings of helplessness, resulting from a lack of control over one's life, can have devastating effects on one's self-esteem, attitudes toward others, and behavior. Overprotection, although it may be motivated by the best intentions, unnecessarily limits the disabled person's potential for achieving independence. Learning to cope with problems and make decisions involves an element of risk. Risk, however, is an integral part of life. To deprive the disabled person of choice and risk is to condemn him or her to permanent childhood. Making a mistake may cause temporary unhappiness; being treated as a dependent non-person often results in lifelong isolation, confusion, frustration, and boredom. With appropriate education, training, and experience, all disabled people can have at least some significant level of control over their own lives. This level is almost always higher than the evaluation made by nondisabled "caretakers."

The right to make decisions implies the right to choose one's own values concerning sexuality. These choices should be based on a realistic assessment of one's situation, the social and legal norms, and individual preferences. No one has the right to make these decisions for another adult.

8. **The right to develop to one's fullest potential**. Growth and increased independence in one area of life affects other areas as well. By receiving education and encouragement aimed at enhancing his or her sexual potential, a disabled individual achieves greater self-esteem, confidence, and independence. These changes may then influence the individual's perception of and motivation for other aspects of life, such as work, recreation, and community involvement. Rehabilitation, if it is to be truly meaningful, must address *all* aspects of a disabled person's life. Attempts to compartmentalize these aspects into narrow slots will only serve to undermine the rehabilitation process.

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Chapter 2

The Need for Sexuality Services

Sex education/counseling services need to be available to all persons. A recent survey by the Committee on Sexual Problems of the Disabled (S.P.O.D., 1975) states that between 20% and 40% of the general population presently experiences sexual problems. Furthermore, Masters and Johnson (1970) report that sexual problems occur in approximately 50% of the married population.

Among disabled persons, the percentage is even higher, since these individuals may experience disability-related sexual problems in addition to the non-disability-related problems of the general population. A recent British survey (S.P.O.D., 1975) has supported this fact. More than half of the disabled persons surveyed responded that they were presently encountering problems of a sexual nature. Ninety percent of all respondents in the same survey indicated that a formal program providing sexual advice and counseling is desirable; and 85% further indicated that they would actually use (or would have used at one time) such a service.

The Sex and Disability Project survey (1978) produced similar results. More than 90% of all respondents indicated that they would actually use at least one of the 12 sex education/counseling services listed on the survey form. Furthermore, each respondent checked an average of 4.4 services of those suggested, which indicates not only a desire for services, but an interest in a wide range of services as well.

A definition of sexuality which includes physical, psychological, emotional, and social elements prepares us to consider a broad range of services that support and maintain sexual well-being. These service options are not all-inclusive; there are other ways that sex education/counseling services can be offered.

The Sex and Disability Project survey of disabled consumers researched these specific options. Disabled individuals were asked which of these services they had received in the past, and which they would actually utilize. The results of this questioning are presented in Table A, which vividly demonstrates the large discrepancy between services received and those requested. A more detailed analysis of these findings is given in Appendix A.

All of the services listed below may be useful to any individual at some point in his or her life. It is possible, however, to generalize somewhat and identify those services which may prove to be particularly useful in certain situations. For example, individuals within one disability group may find one approach especially beneficial to their needs. Similarly, factors related to the disability, such as age at onset of disability and length of time disabled, may prove to be significant in determining which of the services is most needed.

It is important, however, to remember that we are generalizing. The particular needs and goals of each individual, regardless of his or her specific disability or the factors related to that disability, are the only criteria which should be used in the selection of appropriate sex education/counseling services.

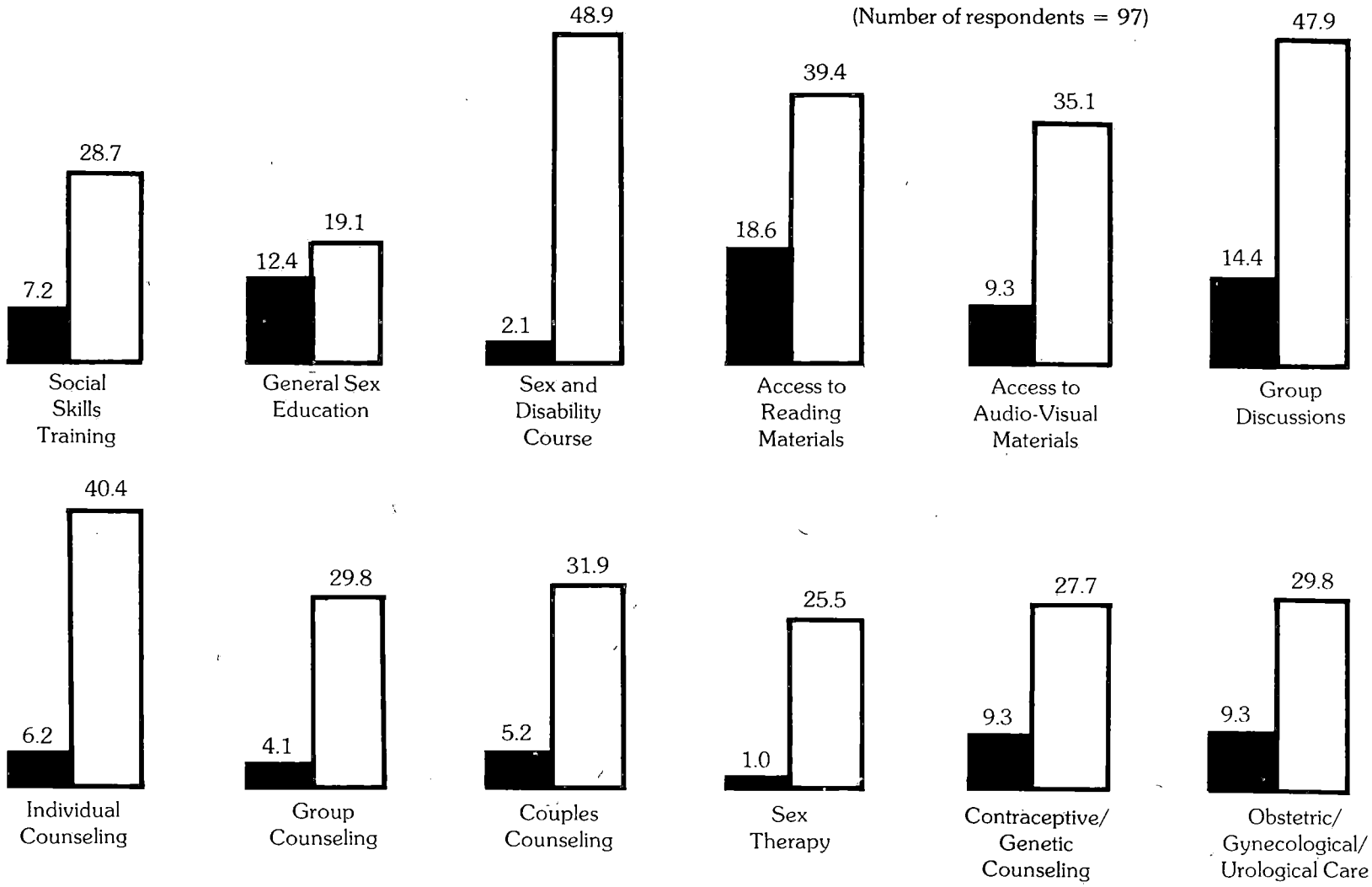
SOCIAL SKILLS TRAINING

In order for a person to become successfully integrated into society, he or she must learn society's standards for behavior. These norms and customs are generally learned during childhood and adolescence through the person's day-to-day interaction with others. Social skills range from basic competencies such as the correct use of polite phrases ("please," "thank you") to more complex abilities such as expressing anger appropriately. Development of these competencies can be useful in almost all areas of a person's life. Establishing and maintaining close relationships depend upon social skills. The ability to conduct oneself appropriately during a job interview is also a reflection of one's social competencies. Training in social skills needs to be specific and practical, and the opportunity to rehearse newly acquired skills is vital.

TABLE A

COMPARISON OF SERVICES RECEIVED AND REQUESTED

(Number of respondents = 97)



Social skills are usually learned and practiced informally as a person matures. Children, for example, naturally try to imitate adult behaviors (e.g., talking on the telephone, playing house, trying on adult clothes, and pretending to go to work). In adolescence, these skills become more complex and include a new interest in romantic relationships: asking for a date, dancing, putting on make-up, planning a party, and discussing sexuality with a friend.

Frequently, a disabled child is denied this important informal social skills training. Because of parental overprotection, the child may be discouraged from participating in ordinary interaction with others. Thus, the child will learn only those social skills expected by his or her immediate family. The child may adopt the attitudes of an older generation, which may cause later problems when interacting with peers. Or, the family may be overly permissive, allowing the disabled child to get away with things that may not be socially acceptable outside the family circle.

In addition, persons disabled from childhood may lack competence in certain social skills simply because they lack socialization experience. For example, disabled children who spend much of their childhood and adolescence in residential schools may also be socially isolated. Although they may spend a great deal of time with peers, interactions with these peers may be severely restricted. Many residential schools, for example, still practice strict segregation of the sexes. In addition, the residential setting may not be "normalized." The child may have little contact with the outside world—nondisabled peers, current attitudes and customs, usual day-to-day social interaction. He or she may need specific instruction in areas such as: introducing himself or herself to a stranger, maintaining small talk, expressing interest in the other person, learning to express and interpret nonverbal cues, and judging when sexual advances and/or responses are appropriate.

Social skills training affects sexuality directly. Appropriate dress, body care, and manners are important in attracting potential sex partners as well as building self-esteem. Knowledge of sexual norms and customs are of prime importance in developing meaningful sexual relationships. If the individual's environment does not offer the opportunity to learn these norms through early socialization experience, he or she may become sexually isolated.

The literature supports this fact strongly. Four separate surveys have shown that individuals with cerebral palsy are much less likely to marry (Morgan, 1969) or to have any dating experiences at all (Morgan, 1969; UCP, undated). Similarly, a study of hearing-impaired persons in a residential school (Evans, 1975) demonstrated that deaf young adults are only half as likely to date, and they perform poorly on a test of dating norms in comparison to hearing peers.

Disabled people also tend to have less sexual experience than their nondisabled peers. Kinsey, et al. (1948, 1953) found that more than 90% of their samples had had considerable sexual experience *prior* to marriage. However, S.P.O.D. (1975) surveyed disabled people and found that only 60% of their sample had had the variety and extent of sexual experiences reported by Kinsey either prior to or *during* marriage.

However, the need for social skills training is not restricted to persons disabled in early childhood. People progressively or traumatically disabled later in life find social skills training useful in adjusting to changes resulting from their disability. Dunn (1977) conducted a survey and found that the group admitting the greatest social skill discomfort was paraplegic or quadriplegic males who had been disabled less than two years. In his study, the most frequently mentioned source of social discomfort were elimination functions, public embarrassment, and the refusal of unwanted help.

The Sex and Disability Project survey (1978) also found a strong interest in social skills training among spinal cord injured respondents. Nearly 30% indicated they would take advantage of social skills training if it were available, yet less than 5% had ever received such services.



GENERAL SEX EDUCATION COURSES

Much sex education (both positive and negative) occurs informally at home, in the movies, in conversation with friends, by trial and error, etc. General sex education courses, however, are more formal and may be found at all levels of the educational system, from kindergarten to post-graduate studies. General sex education varies in content and format depending on the age and previous education of students. Many sex education courses include such topics as:

- anatomy of sexual organs
- the sexual response cycle
- typical sexual development
- varieties of sexual behavior
- conception, gestation, and birth
- contraception
- interpersonal relationships
- sexual values and decision making
- venereal disease
- relationships between self concept and sexuality

General sex education courses may also be offered outside the formal education system. Community organizations, such as Planned Parenthood or National Paraplegia Foundation may also provide this service.

Despite the great importance of this type of training, sex education is frequently unavailable or inadequate. This deficit is particularly noticeable among disabled persons. Studies have shown that parents are less likely to discuss sex with their disabled children than with their nondisabled children (Dickman, 1972). In addition, it has been found that schools for disabled persons are less likely than public schools to have any sex education at all (Cataruzolo & Enis, 1971; Davis, n.d./ Fitz-Gerald & Fitz-Gerald, 1976). Available programs frequently involve only hygienic information and/or warnings about the expression of sexuality, thus serving to control, rather than instruct, the individual.

A survey of parents of disabled adolescents by Alcorn (1974) emphasizes the severity of the problem. Eighty percent of the parents indicated that they felt that they should bear the primary responsibility for the sex education of their children, yet more than half stated that they were unsure of their ability to provide this training. More importantly, Alcorn found that the parents had not carried out this responsibility; only 30% of the disabled adolescents had been informed of the body changes that already had taken place or would soon occur.

The greatest need for general sex education would, therefore, be among persons disabled since birth or early childhood. The Sex and Disability survey supports this fact. We found that persons disabled by age ten were twice as likely as those disabled at a later age to indicate that they would use a general sex education course, if such were available.

It is not enough that sex education is available; it must also be accurate. A test by Edmonson and Wish (1975) of mentally retarded adult males found that these men had, in fact, gained a significant amount of inaccurate sexual "information." They scored very poorly on the test, and the nature of the errors indicated that they were the result of incorrect information rather than embarrassment or a lack of any information.

In addition, it is necessary that the sex education program be adequate to meet the needs of its participants. This may require special materials or methods (for example, audio-tactile teaching resources for visually-impaired people or visual materials and an interpreter for hearing-impaired individuals). A study by Foulke and Uhde (1974) emphasizes some of these special needs. They found that visually-impaired youths who had participated in a formal sex education program scored considerably higher on a test of sex-related words than those who had not, yet follow-up interviews showed that there was an incomplete understanding of many of these terms. One young boy, for example, was able to give an acceptable definition for the term "intercourse," yet on further questioning, it was discovered that he believed the location of the vagina to be somewhere below the woman's right breast!

This emphasis on sex education for children and adolescents does not mean that adults have no need for sex education. As the above study of mentally retarded men and numerous other studies of disabled adults have shown, sex education should be available to all persons regardless of age. Such programs as those offered by Planned Parenthood and other continuing education programs are needed as accurate sources of training in sexuality. Over 15% of the respondents to our survey who were disabled after age ten indicated that they would take advantage of a general sex education program, if it were available. It is assumed that a similar proportion of the nondisabled population would also find a sex education course useful, and the popularity of such training in adult

education programs attests to this fact. It is, therefore, very important that sex education be available to all sectors of the population, whether child, adolescent, or adult, disabled or nondisabled.

SEX AND DISABILITY COURSES

Sex and disability courses often contain material found in general sex education. Special topics related to disability, however, are also introduced. These subjects may include:

- myths
- the effects of specific disabilities on sexual functioning
- options and modifications for enhancing sexual expression
- varieties of arousal techniques
- effects of disability on sexual self image
- sexual communication following disability

Sex and disability courses may be offered to the general public, to disabled populations, or to professionals in training. Including both disabled and nondisabled participants in the same course increases the possibilities for exploring more than one point of view.

Depending on program objectives, sex and disability courses may be conducted in different ways. Examples of some formats include: presentation of highly visual sexual presentations and readings; guest speakers and panels; and simulation of disability.

When respondents to the Sex and Disability Project survey (1978) were asked which sex education/counseling services they would use, they chose "sex and disability course" more frequently than any other service; it was indicated by 50% of our sample. Unfortunately, our respondents also indicated that this service was received by only 2% of them, thus making it one of the two least frequently provided services. Obviously, this great discrepancy indicates that further development in this specialized type of sex education is of primary importance.

Since a sex and disability course would deal with specialized sexual issues related to disability, it appears likely that persons exhibiting the greatest need for this type of course would be those whose disability most directly affects sexual functioning. Our survey results support this assumption strongly. More than half of all spinal cord injured respondents and other mobility-impaired persons indicated a need for this service. These statistics may be compared with the percent of persons whose disability does not affect actual sexual functioning; only 20% of all respondents with hearing or visual impairments indicated that they would utilize this service.

Our survey shows that newly-disabled people have the greatest need for a sex and disability course. Over 65% of those persons disabled for ten years or less indicated that they would use this service, compared to only 40% of those persons disabled for a longer period of time.

Clinical evidence has shown that the sexual adjustment of spinal cord injured persons is greatly facilitated by information given on sexual capabilities (Teal & Athelstan, 1975). Such information can easily be incorporated into a sex and disability course available to newly-disabled persons. It should be considered an integral part of the rehabilitation process.

The above information is not intended to discourage the availability of sex and disability education to persons with communication disabilities or to nondisabled persons. This service, as well as the other services described in this section, must be made available and accessible to all interested persons.

ACCESS TO READING MATERIALS

Many books, pamphlets, and articles are currently available on the subject of sexuality. Printed materials related to the specific sexual concerns of disabled persons are also gaining wide recognition as useful aids in the delivery of sex education/counseling services. Often a sexual concern or question can be answered simply by reading appropriate materials. Relevant and usable printed materials can be provided in a number of ways. Possibilities include:

- setting up a special section in a community or school library
- making a small private collection available to clients
- putting such materials in waiting rooms, reception areas, recreation facilities, and social centers
- using such materials as part of patient/client education packages

In our survey, we found that the same disability groups who had shown greatest interest in a sex and disability course also indicated a great need for access to reading materials on sexuality. Again, there was particular interest among persons whose disability most directly affects sexual functioning. Half of all mobility-impaired respondents indicated they would take advantage of this service compared to only 20% of those respondents with visual or hearing impairments. In addition, recently disabled persons chose this service more frequently than those who had been disabled for a longer period of time, although the difference was not as great.

Publications related to sexuality are numerous, yet less than 20% of our survey respondents indicated that they had obtained this service in the past. All facilities and individuals dealing with disabled persons should have reading materials available to their clients or, at minimum, should be able to provide resource listings to their disabled clientele. Every effort should be made to assist interested persons in obtaining this available information.

ACCESS TO AUDIO-VISUAL MATERIALS

Access to audio-visual materials on sexuality is a service usually provided as part of an education or counseling program. These materials include films, audiotapes, videotapes, and models (e.g., male and female torsos). Audio-visual resources enhance many other sex education/counseling services.

One-third of all respondents to our survey indicated that they would like to have access to audio-visual materials. It was selected as a needed service by the same groups who had most frequently requested access to reading materials. Twice as many newly-disabled persons as those who had been disabled longer than ten years chose this service, and it was particularly popular among spinal cord injured respondents.

However, these materials may also be very useful for persons who have visual or hearing impairments from birth or early childhood or individuals who have difficulty reading or responding to abstract stimuli. Audio, visual, or tactile resources enable these groups to gain access to information on sexuality which may otherwise be unavailable to them.

Unfortunately, our survey results also indicate that less than 10% of our respondents have obtained this service in the past. Although there is a definite need for the development of more audio-visual (and audio-tactile) resources, some excellent resource materials presently exist (see Appendix G), and every effort must be made to make them more accessible (either directly or by referral) to all persons, including disabled persons.

GROUP DISCUSSIONS

Group discussions are formal or informal sessions in which individuals meet to exchange information and offer interpersonal and group support. Some groups choose a leader; many, however, do not. Group discussions are frequently part of another service (e.g., sex and disability course, contraceptive counseling) or may be offered as a separate service.

Group discussions can be useful for a wide range of topics and purposes. Many women's groups have "rap" sessions on sexuality. In some rehabilitation facilities, clients meet once a week to discuss issues of mutual concern. They may even invite guest speakers to present information preceding their discussion. A disabled consumer group or local organization may meet monthly to discuss sexual well-being, exchange information, and offer each other encouragement.

Group discussion was the second most frequently chosen service suggested in our survey. Nearly half of all respondents indicated this as a service they would actually use. One mobility-impaired respondent suggested a possible reason for the popularity of this service. She stated that sex education services could be improved,

> ...by emphasizing the people rather than the disability and by using peer counseling. My experience has been that professional counselors (no matter what profession) talk like they've read the book but don't understand the subject.

Too frequently, a person's disability becomes the only concern in a sex-related service, and the person himself or herself is treated as merely a vehicle for the disability. In many situations, the person's sexual concern may not even be related to the disability, and an emphasis on the disability may be more distracting than helpful.

On the other hand, if the sexual concerns of the individual are related to the disability, an open and honest discussion which includes other disabled persons may be particularly helpful to all members of the group. Participants who have overcome similar difficulties can offer support and information to new group members and can serve as role models. Frequently, just knowing that others share the same sexual concerns can be encouraging.

A 1978 survey of spinal cord injured males (Berkman, et al.) found that over 70% of all respondents felt it was important to discuss sexuality with other spinal cord injured people. In another study of paraplegic and quadriplegic males (Paraplegics discuss..., 1972), one man summarized this need very clearly:

> I think perhaps one of the best things you can do is to get a quad who is married, or has had some experience, to come in and talk with the patient. I remember my first fear was that I would never be able to masturbate again.

Although nearly half of our survey respondents indicated a need for group discussions, less than 15% stated that they had ever received this service. It is apparent that more attention needs to be focused on the availability and accessibility of group discussions for all persons.

INDIVIDUAL COUNSELING

Individual counseling occurs between two persons—one who is receiving services (client/patient) and the other who provides services (usually a trained professional). The topic of sexuality may be the primary reason for individual counseling sessions, or it might be part of a general counseling program. Individual counseling on sexuality may include discussions between the counselor and client on the following:

- Sexual myths and misinformation
- sexual values
- sexual attitudes
- feelings regarding sexual attractiveness
- sex roles

Individual counseling is particularly useful, either by itself or in combination with other services, when the individual has a specific physical or psychological question or concern related to sexuality. It was selected by more than 40% of the respondents to our survey; however, responses indicated that less than 10% of these individuals had ever received this service.

More than half of all spinal cord injured respondents to our survey indicated that they would utilize individual counseling. Since spinal cord injury usually affects numerous bodily functions, it is likely that this type of service, with its concentration on the specific concerns of the individual would prove particularly useful to members of this group.

Individual counseling is particularly appropriate for persons who: are somewhat inhibited about discussing personal problems in a larger group situation, have specific and unique concerns, or feel uncomfortable with other counseling situations. Romano (1977) notes that individual counseling is also appropriate when there are not enough persons with similar concerns to form a cohesive group.

One of the respondents to our survey, a 28 year old man with muscular dystrophy, emphasizes some of the conditions under which professional counseling on an individual basis may prove particularly useful:

> Circumstances conducive to privacy and lack of inhibition in discussing sexual problems should be provided. Disabled people must know that counseling is readily available in whatever setting (hospital, clinic, etc.) they receive rehabilitation services and that they are *encouraged* to make use of

use of it as a matter of course. A lot of disabled persons (myself included) feel stigmatized by needing help or having uncertainties or questions.

Asking for help is an admission of lack of self sufficiency. Only clear assurance from professionals that this is not so can encourage one to seek counseling. Frank discussions with a knowledgeable, sympathetic person can be very liberating. Family and friends are often too close to the situation to be of much help. One hesitates to bring out deep feelings because one doesn't want to make one's parents feel they may have been at fault.

As might be expected, the persons most frequently requesting individual counseling on sexuality among our survey respondents were those who had been disabled fairly recently. Fifty percent of those disabled ten years or less requested this service, compared to 35% of those disabled for a longer period of time. There are, in fact, many potential providers of this service within the early rehabilitation system.

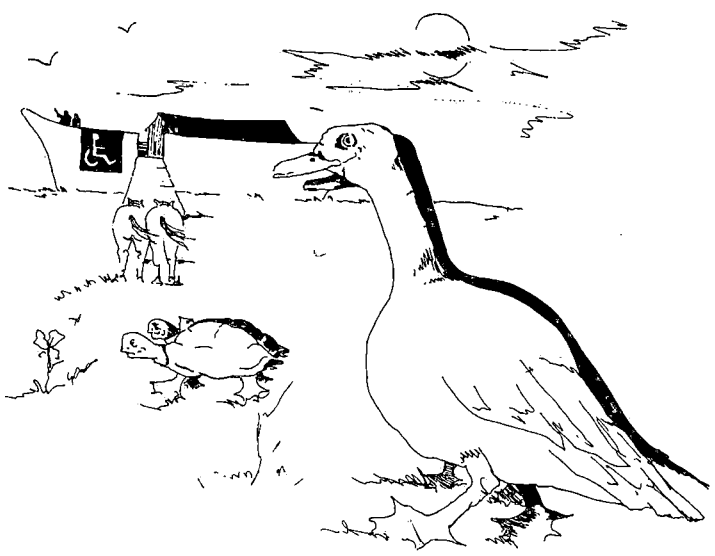
GROUP COUNSELING

Group counseling offers the opportunity to learn how other people feel, to practice new skills and behaviors (e.g., assertiveness), and to obtain feedback from other group members. At least one trained group leader or facilitator is usually present during group counseling sessions. Group members may be selected according to age, sex, location, and/or common concern. A group of spinal cord injured men, for instance, may be placed together on the basis of disability and gender. Another example is adolescent group counseling in which age is the common denominator. It is important that group members are carefully chosen who share somewhat similar interests and goals. This group quality may be based on age, similarity of sexual concerns, similarity of sexual experience or knowledge, specific disability, or any other potentially cohesive element.

Group counseling and group discussion are alike in many ways, and frequently overlap. The formats, group compositions, and areas of concern may be identical. Group counseling differs from group discussions on the basis of intent. Counseling is distinguished by its therapeutic intent; discussion, by its informational exchange.

Under certain circumstances, group counseling may be most appropriate to a person's needs. It may combine the benefits of individual counseling and those of group discussions described above. The sharing of information among participants and the feeling of cohesiveness encouraged by a similarity of concerns may be enhanced by counseling techniques. Mary Romano (1977) adds several other significant advantages of group counseling. She notes that norms and expectations may be established relative to sexual concerns; problem-solving techniques may be enhanced by sharing with others; and an individual may be helped in articulating his or her needs by the support of others.

Although less than 5% of the resondents to our survey had participated in group counseling, nearly one-third indicated that they would actually use this service. This large discrepancy indicates a serious sex counseling need.



COUPLES AND FAMILY COUNSELING

Sexual concerns usually involve an individual's relationship with a partner. In order to improve sexual expression and communication between the partners, couples counseling is frequently recommended. Couples counseling may deal directly with sexual issues or may influence sexual well-being indirectly by improving the couple's relationship. In either case, the focus of counseling is on couple interaction.

In family counseling, the focus is on resolving conflict that affects the entire family. The primary family unit may participate in some or all of the counseling sessions. When conflicts affect family harmony, they are best resolved by the family as a group.

The importance of family/couples counseling has only recently been recognized in the literature. Elliott (1974) has observed, for example, that, although deaf persons marry nearly as frequently as their hearing peers, the divorce rate is approximately three times as great in situations in which one or both of the partners is hearing-impaired.

Our survey found these two services to be very popular among respondents, being indicated by nearly one-third of the persons surveyed as a service they would actually use. In addition, we found that only 5% of all respondents have ever received these services, suggesting a very large difference between services requested and services available.

As might be expected, our survey indicated that the greatest need for couples/family counseling was among recently disabled respondents. Nearly 45% of those persons disabled ten or less years indicated a need for this service compared to 25% of our respondents who had been disabled for a longer period of time.

It is apparent that traumatic injury or progressive illness can have a serious impact on established relationships. Not only must the disabled person adjust to the situation, but so must the person's sexual partner and/or family. Frequently, disabled persons are more readily able to adapt to disability than are others close to them. During rehabilitation, attention is focused on helping the disabled person adjust, yet the family or sexual partner is often ignored. This problem is expressed well by one of our survey respondents, a 27 year old quadriplegic man:

> My wife has a guilt complex—because I'm not able to ejaculate, she avoids engaging in any type of sexual activity even though I try to tell her it gives me relief satisfying her.

Family or couples counseling can be very useful in gaining a comprehensive understanding of the situation. As a result of this counseling, adjustments in life style can be made which are mutually acceptable to all members of the relationship. Whether the disabled individual is an adult or a child, and whether the disability is congenital, traumatic, or progressive, all family members are affected. Rehabilitation efforts should take into consideration the effects of the disability on all "significant others" within the individual's social environment.

SEX THERAPY

Sex therapy is an intensive strategy aimed at specific behavior change. Many sex therapy formats require that both partners in a relationship participate in the therapy. Sex therapists assist their clients by offering information, suggestions, interpretations, and support related to sexuality. Some components of sex therapy are:

- giving information about arousal techniques
- taking a client's sexual history
- conducting a medical examination
- assigning "homework"
- obtaining feedback from the client
- offering encouragement
- suggesting ways to improve communication about sexual needs and desires

One-quarter of the respondents to the Sex and Disability Project survey indicated that they would use this service if it were available to them. Although sex therapy was not chosen as frequently as some of the other services suggested in our survey (perhaps because it is a more intensive strategy), a large discrepancy exists between services received and wanted. Only one respondent (1%) indicated that she had received this service in the past.

It is very possible that this discrepancy is a problem of access. Interested people may be unaware of existing sex therapy services and/or embarrassed to ask for information on this type of program. Increased efforts to publicize available services may prove successful in narrowing the gap between services received and those needed.

GENETIC/CONTRACEPTIVE COUNSELING

Genetic and contraceptive counseling are health services which help clients make decisions pertaining to prospective parenthood. Both may be part of regular obstetrical/gynecological care, or may be offered as specialized services.

> Genetic counseling is offered when clients have concerns related to the possible inheritance of certain characteristics. Genetic counseling may include a physical examination, chromosomal analysis, and the opportunity to discuss the pros and cons of childbearing.
>
> Contraceptive counseling usually includes a medical examination, information on various methods of birth control, and an exploration of the methods most suitable to particular clients.

The Sex and Disability Project survey found a uniform need for these services* among disabled respondents (25%). Type of disability was not a significant factor in selecting these services. Despite the popularity of these services, less than 10% of all respondents indicated that they had received genetic/contraceptive counseling in the past.

The responses suggest a serious oversight in the provision of these services to males. Although more than one-third of those people indicating they would use contraceptive/genetic counseling were males, not one male had ever received this service.

Recent advances in genetic science have made accurate predictions on the inheritance of certain disabilities possible. Therefore, access to this service is particularly important in reducing anxiety for couples considering parenthood when one or both persons has a potentially hereditary disability.

Once a couple has made its family planning decisions, contraceptive counseling offers them a means by which they can carry out their decisions. The couple can plan the number of children, if any, and the spacing of children according to their own wishes and capabilities.

OBSTETRIC/GYNECOLOGICAL/UROLOGICAL CARE

Obstetric, gynecological, and urological care are medical services usually given under the supervision of a physician, nurse, nurse practitioner, or midwife.

- Obstetric care is a medical service offered to pregnant women in order to maintain or restore their reproductive health.
- Gynecological care is a medical service offered to women in order to maintain or restore their genital health.
- Urological care is a medical service offered to both men and women in order to maintain the health of organs associated with urination.

Obstetric/gynecological/urological care* was requested by nearly 30% of the respondents to the Sex and Dis-

* Due to the survey's emphasis on psychosocial factors and de-emphasis of medical factors, these services were listed as a combined service.

ability Project survey; however, less than 10% indicated that they had ever received such services. These services were particularly popular among spinal cord injured respondents, being selected by over half of them as a service they would actually use.

Since these services are readily available to the general public, it is questionable as to why this discrepancy exists. The answer may lie in the accessibility and availability of these services to disabled citizens (see Chapter 6).

SAME SERVICES OR SPECIAL SERVICES?

All sexuality-related services available to the general public must be made accessible to disabled people. It must be up to the individual disabled person to decide whether to use these same services or services designed specifically for disabled people. The decision should not be made for him or her by a provider's unwillingness or by a facility's inaccessibility.

Under certain circumstances, a disabled person may choose to utilize specialized services. The individual may decide that one or more sexuality-related services specifically designed for disabled persons is most appropriate to his or her needs. More than half the respondents to the Sex and Disability Project survey indicated that they would prefer to use these special services. They were particularly popular among spinal cord injured respondents, being chosen by more than 75%. In addition, special services were more frequently chosen by respondents who were disabled ten years or less (70%) than by those disabled for a longer period of time (30%). These findings suggest that special services may be most useful during a person's initial adjustment to a disability.

However, the need for disabled persons to be fully integrated as soon as possible into the general society cannot be overemphasized. Thus, services within the community must be equipped and *willing* to accept all persons, regardless of disability or length of disability.

EDUCATION, COUNSELING, OR THERAPY?

Although sexuality-related services have been described here as discrete categories, they frequently overlap and appear in combination. Three categories which are closely related to one another, but differ both in their intent and provider characteristics, are: sex education, sex counseling, and sex therapy.

Sex education is needed by all human beings. Ideally, effective sex education begins informally at home. As people grow, their need for information about sexuality also grows. Sex education should be developmentally appropriate and continuous throughout the lifespan. The goals of sex education are: to impart basic information, to teach skills necessary for sexual well-being, and to encourage positive attitudes toward sexuality. Sex education is given by parents and family, churches, schools, public media, health institutions, and public agencies. A sex educator is a person who:

- has knowledge about sexuality
- is sensitive about the needs of specific learners
- possesses a positive attitude towards sexuality and teaching sexuality

Sex counseling is a service needed by almost everybody at one time or another. Most of us receive some type of sex counseling through informal channels (e.g., discussions with friends). Sex counseling, however, can be distinguished from sex education by its therapeutic intent. In sex counseling, the goal is to examine specific, rather than general, needs, conflicts, and issues. Sex counseling may be sought to resolve conflicts, explore options, or examine particular feelings or activities. Sex counseling services are usually provided by a trained professional or by someone else with the sensitivity and competence to help people with sexuality-related problems.

Sex therapy is needed by some people at some time. The intent of sex therapy is to provide an intensive, individualized program aimed at problem-solving and behavior change. Most sex therapy formats are highly structured and include a set of techniques to resolve sexual problems. Sex therapy is given by highly trained professionals who have had many hours of formal classroom instruction and who have worked under the supervision of other qualified professionals.

Sex therapy is the most complex form of sexual helping, and includes sex education and sex counseling. It is the most specialized service and is needed by relatively few people. Sex counseling is a less specialized service and is needed by a larger population. Sex education is the least specialized of the sexuality-related services and is needed by everyone.

> *EXAMPLE:* Mary and John are attending a rehabilitation program. They have fallen in love and plan to be married. Both Mary and John need an opportunity to gain information and explore values related to contraception, sexual arousal, sexual communication, etc. They share the need for *sex education* with a great many other young people in similar circumstances who have not previously been educated for sexual adulthood.
>
> Mary and John have some individual concerns, however. They are afraid that since Mary has a spinal cord injury, she will not be able to enjoy a genital sexual relationship. The are both uncomfortable with this situation and want to discuss their feelings with a counselor. They want to learn about each other and explore their present situation. Mary and John are appropriate candidates for *sex counseling.*
>
> If, in the future, Mary and John are unable to establish or maintain a comfortable and meaningful sexual relationship with one another, they may be candidates for *sex therapy.* At that time, they would need a total re-evaluation of their sexual relationship by a highly trained and qualified professional. Sex therapy would be appropriate if specific behavioral changes were warranted.

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Chapter 3

Consider Your Setting

A hospital. A community mental health center. A private home where weekly self-help meetings are held. A vocational rehabilitation office.

All of the above have one characteristic in common: they are all settings. "Setting" refers to any organization, agency, or facility which provides services of some kind. Setting influences the type of sex education/counseling services that can be realistically offered to disabled persons. To assess the appropriateness of a service within your specific setting, you need to consider several factors. They include:

- Emphasis of service
- Purpose and goals
- Characteristics and needs of client* population
- Staff composition
- Policies and politics
- Budget and finances
- Size of facility
- Location
- Laws
- Attitudes

EMPHASIS OF SERVICE

How do you determine the emphasis of your setting? Settings which can provide sex education/counseling services to disabled individuals can be divided into two categories:

1. Settings which provide services based primarily on disability ("disability-oriented settings"), and
2. Settings which provide services to the general community ("community settings").

Disability-oriented settings. Sometimes an individual requires disability-oriented services. Sudden onset of a disabling condition may warrant specially designed services during the initial phases of adjustment. A person recently blinded in an industrial accident, for example, may attend rehabilitation programs for mobility training, vocational assessment, and psychological counseling. During this process, the newly disabled person may find it useful

* The word "client" is used in a general sense and also includes patient, student, or resident, depending upon the setting.

to adapt and re-learn certain social skills, including those related to sexuality. This client learns how to cook a meal and operate a machine without sight. He or she also needs to learn how to make social contacts and participate in lovemaking without the use of vision. Re-learning all these skills is consistent with the emphasis of disability-oriented settings: the provision of rehabilitation services to individuals with disabilities.

Disability-oriented services can also be effective when a specific sexual dysfunction is the direct result of a disability. A spinal cord injured male who wishes to father a child, but is unable to ejaculate viable sperm, may seek a special service beyond that found in most fertility clinics. In this case, a special setting is necessary to deal with a specific, disability-related problem.

Examples of disability-oriented settings are:

- DVR field offices
- special hospital units
- rehabilitation centers
- residential schools for disabled children
- offices of doctors specializing in rehabilitation
- disabled consumer groups
- sheltered workshops
- residential facilities, e.g., halfway houses
- service organizations, e.g., United Cerebral Palsy

In a disability-oriented setting, it is important to examine ways that sexuality-related services can be included in the overall program. Although sexuality issues are not the primary focus of a disability-oriented setting, they still should be incorporated.

Community Settings. Many types of community settings exist which offer sex education/counseling services to the general population. They include:

- family planning clinics
- mental health centers
- hospitals
- doctors' offices
- clinics
- counseling centers
- hotlines
- public service organizations, e.g., Red Cross
- public schools
- colleges and universities
- libraries

- places of worship

- recreational facilities, e.g., YMCA, summer camp for children

- continuing education classes

In such settings, it is important to consider methods of expanding services to include more disabled persons. Architectural and programmatic modifications may be necessary so that disabled members of your community can use services available to nondisabled people. There is no reason, for example, why a woman with cerebral palsy should have to go to a "special" gynecologist for a routine internal examination. Nor should a deaf person have to go to a "special" clinic for birth control information. Marriage/couples counseling should not be "special" simply because one or both partners are disabled.

Disabled people may be automatically referred by community organizations to disability-oriented settings regardless of the concern involved. One of our staff members asked the director of a small mental health center how many disabled clients were served. He replied that few physically disabled people came to the center,* and that those who did were referred to the local vocational rehabilitation office. This response indicated that the director believed that disability was the most important characteristic of a disabled person.

Such an approach is not only dehumanizing, but also ineffective. Many times a disability-oriented setting is not prepared or willing to handle a matter related to sexuality, and so the disabled person, after several referrals, ends up with no services at all. There are many times when referral to a disability-oriented setting is appropriate, and knowledge of these options should be made available to both staff and clients. It should *not,* however, be assumed that, just because an individual has a disability, he or she should automatically be referred to a disability-oriented setting.

According to the Sex and Disability telephone survey of 45 sexuality-related community organizations, many settings have few, if any, disabled clients. The overall response to this survey indicated that, although there was some awareness of a responsibility to provide sex education/counseling services to disabled people, few community organizations actually did provide these services. Most respondents stated that specialized training in sex and disability is needed to provide adequate services. The underlying implication was that the sexuality of disabled people is markedly different from that of the general population, and, as a result, only a specialist can provide such services. Chapter 4 explores this topic in greater detail.

Although certain situations require special services, community services should be utilized by disabled people whenever possible. This policy of normalization and mainstreaming encourages the (re)integration of disabled people into the community.

PURPOSE AND GOALS

How do the purpose and goals of your setting affect the kinds of sexuality services you can offer? A disability-oriented setting and a community setting may share the same overall purpose and goals. A spinal cord injury hospital unit, for example, has the same general goal as most other hospital units: to provide medical and other services to patients in order to improve health and functioning.

An assessment of the purpose and goals of a specific setting is vital in deciding whether or not various sex education/counseling services are appropriate. Obviously, a general community hotline cannot provide the direct services offered by a comprehensive rehabilitation center. To a great extent, the variety of organizational purposes and goals dictates the type and intensity of sex education/counseling services.

Some settings are capable of providing direct and extensive sexuality services to disabled persons. A spinal cord injury hospital or unit, a residential school for disabled children, and a rehabilitation center are three such examples. These settings may include medical, vocational, educational, psychological, and other rehabilitative services all within one facility. Usually, clients live at the facility for an extended period of time (several weeks to many months).

Comprehensive programs in such settings can and should include sexuality as part of the overall rehabilitation

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* Not surprising since entry into the building necessitated climbing several stairs.

or education process. Craig Rehabilitation Hospital in Englewood, Colorado, for instance, provides comprehensive services to individuals with either spinal cord or brain injuries. The staff at Craig realizes that medical care and rehabilitative training, alone, are inadequate to meet the needs of their patients. Other aspects of life, including sexuality, must be considered. The admitting physician usually discusses sexual issues with the new patient. Later, counselors and doctors are available to explore these concerns in greater detail; workshops and materials about sexuality are available. The entire staff has some training and familarity with possible sexual concerns of the patients, so that problems can be dealt with effectively as they occur, or can be promptly referred to other staff members with more expertise. During the patient's last two weeks at Craig, the patient and his/her family live in a nearby apartment complex to facilitate the transition from hospital to home. Staff is available during this period to help family members work out difficulties, including those related to sexuality and sexual functioning.

One major goal of a residential school is to provide a total education program for the students. Learning about sexuality is part of that overall goal. A residential school needs to examine carefully the sex education/counseling services that can be provided. Increasingly, public schools are offering sex education courses for children. Also, socialization with the opposite sex is an automatic part of a public school child's experience. Children in residential schools need sex education and socialization opportunities as much as, if not more than, public school youngsters. The additional need for services is due to the following:

1. Residential schools take on many parental functions including the role of a sex educator.

2. Disabled children, because of their handicaps, may have special problems learning about sexuality. Mentally retarded youngsters, as well as those with sensory impairments, may need modified learning experiences.

3. Adequate socialization experiences with peers may be lacking due to early deprivation.

In keeping with its comprehensive educational goals, the Perkins School for the Blind in Watertown, Massachusetts, provides services aimed at the sexual and social development of visually-impaired students. The program takes into consideration both the chronological age and the learning ability of students from pre-school through high school. This approach allows for a great deal of flexibility in selecting appropriate topics and formats. In this way, the individual needs of all the students are taken into account. One outstanding feature of the Perkins program is the emphasis placed on increasing contact between the visually-impaired students and their nondisabled peers. This type of interaction helps to eliminate some of the social barriers which may crop up during later years as a result of early segregation.



Like the special hospital unit and the residential school, a comprehensive rehabilitation center provides more than one or two services to clients. Whereas the hospital unit is medically oriented and the residential school concentrates on educational goals, the rehabilitation center often emphasizes vocational adjustment and training. The long-range goal of this type of facility, however, is to enable the client to (re)enter the community with as much preparation as possible. Although job skills are important, competency in other aspects of life are also needed. For this reason, a client in a rehabilitation center may need to continue physical therapy, participate in psychological counseling, receive training in social skills, and learn how to perform the activities of daily living efficiently and safely. Social skills include more than just getting along with co-workers on the job and dealing with the curiosity of nondisabled people. Activities of daily living include more than cooking on a stove safely and managing a leg bag. As Scott Luebking (1975), a quadriplegic, notes, sex is also an "Activity of Daily Living" and should be addressed during the rehabilitation process.

Other settings such as VR field offices, mental health centers, and family planning clinics can realistically offer disabled people sexuality-related services. A comprehensive sex education/counseling program may not be feasible in these settings, yet some direct services can be provided. A VR field office, for example, can provide services such as: access to reading and audio-visual materials, individual and group counseling, and social skills training. A community-based Planned Parenthood may conduct workshops and courses about sexuality and disability, hold group discussions, provide medical care, discuss alternative contraceptive measures, offer counseling services, etc. Such services are consistent with the purpose and goals of these settings.

Provision of direct sex education/counseling services is inappropriate in some settings. A sheltered workshop which aims at providing a work environment as near to normal as possible is unlikely to provide direct sexuality-related services. Nor would such services be desirable in this setting. It would, however, be appropriate and desirable to encourage acceptable social behavior among workers. Also, an adequate referral system could direct disabled persons with sexual concerns to appropriate service providers.

Community hotlines also provide little in the way of direct sex education/counseling services. Those services which are consistent with the purpose and goals of hotline settings include: listening, providing information, verbally supporting the caller, making specific suggestions, and referring the caller to appropriate service providers.

CHARACTERISTICS AND NEEDS OF CLIENT POPULATION

What do your clients need? In order to decide what sex education/counseling services are appropriate in a specific setting, it is necessary to know the characteristics and needs of the clients served. Characteristics to consider include: age, sex, type and severity of disability, length of time disabled, economic status, and background.

Intensive sex therapy is obviously inappropriate in a facility for children. Social skills training and general sex education, however, are needed by all children, including those with disabilities. On the other hand, a program which includes only general sex education will probably not adequately meet the needs of a group of clients who were disabled as adults. More appropriate services would also focus on an exploration of the effects of disability on sexual functioning, sexual options, adjustments within relationships, etc.

Individuals struggling with survival issues—whether related to disability or economics—may have different priorities than those with stable conditions and adequate incomes. This does not mean, however, that sexuality should be ignored. Instead, a greater sensitivity to the individual's specific needs should exist. When assessing services in your setting, don't assume needs. This applies especially to the area of sexuality and the provision of related services. What an individual needs and what other people think that individual needs may be two very different things. For this reason it is important to allow clients to express their needs rather than making assumptions such as: "Oh, he wouldn't be interested in sex at this time" or "She's too sick to think about those things." (See Chapter 2 for further detail.)

STAFF COMPOSITION

Who can provide which services? The staff members working in a particular setting affect the type of services offered by that setting. In a hospital, for instance, the training and expertise of most of the staff are in the area of medical care. Physical functioning and rehabilitation are naturally emphasized. In a counseling center, however, the staff may be primarily social workers and psychologists; the focus in this setting will be on social and psychological concerns. The staff members of both of these settings feel most comfortable providing services closest to their training. What must be kept in mind, though, is that client needs may require the provision of services beyond those which predominate in a particular setting.

Although the training backgrounds of personnel play a part in determining appropriate services, personality traits and attitudes are usually far more significant. An interested and empathetic family doctor is more likely to provide supportive counseling to a disabled person than an aloof and brusque psychologist. Similarly, a rehabilitation counselor who views sexuality as a natural and integral part of a client's life will be a far better service provider than a physician on a spinal cord injury unit who is uncomfortable with his or her own sexuality. See Chapter 4 for a more in-depth discussion of potential service providers.

POLICIES AND POLITICS

What is *really* happening? In our survey of rehabilitation counselors, it was indicated repeatedly that a major barrier to providing sex education/counseling services was lack of administrative support. When assessing a setting, it is important not only to look at the written policy regarding sexuality-related services, but also to examine the reality. Some policy statements include general proclamations about the importance of "social and personal development" and "the whole person." In reality, however, administrators may discourage staff members from providing services in keeping with these goals. Large caseloads, mountains of paperwork, and narrowly-defined goals limit staff ability to provide expanded services.

Politics within an organization need to be recognized and addressed in order to determine the true feasibility of providing sex education/counseling services. If the more influential staff members believe that sexuality-related services are irrelevant and frivolous, it will be extremely difficult for other staff members to provide these services competently and over an extended period of time. On the other hand, if the leadership within an organization views sexuality-related services as an important, or at least acceptable, component of the overall program, the foundation for providing effective services will be established.

The political climate on the local, state, and federal levels can also affect the quality and quantity of sexuality-related services. Political awareness and know-how can help insure that your services are supported by the community. For this reason, political involvement by service providers and policy makers is strongly recommended.

BUDGET AND FINANCES

What about money? The political and economic realities that affect a setting are closely allied. If the priorities within a society or community are toward improving the overall quality of life for all persons, sex education/counseling services will be funded. If, however, the priorities are more along the lines of increasing profits or segregating individuals judged as "undesirable," sexuality-related services will probably receive relatively little funding.

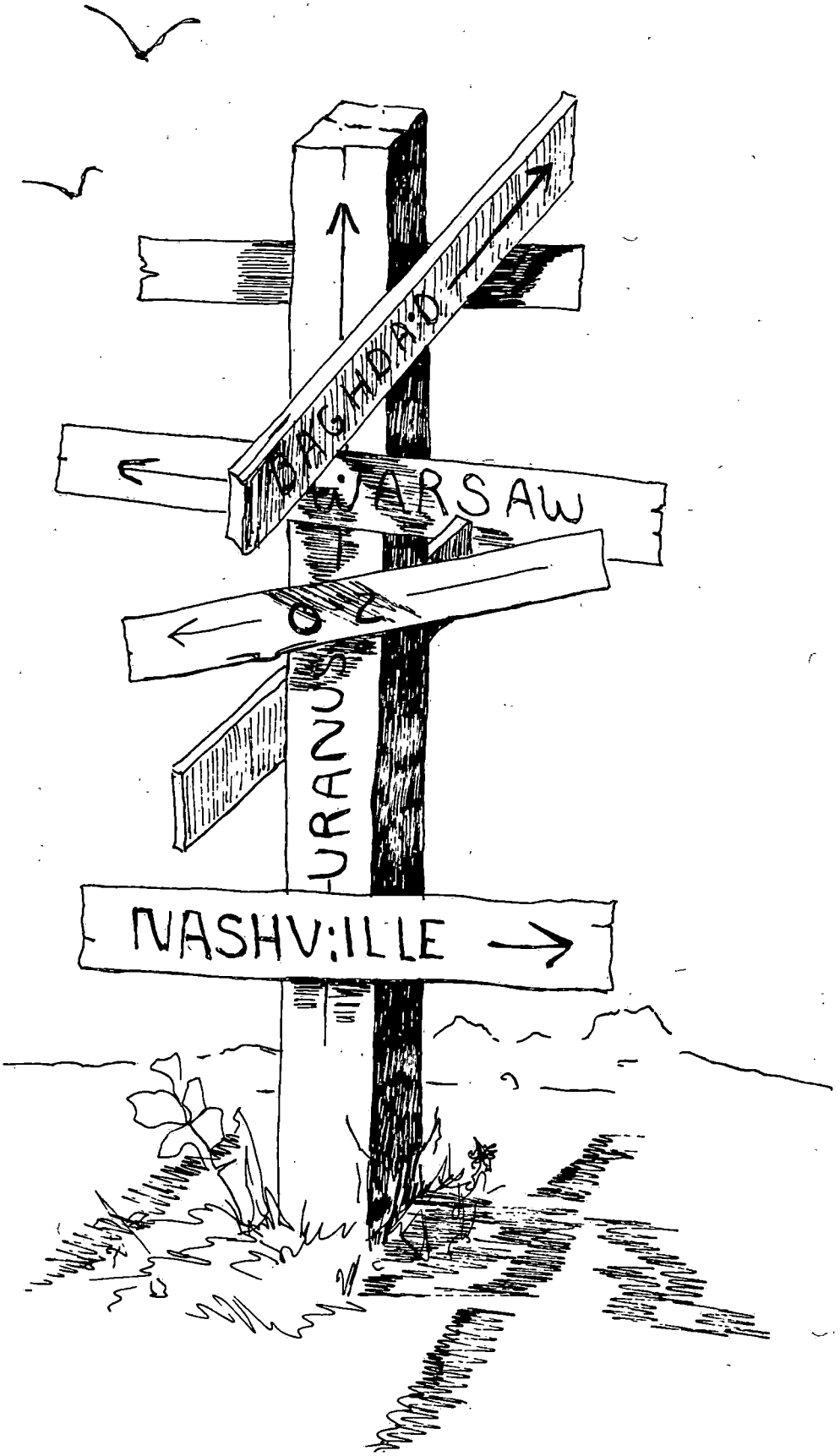
If, out of necessity, an organization is operating on a very tight budget, certain painful decisions may have to be made. A small community counseling center, for instance, may want to provide more sexuality services to disabled people, but simply may not be able to afford it. In such a case, a setting might focus on services which require little expense: access to relevant printed materials, sexuality-related counseling as part of already established counseling services, and accurate referrals to settings which offer more extensive services in this area. Another alternative is to explore ways of getting increased funding. See Chapter 6 for further information on this topic.

SIZE OF FACILITY

Is big necessarily better? The size of a facility may have direct bearing on the amount and type of sexuality-related services offered. This factor, however, is less important than may be originally imagined. A small clinic, staffed by competent, creative, and committed people, will offer more effective sex education/counseling services than a large institution in which staff and services get bogged down in bureaucratic procedures and low morale.

Size is important in terms of the number of people who can be served. Shortage of space causes problems such as long waiting lists, crowding, and lack of privacy. Flexibility in scheduling and format, however, can help alleviate the limitations of a small facility. Usually, shortage of space is a money issue and needs to be addressed as such.

When considering the size factor, it is important to remember that big does not necessarily mean better. In fact, a huge facility may defeat itself by its very size.


BAGHDAD
WARSAW
URANUS
NASHVILLE

LOCATION

Where is the setting? Is it in midtown Manhattan, the West Virginia hills, or a suburb in Southern California? Obviously, the location of a setting is going to make a big difference in determining appropriate sex education/counseling services. Format of services, for example, will vary depending on the location. In a large metropolitan area, groups based on specific disabilities may be practical. A group of deaf persons, for example, can meet regularly to discuss their mutual concerns. In an area where the population is widely dispersed, however, there may be only one or two people with a certain disability. In this situation, alternative ways of providing services are needed.

Physical accessibility is an important issue related to the location of services. A college counseling center, for instance, which is located up a flight of stairs, will be unable to provide services to persons in wheelchairs unless modifications are made. This and other accessibility issues are discussed in Chapter 6.

LAWS

What are the legal considerations? Certain laws may affect the provision of sex education/counseling services to disabled people. In order to avoid legal problems, knowledge of local, state, and federal laws is vital. Some laws require that certain services be provided to disabled people (Rehabilitation Act of 1973, PL 94-142). Others prohibit the provision of certain services, especially in the area of sexuality. In some states, for instance, use of explicit audio-visual and printed material is illegal, whereas in other locales, its use is perfectly acceptable and legal.

ATTITUDES

Why are positive attitudes so vital? A trained staff, many clients, piles of money, and a brand new facility will not insure effective sex education/counseling services to disabled individuals. If attitudes are negative or stereotyping, service delivery will automatically suffer.

Attitudes are especially important when dealing with sensitive topics such as sexuality and disability. Sexual problems cannot be surgically removed by an indifferent specialist. Rather, positive interaction and sensitivity are required. Assessing the attitudes of staff members, clients, clients' families, administrators, and the public is an important step when developing sexuality-related services. If the service providers within a setting exhibit negative attitudes toward sexuality and/or disability, it is vital that there be a training program focused on attitudinal reassessment before sex education/counseling services are attempted. More information about the training of service providers can be found in Chapter 5 and Section IV.

SETTINGS: SOME QUESTIONS TO CONSIDER

- Are the sex education/counseling needs of disabled people met in your community?
- If not, what settings can best meet those needs?
- If a need is not being met adequately by any setting, what can you offer at your setting?
- Is the staff willing (attitudes) and able (skills) to provide sex education/counseling services?
- Whenever possible are modifications being made in "regular" services rather than creating separate (and stigmatizing) "special" services?

One general rule of thumb in deciding what, if any, sex education/counseling services can be provided is: You can probably provide more services to disabled people than you do now. With positive attitudes, dedication, competence, and creativity, service providers in many kinds of settings can contribute markedly to the sexual well-being of all individuals, including those with disabilities.

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Chapter 4

Who Should Provide the Services?

Up to this point, we have concerned ourselves with the types and formats of sex education/counseling services available to people with disabilities. We must now ask ourselves who should provide these services. Who are the most appropriate people to deal with questions related to sexuality and disability? A 21 year old woman with rheumatoid arthritis, when asked this question on a survey, responded:

> I'm going to be difficult with this particular question. I have spoken with many different people who claim these different titles. Unfortunately, no one can always receive a guarantee of a particular service from a person just because he calls him or herself, for example, a teacher, social worker, etc. It is the person behind the title that I would like to know a bit about before I ask for any services of any kind from him. Many times I have found that a teacher (for example) is also a social worker, psychologist, counselor, etc., and other times people merely carry these titles around with them.

The above response underscores a crucial point: a job title does not always define competencies. Sexuality has fallen victim to stigmatization by professionals who feel that there is a special formula for discussing sexuality with disabled people. In fact, almost anyone can discuss aspects of sexuality and disability with minimal training and comfort. Of course, the intensity of involvement will depend upon the provider's level of interest, comfort, and knowledge. But many potential providers of sex education/counseling services automatically exclude themselves because they don't feel that such services fall within the purview of their jobs. No job title, as we will later see, excludes discussion of sexuality.

Perhaps the most important quality necessary for the provider of sex education and counseling is comfort with sexuality, and with disability. The provider must be aware of the fact that sexuality is, many times, a sensitive area which is fraught with myths and anxieties. If the provider is uncomfortable with his or her own sexuality, this will be communicated to the person seeking advice or reassurance.

The provider needs to be empathetic and sensitive to individual differences, and should not project his/her own morals or values onto the client. If the provider feels comfortable discussing sexuality with a disabled person, and wishes to pursue the subject, (s)he should be aware of resources available on sexuality and disability, and have some basic knowledge of human sexuality. The provider must also be honest about his or her level of competency in dealing with sexual issues, and should be able to refer the client to appropriate sources.

The model described below outlines four levels of involvement which the provider can pursue. Each level requires a greater amount of comfort, knowledge, and skill on the part of the provider.

THE PLISSIT MODEL

The PLISSIT model was developed by Dr. Jack S. Annon and can be adapted to a wide range of settings. It can be used by a variety of helping professionals and allows for a broad range of service delivery, dependent on the level of competence of the provider. The model outlines four ways to approach questions related to sexuality:

Permission - Limited Information - Specific Suggestions - Intensive Therapy (P-LI-SS-IT). The beauty of the model lies in its adaptability to the service provider's level of competence and its guidance in determining the appropriate time for referral. The PLISSIT model was developed to conceptualize levels of intervention in sexual matters related to all persons, and lends itself particularly well to sexuality and disability. Annon states:

> How many levels of approach clinicians will feel competent to use will directly depend upon the amount of interest and time they are willing to devote to expanding their knowledge, training and skill at each level.

I. **Permission.** Many potential problems regarding sexuality can be eliminated simply by giving permission. Everyone needs to know that they are OK or normal in their sexuality, and they need to hear this from someone whom they consider to be in a position of authority. In some cases, people are worried that their sexual preferences are not socially acceptable—that others consider them "bad" or "perverted." A provider who gives permission acts as a sounding board. (S)he lets the client know that they're not alone or unusual. Permission to continue along their present course is, in some cases, enough to resolve a problem.

Permission (reassurance) is especially helpful in relieving anxiety over sexual thoughts, fantasies, and dreams; sexual arousal; and particular behaviors (positions and frequency of intercourse). A provider should not give blanket permission for all activities and has a responsibility to make sure that the client is informed of adverse consequences of some behavior (e.g., legal consequences).

At the permission level, the provider needs to be comfortable discussing sexuality, needs to be a good, non-judgemental listener, and should be relatively familiar with typical societal attitudes about sexuality. No special knowledge about human sexuality and disability is necessary to give permission and reassurance. Proceeding to the next level will depend on the provider's level of comfort and knowledge.

> *Example of Permission.* Ms. Jacobs is a 30 year old paraplegic, recently injured. She still has sexual desires, yet feels that there is something abnormal about her continued interest in sex after her injury. Ms. Brown, a rehabilitation counselor, tells Ms. Jacobs that it is perfectly normal to continue to have sexual feelings, just like everyone else. Ms. Brown has given Ms. Jacobs permission to express her sexuality.

II. **Limited Information.** Sometimes permission needs to be augmented with information. At this level, the provider gives the client specific factual information directly related to his/her sexual concern. This information could be as simple as distribution of reading material. Limited information provides the client with a foundation for reassessment of sexual values and beliefs and possible behavior change. It is always given in conjunction with permission. Level II is particularly effective in dispelling myths and concerns about subjects such as genital size and masturbation.

To give limited information, the provider should have the qualities necessary to give permission, plus some additional knowledge about human sexuality and disability.

> *Example of Limited Information.* Joe Smith is a 14 year old boy, blind from birth, who tells his caseworker that he is completely unfamiliar with female anatomy because he hasn't been able to see pictures of women. Ms. Jones gives Joe a plastic model of an adult woman which he can feel. Ms. Jones explains and describes each part of the anatomy as Joe touches the model. Ms. Jones has given Joe permission to learn about sexuality and has provided limited information about the anatomy of women.

III. **Specific Suggestions.** Some sexual concerns require that the provider make a specific suggestion about how to change behavior. Although Levels I and II don't *necessarily* imply a behavior change, Level III helps a client set and reach a specific goal. In order to provide specific suggestions, the provider must have qualities necessary to give permission and limited information, plus should be able to give accurate neurological, physical, and psycholo-

gical information. Because Level III is very individualized, it is necessary for the provider to obtain from the client all relevant information about that client's particular sexual concern(s). This level is particularly effective in dealing with concerns over arousal, erection, ejaculation, orgasm, or painful intercourse.

> *Example of Specific Suggestion.* Mr. Chambers tells his doctor that since his spinal cord injury he has been unable to have an erection and has therefore avoided having intercourse. Dr. Williams takes a sexual problem history, and then explains to Mr. Chambers that the location of his spinal cord injury (very low back) often prevents erection. Dr. Williams explains the "stuffing technique," where one partner tucks the flaccid penis into the vagina. Dr. Williams also explains to Mr. Chambers that very satisfactory sexual involvement can occur without intercourse and explains a variety of options to intercourse (e.g., oral-genital sex).* Dr. Williams has given permission to be sexual, limited information about sexuality, and specific suggestions directly applicable to the client's specific concern.

IV. **Intensive Therapy.** This level is a highly individualized treatment program which is necessary when permission, limited information, and specific suggestions are not sufficient to meet the client's goals. To enter Level IV, the provider must be *specially trained* in both physical and psychological aspects of human sexuality and disability. It is at this level that most providers must refer their clients to certified professionals who have the knowledge and skill to apply a specific program of services to a particular problem or concern. Intensive therapy applies to emotional and psychological sexuality, as well as physical concerns, and includes giving of permission, limited information, and specific suggestions. Only if these three levels of intervention fail to help the client with his/her concern will an individualized course of treatment (intensive therapy) be initiated.

> *Example of Intensive Therapy.* Mr. and Mrs. Scott had been married for 7 years when Mrs. Scott developed multiple sclerosis. Both obtained information and participated in discussions about the effects that MS might have on their marriage, but their concerns regarding sex, family, and their relationship continued to create problems. Mr. and Mrs. Scott go to a marriage and family counselor to get help. The counselor takes a medical and sexual history, determines with the couple the goals they want to meet, and sets up a schedule of meetings. The sessions include "homework" assignments for the couple. The therapy ends when the couple's goals are met.

WHO ARE THE SERVICE PROVIDERS?

As the PLISSIT model shows, anyone in the "helping professions," regardless of job title, can provide some aspects of sex education/counseling for people with disabilities. A social worker is as competent to give permission as a psychiatrist—perhaps even more competent if (s)he is more respected by the client.

The following analysis shows who is currently providing sex education/counseling services to disabled people, and who disabled people, rehabilitation counselors, and rehabilitation policy makers expect to provide services. The information for this analysis was obtained from Sex & Disability Project surveys and from professional literature. Disabled subjects in the survey were asked the following questions:

- Who do you think should help you with a question or concern about sexuality?

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* State laws vary on the subject of oral-genital sex, as well as other sexual options. Service providers are encouraged to find out what their state laws are before making recommendations to clients.

- Who do you think are the most appropriate providers of sex education/counseling services?

- Of the services you have already received, who provided the services?

Respondents were given the following list of providers to choose from: clergy, psychologist, teacher, other disabled person, social worker, hotline staff member, physician, other medical personnel, rehabilitation counselor, Planned Parenthood staff member, or sex counselor/therapist (see Table B). Each provider on the above list will be discussed below.

It is important to remember that the list of possible providers discussed here is a *partial* list. A job title does not automatically exclude someone from taking an active part in recognizing the sexual concerns of disabled people.

Physicians. The role of the physician in providing sex education/counseling services is very important. Because physicians are seen by many to be persons of knowledge and authority, they are expected to be able to provide such services. Of the disabled people surveyed, 64.2% expected physicians to provide services and 50.6% ranked them as being the professional *most* expected to provide sexuality services. Rehabilitation counselors and policy makers ranked physicians second only to sex counselors and therapists as being the best potential providers of sex education/counseling services for disabled people. Physicians surveyed (OB/GYNs and urologists) indicated that they did provide obstetric/gynecological and urological services, but were hesitant to provide other sex education/counseling services. And, unfortunately, many disabled people surveyed indicated that they were *not* receiving sex education/counseling services from physicians. This discrepancy is troubling. It indicates that disabled individuals are not getting needed services from the people expected to provide them.

A study of 212 disabled people conducted by the Research Institute for Consumer Affairs in 1975 showed that only one-fifth of those surveyed had been given any sexual guidance by a physician. The effectiveness of the advice given by medical professionals was rated *lowest* of all other professionals. When asked to whom they would turn with a sexual concern, 88 of the 212 disabled people surveyed said they would go to their family doctor. Of those who had already received services from physicians, their attitude was that, effective or not, this was the only likely source of advice know to them.

The importance of these findings is clear. A disabled person with a concern about sexuality can be frustrated and can feel that there is no one to turn to if their physician is not open to discussing sexual concerns with them. The responsibility of the physician to receive training and knowledge regarding sexuality and disability is great. Physicians are likely to be the first authority figures encountered following onset of a disability. It is logical and desirable for physicians to be the first persons to discuss sexuality with disabled people. Physicians, with training, can give permission, limited information, and specific suggestions to patients which could prevent sexual problems from arising at a later date. It is vital that physicians recognize the sexuality of disabled people and the need to provide sexual guidance to disabled patients.

At present, the literature indicates that most physicians limit their involvement in sexuality and disability to providing physical examinations, fitting prosthetics, and explaining anatomy as it relates to sexual functioning. Many physicians are hesitant to bring up the subject of sexuality at all. The biggest current limitation of physicians is the attitude that disabled people are not sexual persons. Most physicians are not trained to help disabled patients with their sexual concerns and, therefore, avoid the subject completely. Through their avoidance, physicians could reinforce a negative, asexual self concept held by a disabled patient. One of the disabled people surveyed commented:

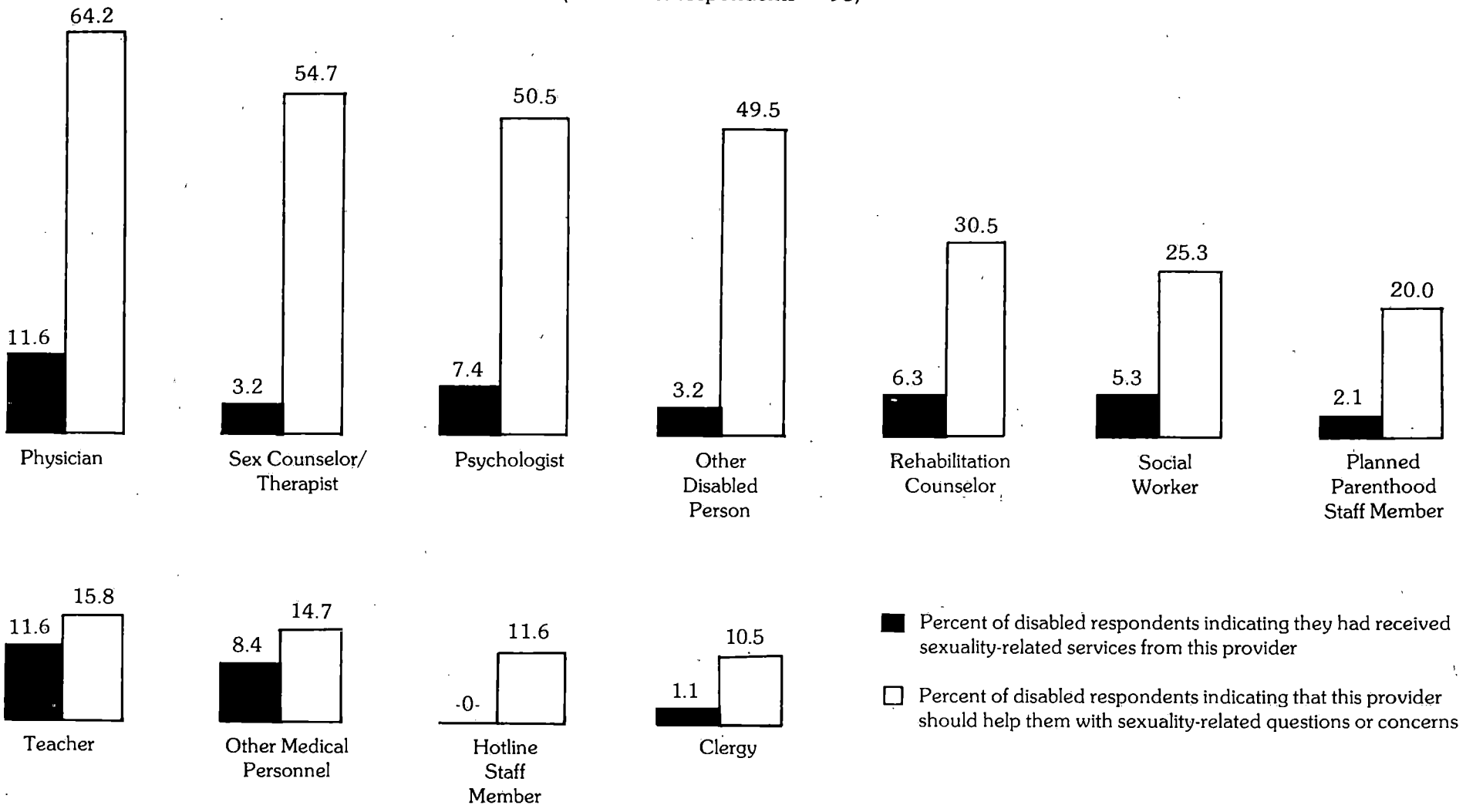
> Doctors could be a lot more open, and cooperative. My doctor says, "just keep experimenting till you find out what works."

Clearly, a great deal of faith has been placed with the medical profession in providing sex education/counseling services to disabled people. It is, therefore, vital that physicians meet these concerns with interest, knowledge, and skill.

Other Medical Personnel. Following the onset of a disability, nurses, physical therapists, occupational therapists, and other medical personnel will be encountered. A 45 year old man, disabled by polio during his adolescence, commented:

TABLE B

SEX EDUCATION/COUNSELING SERVICES: WHO PROVIDES VS. WHO SHOULD PROVIDE*
(Number of respondents = 95)



*These percentages reflect responses by disabled people to Questions 9 and 12 on the Consumer Survey (See Appendix A).

Medical staff (including nurses) in rehabilitation facilities should be trained to offer sex education/counseling. Education and counseling needs to run the gamut from emotional coping to sexual techniques.

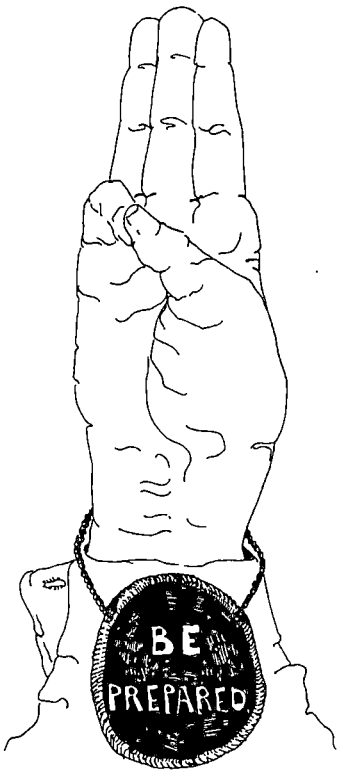
Disabled people surveyed indicated that they were receiving some guidance from medical personnel, but very few expected medical personnel to be the most appropriate providers of sex education/counseling services. What was said of physicians related directly to other medical staff. The opportunity for helping exists, but negative attitudes and limited knowledge stand in the way of high levels of involvement with the topic of sexuality and disability.

It is very likely that a disabled person will turn to medical staff for permission and limited information. These can be given without specialized knowledge and training. Medical personnel could meet a great need simply by having a library of sexuality and disability materials available to patients, and by taking some time to discuss anxieties and concerns about sexuality. Often, simple permission and a few books will alleviate a problem. If further advice is desired, the patient will then feel more comfortable to pursue the topic of sexuality with someone else.

Teachers. Teachers play a vital role in providing educational services to disabled people. Surveyed disabled people who had previously received services said that teachers had provided them with services more often than any other professional. The survey showed that teachers most often provided reading and audio-visual materials on sexuality and anatomy.

Not all disabled people go through the rehabilitation process, but almost all go to school. Often, the school teacher who provides sex education is the sole source of information on sexuality for a disabled person. Many people with sensory disabilities (blindness, deafness) indicated that teachers provided them with the only sex education they received.

But many teachers are uncomfortable with their role as sex educators because they have not received encouragement or training. Fear of parental or administrative complaints cause many teachers to avoid sexuality as an educational concern. Teachers can logically give permission and limited information to students, without having to assume a counseling role. A disabled person, on a survey, stated that sex education/counseling services for disabled people could be improved by "informing parents, educating and desensitizing teachers, encouraging and creating an atmosphere of trust and freedom to discuss issues." Teachers, themselves, can take an active role in educating administrators about the importance of sex education in schools. They can also gather resources (books, pamphlets, films, guest speakers) which will be valuable learning tools for their disabled students.



Planned Parenthood. "Individuals involved in generic services pertaining to sexuality could be utilized to a greater extent. But they do need to be sensitized to the special needs of the disabled. By *only* using special services, the disability of the person is made more prominent." This statement was made by a parent of an 11 year old boy with mental retardation. The concept of normalization, expressed here, is crucial to destigmatizing disability. Planned Parenthood could play a role in providing sex education/counseling services to disabled people in a non-segregated, comfortable setting.

Planned Parenthood staff members are already trained to provide sex education and counseling to the general public. Depending upon the comprehensiveness of its service delivery system, a Planned Parenthood could give permission, limited information, and specific suggestions to disabled people. With appropriate training and information, staff members could provide services to disabled people equal to those offered to the general public. Planned Parenthood could also serve as a referral service for disabled people who feel that they need information more specific to their disability.

Social Workers. Social workers provide direct counseling and other services to a wide range of people, many of whom have little or no access to sources of reliable information about sexuality. Social workers often function as counselors, advocates, community organizers, and educators. In performing these roles, the social worker is bound to be confronted with questions or concerns regarding a client's sexuality. Yet, in a study conducted by Abramowitz (1971), it was found that social work students were less knowledgeable about human sexuality than other professional students at the same educational level.

As a counselor, the social worker has the responsibility and skill to deal with such sexuality issues as marital and/or social adjustment. As an educator, community organizer, and advocate, the social worker can contribute greatly to the development and utilization of sex education programs for disabled people.

It is vital that resources in the *community* be available to disabled people with sexual questions and concerns. Placing sexuality resource people only in institutional/medical settings can label sexuality as being a physical "problem" area. Disabled citizens need to know that there is someone in their community who can and will talk with them about sexuality. Much of this sharing of information can be instigated by social workers and community resource service providers. Again, with a little training and information, social workers can become effective sex educators and counselors.

Clergy. Counseling is often a vital role of the clergy in today's religious institutions. Certainly, the beliefs of the particular religious organization will bear directly on the approach taken by clergy regarding sexuality and disability. Our surveys show that, presently, disabled people are not receiving or expecting to receive sex education/counseling services from the clergy. However, members of the clergy do have a responsibility to be aware of other resources in their community to which they could refer someone who has a concern about sexuality.

Sexuality includes many aspects of daily living, from self-image to marital concerns and family planning. It is probable that a member of the clergy will discuss some of these concerns with individuals in his or her congregation. Depending on the individual's level of comfort, skill, and knowledge, a member of the clergy could very effectively give both permission and limited information.

Hotline Staff Member. Telephone hotline services are becoming more and more popular as a means of disseminating information. The role of the hotline staff member in dealing with concerns related to sexuality and disability is basically one of referral. A hotline staffer could give permission and limited information by making referrals from directories of persons and organizations dealing with the caller's concern(s).

Psychologists. In our survey of disabled people, psychologists were ranked high on the list of those considered to be the most appropriate providers of sex education/counseling services. Yet, we have also found that disabled people are not receiving such services from psychologists. Why? Most psychologists have had no specialized training in either disability or human sexuality. A psychologist is in a unique counseling position to be able to give permission, limited information, and (depending on comfort, skills, and knowledge) specific suggestions and intensive therapy.

Many sexuality concerns deal with self-image, personal adjustment, development of relationships, and anxieties and questions about "appropriate" behaviors. Both disabled and nondisabled people share these concerns. Psychologists should remember that people with disabilities are people, first. The disability, itself, may or may not be directly related to a sexual concern. The psychologist cannot automatically assume that a disabled client's sexual problem is the *direct result* of the disability, for disability is only one factor in the client's life. The level of effect the disability has on the client's well-being will differ with each individual, and a sexual concern could have no direct relationship to the presence of a disability.

A psychologist can be very effective in offering guidance in social skills development as well as individual, group, and/or couples counseling. It is vital that people providing psychological support services recognize the sexual needs and concerns of disabled people, for other helping professionals and disabled citizens are turning to psychologists for guidance. Psychologists must be prepared, educated, and trained to meet these expectations.

Rehabilitation Counselors. Sexual well-being affects all aspects of the human make-up; it is not an isolated or clearly defined characteristic. Professionals now recognize that a sexually happy person is likely to be more effective in both personal and vocational life. The goal of the rehabilitation system is to facilitate social and physical adjustment to disability and to help the disabled person become a fully-functioning member of his or her community. The rehabilitation system is therefore beginning to recognize the importance of sex education and counseling to the total rehabilitation program. One counselor surveyed summed up the close relationship between vocational and sexual well-being in the following comment:

> I feel that a counselor's failure to help a client work out social/sexual concerns contributes to vocational failure. In a comprehensive facility we see numerous clients who experience their first sense of social/sexual peer acceptance. If they are not helped to deal with their sexuality during this time, they return to the community where they had previously been sexually rejected and must fail in order to return to a "handicapped environment" but where their social and sexual needs are met.

As a result of this recognition, the rehabilitation counselor has the responsibility to initiate and offer guidance in discussions of sexuality with disabled clients.

The Sex and Disability Project surveyed 156 rehabilitation counselors in two states. Although many counselors indicated a willigness to offer sex education and counseling, few were actually providing such services. Only 15% of those counselors surveyed gave clients access to reading materials on sexuality; 7% gave access to audio-visual materials. Only 28% of the counselors had received training, of any kind, in sexuality and disability.

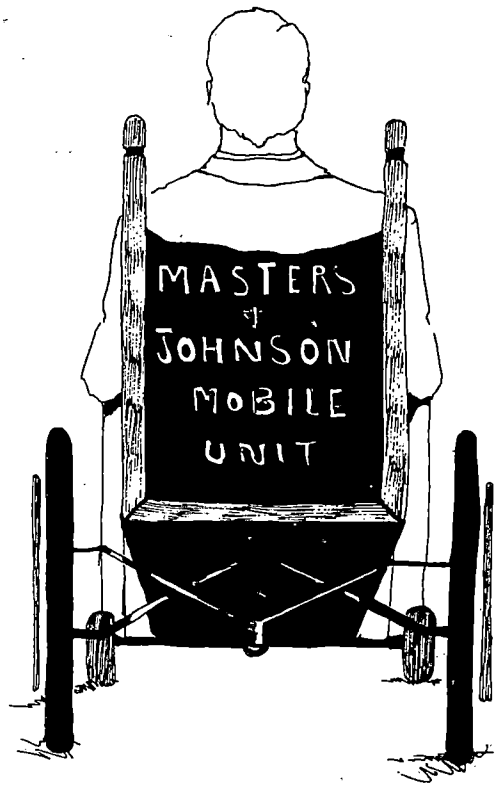
The counselors listed many reasons why they do not provide sex education/counseling services. Among these were: lack of specialized training, lack of agency support, lack of time to do actual counseling, lack of appropriateness in a vocationally focused program, and lack of awareness that sexuality could be a problem for a disabled client. One respondent stated:

> In general I would say that VR counselors are not prepared to deal with the subject. Agency requirements make it impractical to expect the counselor to have the time to do effective counseling in the areas of social skills, sexuality, personal problems, etc. The VR counselor who has good rapport with his clients might be the best person to provide the service.

Comfort with sexuality was not seen to be a problem by rehabilitation counselors. Of those surveyed, 84% stated that they felt comfortable discussing sexuality with their clients. Yet, only 19% indicated that they ever initiated the discussion. Counselors felt that their lack of knowledge about sexuality and disability inhibited them from being effective counselors regarding sexual issues.

Rehabilitation counselors are receiving contradictory messages. While rehabilitation policy makers are making the statement that sexuality should be a part of the comprehensive rehabilitation process, they are not providing their counselors with the training and support to provide sex education/counseling services. On a policy level, all rehabilitation administrators surveyed felt that the vocational rehabilitation system should address sexuality, yet these same administrators listed rehabilitation counselors as being inappropriate providers of sex education/counseling services. It is not surprising that rehabilitation counselors are confused about their role in providing sexuality services to their clients.

Rehabilitation counselors could be excellent providers of sex education/counseling services to disabled people. Rehabilitation counselors should already have a substantial knowledge base about disability, and they have shown a willingness to include sexuality as part of their counseling programs. Also, rehabilitation counselors are seen by newly disabled people as being the major coordinators of rehabilitation services. With encouragement, minimal training, and access to resources, rehabilitation counselors could be the vital link to the provision of sex education/counseling services to disabled people.



Other Disabled People. A very desirable provider of sex education/counseling services to disabled people would be a trained, competent disabled peer. A disabled professional would have both the technical and personal knowledge to most effectively provide services to the disabled community. But a disabled person, of any profession, can provide services through community channels such as disabled consumer groups (e.g., National Paraplegia Foundation). Peer self-help groups often can provide permission, limited information, and specific suggestions by sharing experiences and concerns. Hopefully, more disabled people will enter professions in medicine, social work, psychology, and education, thereby filling a need for disabled people seeking information. But having a disability does not automatically qualify someone to provide adequate sexuality services. Comfort, knowledge, and skills are also needed by the disabled person in order to deal effectively with many sexual concerns.

A most important element in peer counseling is the support which can be obtained by people who feel alone or different because of a disability. A surveyed disabled person who had taken a course taught by other disabled people said:

> The course helped me in the fact that I was able to meet and speak with other handicapped couples. I felt for the first time that I was not an isolated person with an isolated problem.

This feeling of belonging is one of the strongest elements of permission, and may prevent future problems related to sexuality.

Sex Counselors/Therapists. The vast majority of surveyed disabled people, counselors, and rehabilitation policy makers indicated that sex counselors and sex therapists would be the most ideal providers of sex education/counseling services to disabled people. Yet only three of the surveyed disabled people who had received services in the past got those services from a sex counselor or therapist.

Perhaps the desirability of a sex counselor/therapist as a service provider for disabled people is tied in with the mistaken belief that special training is always needed to deliver sexuality services. Throughout this section we have seen that most of the PLISSIT model does not require the degree of specialization possessed by the sex counselor/therapist. Intensive therapy should only be considered after permission, limited information, and specific suggestions have failed to meet the client's needs. Although a sex counselor/therapist can progress through all four levels

of the PLISSIT model, in many cases other professionals can offer two or three levels which are sufficient to meet client needs.

This is not to say, however, that sex counselors and therapists should not become involved in sexuality and disability. Some disabled clients' goals *do* require intensive therapy or specific suggestions which a sexuality professional is best trained to give. Sex counselors/therapists must be made aware of the sexual concerns of disabled people so that appropriate services can be provided when they are needed. As counselors dealing with sexuality (often a sensitive subject), it can be assumed that sex counselors/therapists already have most of the skills necessary to provide services to disabled people. With a positive attitude and knowledge of some medical and psychosocial aspects of disability, sex counselors and therapists can provide competent and needed services to the disabled community.

SEX EDUCATION AND COUNSELING AT HOME

> We need to consider that some of the best education is done by "unqualified" people. I have not noticed that teachers, nurses, or doctors are, in general, especially good sex educators. We have, perhaps, overstated the importance of expertise when what counts is attitude and good will.
>
> — Sol Gordon, 1974

All sex education begins at home. This may seem to be an outrageous statement. You may say, "But my parents never discussed sex with me! I got no sex education at home." The mere fact that sex is not discussed at home provides an element of sex education. Lack of recognition of sexuality indicates a "hands off" attitude toward sex; therefore the child is "taught" to think that sex is a mysterious, even "dirty," aspect of life. All too often we think of sex education as formal or informal explanations of sexual anatomy, intercourse, and contraceptives. This is, in fact, part of sex education. But subtleties, attitudes, and role models are the first aspects of sexuality learned by the child, and these are demonstrated, knowingly or unknowingly, by parents.

Parents, then, play a crucial role in sexual development and maintenance of self-image. In many homes, children receive helpful information about sexuality; but more typically sex is rarely discussed. Disability is an added dimension to parental hesitancy about discussing sexuality. Overprotectiveness, embarrassment, lack of information, and misconceptions all contribute to the avoidance of sexuality discussions by the parent of a disabled child.

Parents can be the first and foremost providers of permission and limited information, if they can become comfortable with their disabled child's sexuality. They can be the foundation for a disabled person's positive self-image, sexual independence, and comfort. Most important, parents need to realize that ignoring sexuality does not cause it to go away. Parents have a responsibility to provide effective and relevant information about sexuality to all their children, disabled or not.

BUT NO ONE EVER ASKS ABOUT IT!

One of the most common reasons given in our survey for not providing sex education/counseling services was, "But no one ever asks me about it." From physician to clergy, social worker to rehabilitation counselor, professionals tried to deny that disabled people had sexual concerns because disabled clients did not initiate discussions about sex. Many surveyed rehabilitation counselors recommended that it be advertised that they can give sex counseling services so that more disabled people would initiate the discussion. But the point is, do rehabilitation counselors wait for their client to initiate discussions about vocational adjustment? Why, then, do they not initiate discussions about sexual adjustment?

Research has shown that recognition or diagnosis of sexual problems usually occurs through initiating the discussion. In a 1967 study by Burnap and Goldun, 66% of physicians who routinely asked about sexual problems identified sexual problems in half their patients. But over 75% of those MD's who did not actively inquire estimated that less than 10% of their patients had sexual problems. This study indicates that professionals who don't ask about sexuality are unaware of the many people who have sexual concerns. These professionals don't consider sexuality to be significant to disabled people. Seventy percent of the rehabilitation counselors surveyed (90 out of 130) said they don't provide services because clients don't request them; therefore, they believed that disabled clients had no overriding sexual concerns.

Comfort, knowledge, and skill; a resource library; training; a comprehensive service package—all are useless if the subject of sexuality is not brought up by the service provider. Not all disabled people have sexual concerns which they need to discuss with professionals. If that is the case, when asked about sexual concerns, they will simply say they have no problems. But the watchword for the professional is "ask, first." It is unfair and often erroneous to assume that no sexual problems exist if the client does not initiate discussion.

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Chapter 5
Training Needs and Options

> All professionals should be able to deal with this subject /sexuality/ accurately and openly.
>
> —A rehabilitation counselor

Easier said than done!

Although it is not our purpose here to discuss all the available literature on the training needs of service providers, the literature to date strongly supports the following conclusions:

- No professional label (e.g., doctor, psychologist, counselor, teacher) guarantees competency in providing sex-related services.
- The personal attitudes of the provider toward sexuality and disability can significantly affect the sexual well-being of the client.
- Where training has been initiated, many potential providers show a willingness to participate.
- A wide variety of training approaches have been developed and many have proven highly successful. (See Section IV)

The importance of training professionals to provide sex education/counseling services seems evident. For most professionals, training in sex education/counseling skills has been almost nil. Yet many professionals are perceived by clients to be experts in the field; and other service providers who have frequent contact with disabled individuals could contribute to sexual well-being if training were available. Many who could or should be knowledgeable about sexuality simply aren't. The reason is quite simple—they were never taught about it!

In our survey, over 70% of the rehabilitation counselors had never received any training in human sexuality. Over half of the rehabilitation counselors cited lack of training as a reason for not providing sex education/counseling services. When asked how sex education/counseling services could be improved, one counselor stated:

> 1) Provide more and better training opportunities for counselors.
>
> 2) It should be clear /that/ counselors are expected to attempt to deal with client sexuality issues.

Many people do not yet realize that sexuality is an important aspect of rehabilitation. Less than 20% of the counselors in our survey initiated conversation about sexual issues with clients. Lack of agency support and lack of training are cited as primary hindrances.

Training is also needed for professionals outside the direct realm of rehabilitation. Ebert & Lief (1975) report a study in 1959 in which it was found that sex knowledge of medical school graduates was not significantly greater than that of other professional school graduates. Furthermore, they found that these new physicians held many myths about sexuality. Over 50% believed that masturbation caused mental illness—and an amazing 20% of their professors agreed with them! As late as 1975, they found that 15% of medical school students still believed that autoeroticism and mental illness were related.

As we discussed in Chapter 4, many individuals can have an impact on the sexual well-bring of disabled citizens. The critical link between consumer needs and adequate services is the availability of competent providers. Although the roles in providing services may vary, training is essential to insure that a sufficient number of providers

are being prepared to offer relevant and needed services.

WHY ISN'T TRAINING BEING DONE?

If the need for services is great and the availability of providers is limited, why aren't people being trained? The reasons are many. We would like to explore three of the most common ones.

1. **Lack of Administrative Support**

> A primary barrier has been, not only lack of administrative support, but a direct prohibition against such training.
>
> —A rehabilitation trainer

In some settings policy makers, by silence, give their consent to inaction. In other settings, strong directives for non-involvement are given as quoted above. Between these two positions are a variety of non-supportive strategies such as delaying decisions on providing training or placing human sexuality training at a low priority ("no money").

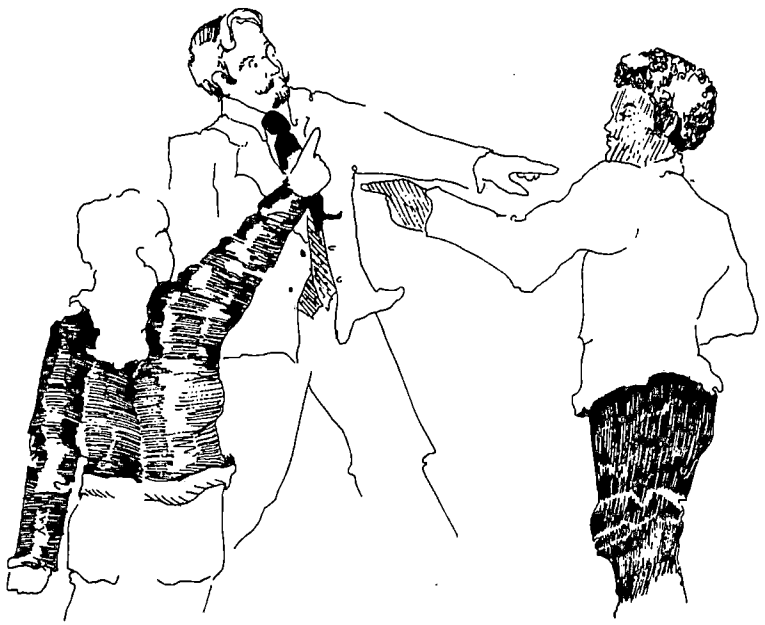
In our survey, when rehabilitation trainers were asked why they hadn't adequately addressed the training need, the most frequent response was lack of administrative support.

2. **Not My Job**

> The consensus of our supervisors statewide who coordinate in-service training is that training of counselors in human sexuality is not a part of our training mission.
>
> — A rehabilitation trainer

The relevancy of sexual well-being to total well-being is as yet unclear to some rehabilitation trainers. The need for sex education/counseling is unrecognized or ignored. The corollary to the "it's not my job" stance is the "it's someone else's job" position. In this corollary, the need for training is recognized, but the responsibility is placed on "someone else." As in most situations, there is no "someone else."

In our survey of trainers, more than one-third stated that they did not meet the training need because it is "not our mission." Yet less than 15% of the trainers thought that rehabilitation personnel should *not* be involved in sex education/counseling services. Ninety-eight percent saw the role of rehabilitation agencies as one of referral (78%) or provision (58%). The question remains, who is to train the rehabilitation professional to refer knowledgeably or provide skillfully? If it's "not my job," then whose is it?



3. **Inadequate Preparation**

For many rehabilitation trainers, experience and expertise in the area of human sexuality are lacking. Because they have had little experience in sex education, they feel unqualified to deliver training. In our survey, 23% of the trainers cited inadequate preparation as a major hindrance. Trainers most frequently cited five program aspects for which they needed assistance: knowledge of audio-visual materials (82%); availability of training materials (77%); training for themselves (59%); program content (47%); and program objectives (41%). It is evident that "training the trainers" is a much needed activity.

TYPES OF TRAINING PROGRAMS

These three major obstacles discussed above represent some of the most common stumbling blocks to training potential providers. Yet many training programs have overcome these barriers and have proceeded to initiate training. These exemplary programs fall into four major categories.

A. **College and University Pre-Service**

Today many human services curricula, from social work to medicine, from health education to rehabilitation counseling, include sexuality training as part of their total program. For example, the University of Minnesota Medical School provides course work and practicums in sexual health for medical students, as do some other medical schools. Some pre-professional programs offer specializations in human sexuality, while others incorporate sexuality into courses on family dynamics, psychosocial adjustment, human growth, counseling, etc.

More recently, several institutions of higher education have begun offering degree programs in human sexuality, for instance the Institute for the Advanced Study of Human Sexuality in San Francisco, California. Colleges and universities are becoming a major training resource in the area of sexuality services.

B. **Continuing Education**

A broad range of training activities has been offered in the last few years as continuing education. For many people, returning to full-time student status at a college or university is both unfeasible and undesirable. In order to provide much needed training in human sexuality and disability, short-term training has been initiated.

Program content, duration, and target audience vary widely. A selected list of short-term training efforts appears in Appendix D. These programs represent a small sample of those offered from 1976 through 1978. They suggest that many options are available to those who seek to improve their skills as providers of sex education/counseling services.

C. **In-Service Training**

In our survey, an overwhelming majority (76%) of rehabilitation counselors indicated in-service education as the most efficient way to provide training in sexuality and disability. Over one-third believed that an in-house consultant on sexuality could provide needed training to staff. Many human services facilities and agencies have already begun to provide training to staff members in sexuality. Training may be provided by the agency directly or may be purchased from outside trainers. Coordination and delivery of training are managed as an intra-agency activity. Common elements of in-service training include:

- orientation to the agency/facility policies
- procedures and activities
- special needs of clientele
- improvement of professional competencies

In many rehabilitation settings, sexuality and disability has become part of in-service education. The Multi-Resource Center, Inc.'s Center for Continuing Education in Region V offers workshops upon request to state vocational rehabilitation agencies. Another example of in-service education is the training offered by the Southern

Adirondack Planned Parenthood (see Appendix D). They have designed in-service programs for developmental disabilities centers. Their program consists of eight sessions over a two month period. In 1976, the Carolina Population Center in Chapel Hill, North Carolina, offered a similar series of workshops for the staff of residential centers for mentally retarded citizens. An outcome of the training endeavor was the publication of a manual for trainers (see Section IV).

The importance of in-service education cannot be overstated. Before most services can be provided, qualified personnel must be obtained. In most settings, however, the quality of services will depend not only on the expertise of the direct provider but also upon the understanding and positive acceptance of the service by other personnel. All staff should be included in training efforts because all will, in some way, affect the quality of services.

D. **Community Education**

This broad category of educational activities includes public forums, television and radio programs, newspaper features, and a host of other activities aimed at increasing knowledge and acceptance of sexuality services. Community education helps build the necessary foundation for sexual well-being by destigmatizing the topic of sexuality.

Programs on teenage parenting, contraception, childbirth, marital harmony, etc., have been increasing. More recently, community education on sexuality and disability has been developing. For example, in 1975 the Family Life Council of Greensboro, North Carolina, sponsored an evening public forum on sexuality and disability. The program was attended by over 400 citizens, many of whom were disabled. Frequently, disabled citizens and rehabilitation professionals are invited to appear on TV talk shows or radio programs to present information to the public. The British Broadcasting Company produced a film documentary about a couple with cerebral palsy for use on TV. This documentary, "Like Other People," has not been widely disseminated to the general public in this country, though it was aired in England.

The potential for community education, however, is largely untapped. Because the socio-sexual well-being of disabled citizens depends to a great extent on the attitudes and acceptance of the community at large, this vital channel for education should not be overlooked.

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Chapter 6
Are Your Services Accessible?

Throughout this handbook we have been discussing the need for available sex education/counseling services for people with disabilities. We have determined that some services and training programs do exist, even though many disabled people have not received them. One of the problems with present service delivery seems to be access. Existing and future services are of no value unless they are accessible to disabled individuals.

The term "access" as it will be used in this chapter, implies much more than ramps and wide doorways. For services to be accessible, the following things must be taken into account:

- Professionals and consumers must be **aware** that the services exist.
- The service delivery staff must have positive **attitudes** toward both sexuality and disability.
- The service delivery site and facility must be free of **architectural and environmental barriers** for all disabled populations (including those with sensory disabilities).
- All materials connected with the service (including advertisements) must be provided in a form easily understood by everyone. Alternative forms of **communication** (e.g., sign language, tactile models) must be used to insure availability of services to all disabled people.
- Services must be financially accessible. Considerations for **financial access** include type of service, transportation cost, and target population.

This section of the handbook will address the importance of the above issues, including specific guidelines to enable you to evaluate and improve the accessibility of your services.

PUBLIC AWARENESS

One of the biggest problems in the field of sexuality and disability is poor advertising of services. Often, the public is unaware that sex education/counseling services exist. Perhaps they do not receive professional journals or belong to organizations which announce service availability. In many cases, professionals, themselves, do not know where to refer disabled people who request sex education/counseling services.

One result of this lack of communication is a decrease in the number of services. In some cases a program which has not done adequate outreach will discontinue because of low attendance. The assumption made is that the low attendance reflects a lack of need, when, in fact, the public may simply be unaware of the availability of the service.

> *Example:* The Women's Co-op decides to begin a weekly group discussion on sexuality and disability. They advertise their intentions in medical professional journals and send news releases to other women's organizations. They forget to contact local disabled consumer organizations or to advertise in their local newspaper. When they begin their sessions, no disabled women show up. The Co-op assumes that disabled women must not need the service, so they abandon the idea.

The result of service discontinuation affects many disabled consumers. Because services are not adequately advertised, or are discontinued before "word of mouth" announces their availability, disabled consumers don't think any services exist. Because physicians, counselors, and referral agencies are unaware of the programs, disabled people seeking services are not referred to them.

Public awareness of your services can be facilitated through publicity, referral, and outreach. When publicizing your program, make sure that you contact all possible target populations and referral sources (e.g., medical and rehabilitation service providers, disabled consumer groups, social service providers). Make use of bulletin boards (e.g., in grocery stores, community centers), local radio and TV stations, local newspapers. Also, make sure your service is known to people who are likely to refer (e.g., hotlines, physicians, community mental health centers).

Public awareness is the first step toward public acceptance. Effective publicity and advertising not only insure participation; they also help to destigmatize sexuality and disability in the community.

CHECKLIST 1: PUBLIC AWARENESS

Have You Done the Following Things?

Sent program announcements to:

- Disability-related journals _____
- Professional journals _____
- Disabled consumer organizations _____
- Local radio stations _____
- Local newspapers _____
- Local physicians _____
- Local psychologists _____
- Local community mental health centers _____
- Local Planned Parenthood offices _____
- Local college & university activities centers _____
- Local hotline services _____
- Local Office of Vocational Rehabilitation _____
- Local social service agencies (e.g., United Way) _____
- Local civic organizations (e.g., Jaycees, Kiwanis) _____
- Local health care centers (e.g., clinics) _____
- Local recreation programs _____
- Local rehabilitation facilities _____

Distributed posters/notices to:

- Schools & universities _____
- Local store windows _____
- Community activities centers (e.g., YMCA) _____
- Residential facilities (e.g., halfway houses) _____
- Laundromats _____
- Shopping centers _____
- Places of worship _____
- Recreational facilities _____

To locate and contact the above resources, look in the telephone book and/or obtain directories of social services.

ATTITUDINAL ACCESSIBILITY

Attitudes can make or break the services offered to disabled people. Careful program planning and effective public relations will be wasted efforts if the service providers involved have negative attitudes about sexuality and/or disability. A program of services that looks like dynamite on paper will fizzle like a wet firecracker if the staff displays stereotyping or negative attitudes. Two examples:

> A general sex education course is set up in a junior high school. The teacher believes that sexuality involves only physiological functioning and hygiene. He emphasizes the "crisis" aspects of sexuality such as venereal disease and unwanted pregnancies. The psychological and social aspects are not explored, and, as a result, some of the students emerge from the course with a mechanical and limited view of sexuality.

> A nurse in a rehabilitation hospital believes that it is her mission to "help those poor, suffering, handicapped people." When a newly disabled patient tries to ask some questions related to his sexual functioning, she is shocked at the thought of a disabled person even considering sexual activity. Her patronizing attitude has abruptly ended any discussion of this topic, and the patient becomes confused and frustrated.

Negative attitudes, then, not only prevent the provision of effective services, but can also cause real harm to disabled individuals. The adolescents in the first example may grow up limiting their sexuality unnecessarily. The patient in the second example may hesitate to ask someone else about sexual concerns and may even assume that sexual activity can no longer be part of his life.

Stereotyping and negative attitudes can also be communicated through language. If staff members talk about "cripples," "victims," "sufferers," "the unfortunate," and "retards," services to disabled people will inevitably suffer. The language used in publications and other material distributed by your organization needs to be scrutinized carefully for words, phrases, images, and illustrations reflecting poor attitudes.

Increased awareness of negative and limiting attitudes is the first step in making services attitudinally accessible. Positive measures to change these attitudes are the necessary second step which will help insure that the sex education/counseling services offered to disabled people will be useful and used.

CHECKLIST 2: ATTITUDINAL ACCESSIBILITY

Some Questions to Consider

1. Do staff members view *all* people as sexual beings?

   or

   Are some people (e.g., disabled individuals) considered asexual?

2. Do the service providers define sexuality as including social, psychological, mental, *and* physical components?

   or

   Is sexuality considered to be simply a matter of physical functioning?

3. Are sexual options discussed, and is experimentation encouraged?

   or

   Is genital performance considered all-important?

4. Do service providers initiate and encourage discussions about sexuality?

   or

   Is the topic of sexuality ignored, avoided, or suppressed by staff members? Are sexual issues raised only when the client initiates the subject?

5. Can staff members provide services to individuals who have different sexual lifestyles or preferences (e.g., communal living, homosexuality)?

   or

   Is it assumed that all clients should accept the values and preferences of the service provider?

6. Do staff members take responsibility for providing sex education/counseling services to disabled individuals?

   or

   Is there a "pass the buck" approach used when dealing with sexuality-related matters, e.g., "Parents (voters, neighbors, teachers, funders, supervisors) won't like it"?

7. Do clients have opportunities to socialize freely with peers of both sexes?

   or

   Are clients segregated and discouraged from socializing?

8. Do clients have privacy?

   or

   Are clients constantly supervised and/or crowded?

9. Is socially appropriate behavior expected, taught, and encouraged?

   or

   Is inappropriate behavior tolerated because clients are considered too helpless and child-like to be responsible?

10. Do clients have control over their lives, e.g., planning leisure time activities, seeking jobs, making responsible decisions about sexual expression?

    or

    Are all decisions made for clients?

11. Is there an emphasis on capability (what a person *can* do)?

    or

    Is there an emphasis on disability (what a person *can't* do)?

12. Is the principle of normalization adhered to in the delivery of sex education/counseling services?

    or

    Are services unnecessarily different from those offered to the general population?

13. Are disabled women encouraged to experiment as much as men?

    or

    Is it assumed that women will take the passive role in sexual activity?

14. Is the sexual partner included in the program? Is attention paid to problems related to meeting and attracting potential partners?

    or

    Are sexual concerns considered in isolation, without reference to relationship issues?

15. Are basic human rights considered to apply to all disabled clients?

    or

    Are basic human rights treated like privileges when disabled people are involved?

16. Are disabled clients viewed and treated as individual people with individual needs?

    or

    Are disabled people lumped together under various labels and treated as though they all have the same needs and preferences?

ARCHITECTURAL ACCESSIBILITY

Architectural barriers are obstacles to access resulting from structural problems of a building (e.g., stairs, doorways). **Environmental barriers** are obstacles to access caused by additions to the structure (e.g., thick carpeting, high elevator controls, narrow bathroom stalls).

Your services may be just what the public needs. But have you considered whether or not wheelchair users can get in the door? Can they use the bathroom? Obtain parking close to your building? How about elevators, curbs, stairs, and floor coverings? Are there raised numbers in elevators for people who are blind or visually-impaired? How about visual fire alarms for deaf individuals? These are just a few of the many things to consider when determining the architectural and environmental accessibility of your services. You cannot consider a facility accessible unless it provides for the limitations of the most severely disabled person. And a facility which is accessible to disabled people will be more easily used by *all* people!

Requirements for accessibility under the law vary state by state. Some facilities are required by law to be architecturally barrier-free, and regulations governing the requirements depend upon the type of funding your program receives. To determine what regulations your facility should meet contact:

Architectural & Transportation Barriers Compliance Board
330 C. Street, S. W.
HEW South - Switzer Building
Washington, D.C. 20201

The Task Force on Concerns of Physically Disabled Women also has a very helpful handbook on architectural and environmental accessibility which includes illustrations, dimensions, and specific information on making services barrier-free. The book, entitled *Within Reach*, is available for $2.95 from:

Human Sciences Press
72 Fifth Avenue
New York, NY 10011

CHECKLIST 3: BARRIER-FREE ACCESS

The following considerations should be noted when evaluating your facility for architectural and environmental barriers:

IF...	THEN,
SITE:	
Your site is on a hill or slope	Modify landscaping and walkways to provide easier access.
There are steps to the entrance	Build ramps with slope no more than 1" rise to every 12" length.
There are obstacles on the walkway	Clear walkways of bicycles, directional signs, etc.
The walkway is not paved	Make sure surface is level (no potholes or gravel).
No accessible mass transportation available	Provide alternative transportation.
There is no parking close to the site	Build parking spaces nearby designated for use by disabled people.
There are curbs at or near the site	Modify them by ramping and building curb cuts.
DOORWAY OF FACILITY:	
There are narrow doors	Widen them to 32".
There are door mats	Remove or modify them so they are non-skid and adhere to the floor.
There are door knobs	Lower them so that they're within reach of wheelchair users.
There are double doors (one right after another)	Make sure there is a 7' space between them, or remove one door, or provide an alternative entrance.
STAIRWAYS:	
There are steps	Make sure an alternative (e.g., elevator, ramps) is available.
Steps are more than 7" high	Modify to lower steps.
Handrails are not built-in	Modify and build to continue at least 1' beyond end of stairs, 32" from base of each step.

ELEVATORS:

Control panel (*all buttons*) is more than 4' from floor	Lower entire panel or hang a stick from a chain which can be used to press the buttons.
Elevator is less than 4'x4'	Modify for wheelchair maneuverability.
Control buttons have numbers even with the surface of buttons	Install raised numbers for blind users.

FLOORS:

The surface is tile or linoleum	Make sure it is non-skid.
There is carpeting	Make sure it is *not* thick (e.g., shag); scatter rugs are also dangerous.

BATHROOMS:

There is a swinging door	Modify to swing both in *and* out when pushed.
Mirrors, sinks, towels, soap, etc. are available	Lower them to no more than 4' (at highest level) from floor.
There are toilet stalls	Modify to widen them for wheelchair use.

MISCELLANEOUS:

There are emergency alarms	Install both sound and visual (e.g., flashing light) alarms.
You have a water fountain	Lower for use by persons in wheelchairs.
You have a public phone	Lower for wheelchair user access & install TTY for deaf users.

Additional Suggestions

- Obtain local government regulations regarding your facility.
- Review regulations and items above to evaluate accessibility.
- Organize and meet with a panel of disabled people to get suggestions on how to make your facility more accessible.
- Include disabled people in all aspects of service planning.

ACCESS TO INFORMATION

Many people who have disabilities (e.g., blindness, deafness, mental retardation) find it almost impossible to obtain information in a medium which they can use. For example, a great deal of available written material has not been transcribed to audio-tape; films are not captioned; and sexuality and disability material is unavailable in most bookstores. The importance of this becomes clear when you stop to consider how much sexual information is obtained through media such as television and radio. Our sexual mores and self-concepts are shaped, in part, by television commercials, movies, magazines, and books. Many disabled people have no physiological sexual problems which result directly from their disability. But the inaccessibility of helpful information on sexuality is sometimes a barrier to their sexual well-being.

The General Disabled Population. Books and magazines are a crucial source of information on sexuality and disability. Yet most bookstores have no such material in stock. Another problem may be the physical inaccessibility of the stores themselves. Often book and magazine racks are placed too high for wheelchair users to reach them, aisles are narrow, and stairways separate store sections.

The Mentally Retarded Population. Many materials on sexuality are complex and assume some type of previous knowledge regarding human sexuality. Sex education materials which are highly illustrated and written in non-technical language should be made easily available.

The Deaf Population. Because only 2% of parents of deaf children know manual communication, sexual information is usually not offered in the home. Many deaf students attend residential schools in isolated settings which further inhibits access to information from the media and hearing peers. It is also important to note that English is a second language for many deaf persons (manual communication being their first language), and much of the written material on sexuality is written in difficult, technical language. Films and television programs are rarely captioned, which reduces their effectiveness for deaf individuals.

The Blind Population. People who are blind from birth have never had the opportunity to see a human body, and our society inhibits tactile exploration of the body. Visually-impaired people are also deprived of access to sexually-oriented literature, which is rarely transcribed to audio-tape. Isolated school settings, inability to pick up visual cues (body language), and stigmatization contribute to problems with socialization and dating.

CHECKLIST 4: ACCESS TO INFORMATION

The key to providing accessible information for service recipients is to *ask them* what they need. Not all people with hearing impairments want interpreters; sometimes amplified earphones are enough. Some visually-impaired people require large-print written material, while others prefer Braille or audio-tape. You can't necessarily assume that a person with "disability X" requires "adaptation X."

It is helpful if you ask for communication information on the registration form, intake form, or during an initial personal contact. You can anticipate, however, some of the accommodations people may request. The following is a list of commonly-requested adaptations. During your program/service planning stages, you should investigate how, where, and when you can obtain these adaptations if one or more are requested.

- **People with hearing impairments may request the following:**

  Sign language interpreters (AMESLAN and/or Sign English)
  Written film transcripts
  Highly visual films (e.g., no narration)
  Written information in non-technical language
  Amplifying earphones for films and/or lectures
  Written, rather than oral, instructions

- **People with visual impairments may request the following:**

  Highly auditory films (e.g., mostly narration)
  Written information transcribed into Braille
  Written information transcribed onto audio-tape
  Information printed in large type
  Tactile anatomical models
  Raised pictures, photographs, and charts

- **People with mental retardation may request the following:**

  Many visual aids (e.g., pictures, anatomical models)
  Written material in non-technical language
  Experiential exercises (e.g., role play, pantomime)

FINANCIAL ACCESS

Lack of money, for both service provider and recipient, is a pervasive problem in human services. Books, films, and other resources are often costly. Consultants, staff pay, overhead, and rent seem to prohibit ideal provision of services. The reaction of many service providers, coordinators, and policy makers to these high expenses is to raise the price of the service, to discontinue the service, or to offer the services primarily to professionals who are sponsored by their employers.

But what about those disabled consumers, their friends and families, and professionals whose agencies don't see a need for sex and disability training or services? How do they obtain the necessary resources to attend available programs? Should the availability of appropriate services depend upon the potential recipient's financial status?

Obviously, good services cost money. Materials must be purchased, rent must be paid, and staff must receive salaries. There are several ways, however, to enable less affluent people to use your services without reducing the quantity or quality of the services.

- Consider a sliding scale based on an individual's income. This practice is utilized by many social service organizations, such as community mental health centers and Planned Parenthood centers. The sliding scale works on the principle that those with higher incomes pay a slightly higher fee than those with lower incomes. Again, the goal is to make the service accessible to everyone who needs it. On most sliding scales, provisions are made for free services if an individual shows a need but is totally unable to pay. Although this practice is a bit complicated administratively, it is fair to all potential recipients of your service.

- If your services are sometimes offered to people who are sponsored by agencies (e.g., in-service training participants), charge them more for the service than non-sponsored people. This practice is already used by some service providers to include full-time students at lower rates, (e.g., sponsored medical and rehabilitation professionals $60; non-sponsored professionals $35; students $20). Using this procedure enables you to collect the needed amount of resources for your services, and shifts the financial burden to those who can best afford it.

- Take a good, hard look at your services to see if excess money is being spent. Maybe you could use cheaper materials, hold your program in a less expensive or donated facility, or obtain qualified staff members who volunteer their time, without lowering the quality of your services. Many times finances are wasted because of poor planning or poor research. Perhaps you haven't considered all of the options available to you. Take some time to really assess your program needs. You will be surprised to see that many extras that add to your budget can be cut. We are not suggesting a sacrifice of quality. We are suggesting that by good planning and awareness you can put together the same program for less money. And many people who previously could not take advantage of your services will be able to use them.

- If you reduce cost to a minimum, and even a sliding scale will not provide enough money for your services, research outside funding assistance. Many government and private funding agencies are available to assist good programs which show a sincere interest in making their services accessible to people of all incomes. Start by checking with the Division of Vocational Rehabilitation, Office of Rehabilitation Services Administration, social and civic organizations (e.g., United Way, Kiwanis Club), National Institute of Mental Health, Bureau of Education for the Handicapped, and community health centers. In some cases a written proposal for funding will be necessary, and in other cases a more informal arrangement can be made. Don't automatically exclude the possibility of obtaining additional resources from outside your organization.

- Service providers often forget about the expense of traveling to and from the service site. In urban areas, many disabled service recipients are unable to use mass transportation. In rural areas, participants may have difficulty arranging and/or affording appropriate transportation. When planning your services, take transportation costs into consideration. Try to locate your services in an accessible area and make arrangements for transportation of those who cannot reach your services. Often, volunteers can be obtained to transport those individuals who need a means of getting to your facility.

Below are some guidelines to help you plan the cost of your services, both to you and to consumers. The idea of charging for your services, is of course, to break even. If you are making a profit, you are probably charging consumers too much. If the amount consumers pay doesn't meet your program needs, you need to consider some alternatives. The guidelines below can be adapted to short-term projects (e.g., workshops) and to continuing programs (e.g., Planned Parenthood). Some of the items listed (e.g., food) may not be applicable to your setting; if not, replace them with other expenditures.

CHECKLIST 5: GUIDELINES FOR FINANCIAL PLANNING

ITEMIZE COST OF: Materials -- rental _____
purchase _____

Rental of space _____

Salaries and fringe benefits _____

Staff transportation _____

Meals and lodging _____

Communications (phone & postage) _____

Publicity _____

Copying of materials _____

Miscellaneous _____

_____ _____

_____ _____

1. TOTAL COST OF SERVICE DELIVERY _____
2. COST TO CONSUMER (include meals & room if appropriate) _____
3. MULTIPLY LINE 2 BY NUMBER OF CONSUMERS RECEIVING SERVICE _____
4. SUBTRACT LINE 1 FROM LINE 3 _____

* If Line 3 is greater than Line 1 (you are making a profit), consider:

- Reducing total cost per participant
- Decreasing cost for some participants through use of sliding scale
- Offering free transportation
- Including more participants through outreach programs

* If Line 3 is less than Line 1 (you are losing money), consider:

- Assessing your budget, cutting unnecessary expenditures
- Increasing costs for some participants through use of sliding scale
- Obtaining outside funding

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Chapter 7
Conclusions and Recommendations

For specific recommendations related to hearing impairment, mental retardation, visual impairment, cerebral palsy, and spinal cord injury, refer to the final section of each literature review (Appendix B).

BASIC CONCEPTS AND POLICIES

- Sexuality should be defined broadly to include not only physiological aspects, but also emotional, intellectual, and social needs and experiences. This expanded definition increases the relevancy of sexuality-related services in a wide variety of settings.

- Sexuality must be recognized as an integral aspect of daily living for disabled and nondisabled people. As such, sexuality needs to be included in any comprehensive service delivery or rehabilitation system for disabled people.

- No individual should be forced to curtail his/her sexual expression simply for the convenience of others. Nor should other people's misconceptions about sexuality and disability be reasons to limit such expression.

- Disabled and nondisabled persons should use the same sexuality-related services whenever possible. If necessary, modifications should be made to accommodate disabled people, e.g., an interpreter for deaf clients. Separate services should be available when there is a demonstrated need and desire among disabled people.

- Accurate information about sexuality should be provided to all children, including youngsters with disabilities.

- Disabled children and adolescents should have the opportunity to socialize regularly with nondisabled peers.

- Disabled individuals in residential institutions (e.g., hospitals, schools, rehabilitation centers) have a right to privacy. Disabled adults should have access to "privacy rooms" in the facility where they can be alone or with their spouse/partner(s).

- Disabled people in residential facilities have a right to socialize with members of the opposite sex. The appropriateness of specific sexual behavior should be determined by current social standards for age groups, not by staff whim or outdated regulations.

- Affirmative action should be taken to include more disabled professionals in the provision of sex education/counseling services. More training opportunities in the area of sexuality and disability should be made available to disabled people who wish to enter service provider fields.

- A sexual problem is not necessarily related to a person's disability. Although a disabling condition may affect sexual functioning, this relationship should not be assumed automatically by either the disabled individual or by others.

SEX EDUCATION/COUNSELING SERVICES

- All services should be accessible to disabled individuals. Accessibility involves: awareness that services exist, positive attitudes toward both sexuality and disability, appropriate communication means, absence of architectural and environmental barriers, and lack of financial obstacles. Inaccessibility, if it exists, should be corrected.

- Type of setting may dictate the kinds of services provided. This relationship, however, is usually flexible. Often, the attitudes of policy makers and staff are more important than the type of setting when deciding whether or not to provide sexuality-related services.

- In settings dealing primarily with disability concerns (e.g., rehabilitation centers, residential schools for disabled children), there should be a focus on including sexuality services in the overall program. In settings dealing primarily with sexuality concerns (e.g., family planning clinics, marriage counseling centers), emphasis should be placed on assuring availability of services to disabled clients.

- When appropriate, family members and others close to the disabled individual should participate in sex education/counseling services.

- Outreach to disabled people should be initiated by providers of sex education/counseling services. Special efforts should be made to contact individuals living in isolated rural areas and those residing in the inner city.

- Information about sex and disability should be included in sex education courses offered to the general public.

- Special attention needs to be paid to the development and practice of social skills. Recognition that many sexual concerns are actually social skills problems is vital. Service providers with clients who have been disabled since childhood should be especially sensitive to a possible deficiency in social skills.

- Sex therapy should be recommended only when less intensive forms of service provision have proven ineffective.

- Group therapy, self-help groups, and other group formats are extremely useful for exchanging information, sharing experiences, and examining attitudes related to sexuality.

- Sexuality should not be treated as a "classroom only" topic. A truly comprehensive sex education program must include opportunities for the students to gain further information outside of class hours. Materials should be available for independent study, and knowledgeable counselors should be accessible to class participants desiring further information.

- Program formats should be developed or amended in order to utilize knowledge gained through research. Genetic counseling programs, for example, should be expanded and made available to individuals with potentially hereditary disabilities.

- Research has identified many of the general sex education/counseling needs of disabled people. However, it must be remembered that disabled people are, in fact, individuals; and services provided to them must be geared to their specific needs. Their disabilities may *suggest* areas of *possible* concern; they *do not mandate* the needs of the individual.

- Listings of consultants and organizations related to sexuality and disability should be developed and disseminated to service providers so that referrals can be made.

- When appropriate, sex education/counseling concerns should be included in a rehabilitation client's Individual Written Rehabilitation Program (IWRP).

SERVICE PROVIDERS AND POLICY MAKERS

- Positive, responsible action toward the provision of sexuality-related services should be substituted for "it's not part of my job" and "pass the buck" attitudes. A narrowly defined job role is not a legitimate excuse for ignoring sex education/counseling issues. Professionals and paraprofessionals in a variety of human service fields can provide aspects of sexuality-related services. Included in this group are:

  physicians

  other medical personnel (e.g, nurses, OT's, PT's)

  social workers

  hotline staff members

  rehabilitation counselors

  sex counselors/therapists

  Planned Parenthood staff members

  teachers

  members of the clergy

  psychologists

  peers

  parents

  Depending upon level of comfort, knowledge, and skill, the above individuals can provide permission, limited information, specific suggestions, and/or intensive therapy.

- Service providers need to be comfortable with their own sexuality and be aware of sexual conflicts in order to be truly effective in their delivery of sexuality-related services.

- The PLISSIT model is recommended as one way for policy makers and service providers to determine their roles in the provision of sexuality-related services. Service providers need to be honest with themselves regarding their competency level.

- Service providers should initiate discussions about sexuality with disabled clients, rather than waiting for the disabled person to bring up the subject first. Sexual issues should be addressed as early in the provider/client relationship as is reasonably possible.

- Service providers should ask clients what, if any, sexuality services are needed. Client needs, interests, and capabilities should not be assumed.

- Service providers should encourage clients to experiment with sexual options and not limit themselves strictly to traditional sexual expression, e.g., genital intercourse.

- Human service providers need to become familiar with available printed, audio-visual, and tactile materials on sexuality. These materials should be made available to clients, their families, other staff members, and other interested persons.

- Service providers should be encouraged to exhibit positive attitudes, creativity, and a willingness to learn about sexuality and disability. Job incentives should reinforce, not discourage, this approach.

- Policy makers should develop a formal policy about the provision of sexuality services in their settings. This policy should be based on positive attitudes toward both sexuality and disability. All staff members should be informed of the policy and know whether they are expected to provide or refer specific services.

- Policy makers should allocate funds specifically for the provision of sexuality-related services. If the budget is tight, additional funds should be sought.

- Disabled individuals and consumer groups should be included in the policy making and planning involved in establishing and modifying sexuality-related services. Service providers and administrators should also include

disabled individuals as resources. Concerned service providers can organize an advisory committee of disabled people to identify needs and to make recommendations concerning sexuality services within a community.

TRAINING

- Service providers need access to information and training on sexuality and disability. The amount of training needed will depend upon the provider's level of involvement with disabled people and/or sexuality. The training should be available at two stages: during preparation for a career (e.g., medical or graduate school) and in-service (e.g., courses and workshops offered to staff).

- Organizations and agencies (e.g., Vocational Rehabilitation offices, local community mental health centers) should offer support (both psychological and financial) and encouragement to staff members seeking training in sexuality and disability. Some settings (e.g., rehabilitation centers) should strongly encourage training in sexuality and disability.

- Policy makers and service providers need to become sensitive to and aware of sexual problems of disabled people. Positive attitudes need to be developed toward disabled people as sexual beings. Attitudes toward disabled people should be addressed in all training sessions on sexuality and disability.

- Training programs should also enable participants to decide what services they can effectively provide, and when and to whom they should refer.

- Training modes should be flexible and varied to meet trainees' needs. Training methods should be continually re-evaluated and modified, and new approaches should be tried.

COMMUNITY ACTION

- Consumer organizations should take more responsibility in providing sexuality-related services. Higher priority should be given to self-help efforts in which trained disabled people provide these services.

- Media presentations about the sexuality of disabled people should be critically monitored for accuracy. Viewers/readers/listeners should send written comments to television and radio stations, authors, publishers, etc., expressing positive or negative reactions to presentations.

- All individuals concerned with the quality of sexuality-related services for disabled people should work actively toward changing outdated and inhumane laws and regulations currently in effect. Restrictions on private sexual activities between consenting adults should be removed. In this category are the laws still on the books in some states which consider oral-genital sex to be an illegal activity. Pressure should also be applied to end all involuntary sterilization.

RESEARCH

- More research should be conducted on the psychosexual needs and concerns of specific disabled populations. This is true not only for disabilities in which sexuality is affected physiologically, but also for disabilities such as visual impairment, mental retardation, and hearing impairment, which do not affect physical functioning.

- The physiological effects of certain disabilities (e.g., cerebral palsy, spinal cord injury) on sexual functioning should be researched more extensively.

- The effects of certain medications and medical procedures on sexual arousal and response need to be documented further.

- The negative and positive aspects of specific contraceptive methods should be studied in relation to different disabilities. This information should be made readily available to family planning counselors, physicians, disabled people, and other involved individuals. Contraindications should be listed on labels.

- Newly developed techniques, aids, and methods for increasing sexual capabilities should receive increased attention from researchers.

- The effectiveness of mainstreamed and special sex education needs to be studied. Appropriate modifications in general sex education courses need to be tested and introduced into the classroom in order to allow active participation by disabled children and young adults.

- Further research needs to be conducted on the relationship between sexual functioning and factors such as self-esteem, vocational satisfaction, and avocational activities.

- Disabled people should be included in studies which focus on sexual response and behavior. Almost all norms which have been established by researchers thus far involve only nondisabled subjects.

- Research efforts in sexuality and disability should focus on the gaining of information which can be applied in a "real world" situation.

II. For Consumers

This section of the handbook is written for you, the disabled consumer. It addresses some personal questions about your sexuality, how you can get sexuality services and from whom, and how you can most effectively use the service delivery system. At the end of this section is a selected list of books and articles. Some are written by disabled people as first-person accounts, and some contain helpful, step-by-step suggestions regarding physical aspects of sex. The list is by no means all inclusive, and shouldn't be substituted for Appendix F, which contains much more information. But it can be used as a guide to help you find out how other disabled people are dealing with their sexual concerns.

The majority of information provided in this section came from disabled people—not from physicians, rehabilitation counselors, or sex therapists. The questions and answers came from your peers. We hope it provides you with some things to think about and some guidelines for action.

GETTING PERSONAL

1. **"Why should I care about receiving sex education/counseling services?"**

Other people—nondisabled people—receive sex education/counseling services, so why shouldn't you? For hundreds of years disabled people have been excluded from all kinds of services and systems for a variety of reasons. Until recently, few disabled people have been at the forefront of professions which determine policy and procedures. Some nondisabled people—due to fear, ignorance, or prejudice—have perceived disability as something different and separate from their experience. As a result, they have avoided including disabled people as just another segment of the population.

Sexuality-related services should be available to everyone. The services range from informal discussions with a friend to intensive sex therapy. Many providers of services feel that your disability prevents you from receiving the same services as everyone else. This is *not necessarily true*! And only you can convince them of this.

2. **"But, I know that I can't have a good sex life—I'm disabled!"**

OK, so maybe you can't have an erection or an orgasm, get turned on by X-rated movies because you can't see them, or hear your lover's verbal requests. All of these things don't guarantee a good sex life, nor are they necessary for you or your partner to experience and enjoy sex.

You may believe that disability puts an end to your sex life. You may also believe that intercourse is the only way to have a satisfying sexual relationship—that you are less of a woman or man because you can't perform sexually exactly as you used to before your disability. Or, if you've been disabled from childhood, maybe you haven't really thought about sexual options available to you. It is unfortunate that our culture seems to define masculinity or femininity according to how many times intercourse can be performed per night, how long an erection can be maintained, and how many orgasms can be achieved. This performance emphasis has haunted nondisabled and disabled people alike.

There are *many* ways to give and receive sexual pleasure. There is no right way or wrong way. Certainly, you will have to experiment to find out what is most satisfying to you and your partner. Some things like spasms, leg bags, cathéters, and lack of sensations, may *seem* to get in the way during lovemaking. But relax, communicate openly with your partner, and don't buy into society's hangups. Having a disability does not cancel out sexual expression. Use your imagination, express yourself creatively, and have fun! There are many books on the market which can help you explore new options; among these are *The Joy of Sex* and *More Joy of Sex*, and *Sexual Options for Paraplegics and Quadriplegics* (see end of this section for publication information.)

3. **"Am I abnormal for feeling sexual?"**

Absolutely not! A disability rarely diminishes sexual desire. You may be asking this question because you've

experienced some negative reactions toward your expression of sexuality. Because some nondisabled people view disabled people as child-like, they may have difficulty perceiving you as a sexual adult. Fear of the unknown adds another dimension to their attitude. People who don't know much about disability may feel uncomfortable thinking of you as a sexual person. It's easier for them to ignore you or react negatively to your sexuality than to learn more about it—so the myth continues.

The media have also perpetuated myths about sexuality by emphasizing the tragic side of disability. People who have little knowledge about sexuality and disability can be easily misled by movies and articles which indicate that disabled people have no sex lives.

Although it's perfectly normal for you to feel as sexual now as before you became disabled, it's also normal for you to be a little anxious about your sexuality. You may have been told subtly that you are different or weird because you want to express your sexuality—because you want to conduct a normal sexual life. Don't believe these prejudices. Express your feelings—everyone is sexual.

4. **"But what if I don't feel sexy?"**

No one has sex on his/her mind all the time. Aside from the distraction, it would be simply exhausting! But if you *never* feel sexually desirable, this indicates a problem. Maybe you need to build up your body image and develop some comfort with your sexuality.

Society has almost brainwashed us into believing that only a Madison Avenue "picture perfect" image is sexy. Advertisements, movies, and magazines imply that if you don't have a slender build, even teeth, and blond hair, you don't stack up. Although most of us realize that this perfect image is unattainable, we are all self-conscious about how we compare with the ideal.

The presence of a disability may have a big effect on how much you like yourself. You may feel unattractive, or be worried about your brace, wheelchair, or scars. Adjusting to your disability and becoming comfortable with aids is much like the experience a nondisabled person has when (s)he gets glasses for the first time. At first, they feel very self-conscious about wearing them in public. They may feel slightly awkward and shy about their new appearance. If they have little support from friends and family, it may take a while to realize that they are still sexually desirable people. Remember the ridiculous myth: "Boys never make passes at girls who wear glasses"? There are many ways to improve your self-confidence. You can start by making yourself as attractive as possible and doing some nice things for yourself. The more you like yourself, the more others will like you.

5. **"I have a lot of problems—like meeting people and making dates—because I'm disabled."**

Leading an active social life is often hard work. You have to go out and make the contacts—they rarely knock on your door. It's not fair to place all the blame for sexual and social inactivity on your disability. Because so many social environments are not architecturally accessible, you may have to demand your right to access. Meanwhile, check out already accessible theatres, bars, clubs and restaurants, and party sites. If you absolutely can't get up the nerve to go out and socialize, have your own party.

There's no doubt that having a disability may cramp your social life if you are uncomfortable and self-conscious. But it's a "cop out" to simply say, "I'll never get a date. Who would go out with someone who's paralyzed?" Lots of nondisabled people sit at home night after night for the same reasons you do—because they are unsure of themselves, shy, or frightened. Don't hide behind your disability.

6. **"I already know how much I can expect sexually. Why should I discuss it with some stranger?"**

Because, if you're like the vast majority of people, you probably aren't aware of all the sexual options available to you. You may never have received any sex education or counseling services. Your doctor or rehabilitation counselor may have ignored your sexuality. You may have never seen a book on sexuality and disability in your local bookstore, and most likely what you've seen on network TV has been confusing or inadequate. Unless you make an effort to ask people about your sexual potential, and demand answers, it's unlikely that you'll pick up accurate information. It's very helpful to discuss your sexual options with friends who have the same disability as you, but sometimes it's actually easier to talk freely and openly about sexuality with someone who doesn't know you. There's a lot of written information available which can help you with general questions. But everyone's different. Look at Appendix E in the back of this book for names and addresses of people you can contact about

questions you may have. They should be able to help you or refer you to someone in your locale who can give you accurate information about yourself, as an individual.

GETTING SERVICES

1. **"How can I tell if sexuality services will meet my needs as a disabled person?"**

When you call regarding a sexuality service, make sure you ask questions about the accessibility of the facility and service. See Chapter 6 to review accessibility in the areas of public awareness, attitudes, architecture, information, and finances.

Although you may, at some time, wish to receive services specially designed for disabled people, many services can be obtained from standard service providers (e.g., physician, Planned Parenthood, teacher). When first calling about a service, tell the provider that you have a disability, identify what special considerations you will need, and ask if they can comply with your needs. For example, a wheelchair user might tell the provider that the chair is 24" wide, and doorways must allow access for that width. By withholding information about access needs, you may be letting yourself in for a frustrating experience. Tell them what you need, and, if appropriate, how they can make your visit easier. You can specifically refer them to a book called *Within Reach,* which provides excellent service access guidelines (available from: Human Sciences Press, 72 Fifth Ave., New York, NY 10011; $2.95).

Also, if appropriate, you may want to ask about staff competencies regarding disability and/or sexuality. Feel free to question the service provider regarding previous experience in dealing with both sexuality and disability, training obtained, and level of comfort. Again, asking *before* you go can help alleviate anxiety and possibly prevent misunderstandings and frustrations.

In many cases you can rely on your friends for referrals. Ask them where they go to receive services. Find out what they know about certain service providers and ask them their opinions. Sometimes a local disabled consumer group will have referral listings which could also help you. In short, take advantage of other people's past experiences.

2. **"Who provides sexuality services for disabled people?"**

Chapter 4, "Who Should Provide the Services?", reviews the present providers of services. Usually providers include: physicians, other medical personnel (e.g., nurses, PT's), teachers, Planned Parenthood, social workers, clergy, hotline staff members, psychologists, rehabilitation counselors, disabled peers, sex counselors and therapists, family, and friends. As we discovered in Chapter 4, all of these people could, with training and willingness, provide some level of sexuality services to disabled people. But, in fact, many of them do not. Some only provide one specific service; some provide no services at all. You cannot, for example, assume that your physician will provide you with sex education or counseling services. The level of involvement in delivering sexuality services to disabled people is entirely dependent upon the individual.

The basic rule to follow here is, "Never assume." It's possible that the above professionals can provide you with services, but until you ask, you can't be certain.

3. **"How do I get a referral, and what do I do if I get the run-around?"**

In many cases, you will have to be assertive and persistent in order to get a good referral. If you ask your physician, rehabilitation counselor, etc., for services, and they tell you they don't provide them, always ask for a referral to someone who can. If they are unaware of who can provide the service, ask them to check into it for you. Appendices C and E of this handbook can be of help to you and the service provider if you have no idea where to start looking. You should also check with your local office of vocational rehabilitation and local disabled consumer organizations.

You can expect a certain amount of passing the buck when searching for sexuality services. In many cases, professionals have a hard time making a helpful referral. There are no national directories available for providers of sexuality services for disabled people. As a result, you *may* be referred to several people who cannot meet your needs. At each step, if the provider can't help you, ask for a new referral. Eventually, providers will get the idea that they need to look into the subject further so they can make informed referrals in the future. The key to eventually getting a good referral is persistence and assertiveness.

4. **"How do I bring up the topic of sex?"**

When we asked service providers why they didn't discuss sexuality with disabled people, the most common response was, "Disabled people never ask about it." The belief that you must initiate a discussion about sexuality gives service providers an easy excuse for ignoring the subject of sex. Although you may feel it is the responsibility of your physician, counselor, etc., to provide you with information about sexuality, the fact is that you cannot rely on them to initiate the discussion. Several people we surveyed actually believed that disabled people must have no sexual concerns since they never asked questions about it.

It's hard to start talking about your sex life—especially if the provider seems formal or detached with you. But, realistically, in many cases your concerns won't be addressed until you gather the courage to ask about them. Not all providers will be able to answer your questions. If they try to put you off, ask for a referral, written information, or available service programs. Many providers will never understand that sexuality is a vital and legitimate concern unless you convince them.

Some hints for initiating a discussion about sexuality:

- There is no "right" or "wrong" way to bring up the subject. Do whatever seems most comfortable for you. Keep in mind that it is your *right* to obtain this information. You're not asking about anything silly or perverted.

- When asking questions, be as specific as you can. Give the provider as much information as (s)he needs to answer your question. Remember, the provider may be just as uncomfortable as you are. Try to be helpful.

- Maintain eye contact. Try not to squirm around and appear embarrassed. If you seem ashamed, this feeling will be passed along to the provider.

GETTING ASSERTIVE

1. **"How can disabled people help each other regarding sexuality-related services?"**

There are growing numbers of disabled consumer organizations in the United States, which function as political, advocacy, and support groups. Most major disabilities are represented by consumer groups (e.g., National Paraplegia Foundation), and other disabilities are represented by advocacy or support groups (e.g., United Cerebral Palsy, Easter Seals). A disabled consumer organization can be your best friend when you are trying to obtain services. It can provide you with referrals, or may provide services, such as counseling and discussion groups. There are hundreds of consumer groups, serving many geographical areas. Below are some national groups which have local chapters. You can obtain information about your local chapter by writing the national office.

- American Coalition of Citizens with Disabilities (ACCD)
  1200 15th St., N.W., #201
  Washington, DC 20005

- National Association of the Deaf (NAD)
  814 Thayer Avenue
  Silver Spring, MD 20701

- National Association of the Physically Handicapped (NAPH)
  7101 Eastman Drive
  Falls Church, VA 22043

- National Federation of the Blind (NFB)
  1346 Connecticut Ave., N.W.
  Washington, DC 20036

- National Spinal Cord Injury Foundation (formerly National Paraplegia Foundation)
  369 Elliot Street
  Newton Upper Falls, MA 02164

- Paralyzed Veterans of America (PVA)
  4330 East West Highway, Suite 300
  Washington, DC 20014

- *Directory of Organizations Interested in the Handicapped*
  Available from: Committee for the Handicapped
  People to People Program
  Suite 610, La Salle Building
  Connecticut Ave. and L Street, N.W.
  Washington, DC 20036

2. **"How do I obtain services in a residential institution?"**

As discussed in Section V, most facilities have either formal or informal policies regarding provision of sexuality services. Your first step is to find out what the policy is, and whether or not it's being followed. If there is no formal policy, get together with some other residents and ask that one be drawn up. Refer to Chapter 6 for suggestions regarding access.

Rules in residential institutions may sometimes restrict sexual expression. Inflexible visiting hours, lack of privacy, segregation of sexes in living quarters, and constant supervision can really be inhibiting and can pose problems if you are trying to lead a normal sexual life. Many times these rules are made for the convenience of the staff, rather than for the convenience of the residents. If you find your facility's policy too rigid, write to the *head administrator* and ask for a written rationale for the procedure. If her/his answer does not satisfy you, ask to have a joint meeting with residents and staff to air your complaints and offer possible solutions. It will be necessary for you to offer specific suggestions regarding policy. Think through your suggestions, discuss them with fellow residents, and put them in writing. Make sure they are *realistic* and *practical.* Often the staff will be willing to change if you offer a good alternative to existing policy.

3. **"How do I get administrators to listen to me?"**

Whether you live in a residential facility or in the community, administrators and policy makers can make or break delivery of sexuality-related services. Many administrators are reactive rather than proactive, meaning that they respond to people's requests rather than taking the initiative. When trying to change or make policy, numbers count. The more people you have behind you when making a request, the better chances you'll have of getting a fair hearing. There are many ways to gain access to policy makers. Here are just a few:

- Try to organize a letter-writing campaign. Do some research, get your request and facts organized, and call on friends to send letters to the administrator(s) in question. Remember, the more letters, the better. In your letter, include the following information:

  1. Your name, address, and phone number
  2. Your age and sex
  3. Your disability, when it occurred, whether it is permanent or temporary
  4. Your service needs, whom you contacted before, and what happened. Be specific.
  5. Why you think the service is needed
  6. What action you expect the person to take in the near future (e.g., "I hope to be hearing from you soon regarding this request.")

  If you get no response within three weeks, send a follow-up letter or call them. Keep copies of *all* correspondence and take notes on phone calls.

- Call for a personal meeting with the administrator. When calling for an appointment, identify yourself and the

reason you feel the administrator should talk with you. Again, do your research *before* you get there so you will have your facts straight and will be informed on the main issues.

- Organize a community or residential meeting with disabled consumers and policy makers. You may be able to work through a local disabled consumer group or community organization (e.g., NPF, Jaycees). Be sure to publicize the meeting well in advance, and personally invite those administrators you wish to attend.

4. **"What might I expect the impact of this handbook to be?"**

At this writing, we can't fully answer this question—but we can take some guesses. Already, people who have read the draft of this handbook have started to initiate sexuality services for disabled consumers, and some readers have been made aware of the need for services for the very first time. However, the first step in making sex education and counseling services available to you may rest with *your input into the system.* We can try to convince the "powers that be" to offer services, but we can't fight the statement, "But, disabled people never ask for these services!" Much of the responsibility for action on the recommendations made in this handbook rests with you.

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III. Counseling & Education

1. "Why should I provide sex education/counseling services to disabled people?"

Most service providers have priorities other than offering sexuality-related services. Physicians, for example, are primarily concerned with medical matters; rehabilitation counselors frequently focus on vocational decisions and job placement. Why, then, should these service providers even deal with the issue of sexuality? After all, isn't that someone else's job?

The reality is that often no one provides these services to disabled people. As one counselor responding to our survey wrote, "The way it is now, everyone assumes 'someone else should take care of that.' Quite often no one does." The physician or rehabilitation counselor may be the only link a newly disabled person has to needed services. If the service providers ignore or avoid sexuality issues, the client may be left to make decisions based on misconceptions and stereotypes. Needless frustration and misery may result.

No one is saying that all service providers should be experts in sex and disability. What would be desirable, however, is for these providers to touch base with the client about sexuality concerns. This approach is well within the scope of most medical, educational, and rehabilitative programs.

For those service providers who at present have little or no contact with disabled people, it is necessary to consider the importance of mainstreaming and normalization. There is no reason why a disabled person should be forced to receive separate services if those offered to the general population are (or could be made) available to everyone.

2. "But I don't have any special training in the area of sex and disability."

The skills needed to provide many sexuality-related services are the same skills used to provide other services. An effective counselor, for example, needs to know how to listen empathically to a client. The topics under discussion may vary (vocational possibilities, childrearing techniques, sexual difficulties, etc.), but the basic skills remain the same. Similarly, a competent sex education teacher demonstrates the same teaching skills used by competent instructors of other subjects. There is no separate and unique way to provide many sexuality-related services. Of course, some level of specialized knowledge is required, but this level depends upon the type and intensity of service being provided. (Refer to the PLISSIT model in Chapter 4.) Distributing relevant pamphlets and books to clients certainly requires no intensive training in sex and disability. Nor does one need to be an "expert" to lead a group discussion about common sexual concerns. What is required, however, is a willingness to discuss sexuality and a sensitivity to client needs.

Some sex education/counseling services do require specific expertise. Medical services, such as obstetric care, obviously will not be attempted by a service provider who does not have appropriate training in this area. Sex therapy is another example of a service which requires a highly trained specialist. Certainly, rehabilitation counselors or nurses will not try to provide this kind of service unless they have extensive training. However, what these individuals *can* provide for a client who needs specialized services is an appropriate referral. If sexual concerns are never discussed, the client may never find an appropriate provider.

3. "What if I don't know how to answer a disabled client's question about sexuality?"

You may shy away from the topic of sexuality because you envision highly complicated and technical questions which you will be unable to answer. Often, however, the client only needs to express some feelings and have those feelings treated as valid and normal (see Section II). He or she may not need a detailed description of physiological responses or exotic sexual positions. Questions may relate to permission issues such as, "Is it OK for me to have sex even though I'm disabled?" Other concerns might focus on self-concept and social interactions: "Will anyone ever find me attractive?" "How do I break the tension when I meet an old friend who knew me before my disability?" You do not have to know the answers to all the questions raised. A counselor, for example, may tell a client that (s)he does not know the answer now, but will:

- look up the information in a book, periodical, or other resource material

or

- call a person who is knowledgeable in the area

or

- refer the client to someone who can answer the question

or

- provide the client with *relevant* books, pamphlets, or audio-visual materials.

4. **"I don't feel comfortable talking about sexuality with clients. I feel it's a private issue."**

Discomfort with the topic of sexuality is not unique. Many people—including some service providers—have problems talking seriously and candidly about sexuality. To expect that all service providers will be comfortable with and competent to provide sexuality-related services is ridiculous. Obviously, some people will have more ease with this topic than will others.

Discomfort, however, need not be a static and permanent condition. For example, a social worker who feels uncomfortable with the subject of sexuality can attend training sessions that will help that person explore his or her own sexual attitudes. As a result, comfort level may be increased, and the social worker may be able to discuss sexuality concerns with greater ease. Even if a service provider is unwilling to provide any sexuality-related services, he or she can assess client needs and make appropriate referrals.

Regarding privacy, sexual expression is indeed a private matter. It is important, however, to distinguish between sexual expression and *discussion about* sexual expression. Other activities of everyday life are also private, such as dressing and going to the bathroom. However, these activities are frequently discussed during counseling sessions. Talking with a client about problems (s)he has dressing because of uncontrollable spasms is not an invasion of privacy. Rather, it demonstrates a concern for the individual. The same holds true for the subject of sexuality.

5. **"What if I have a client whose sexual preference or lifestyle is at odds with mine? For example, what if I consider homosexuality immoral, and I have a client who is homosexual?"**

As discussed in the first chapter of this handbook, no one has the right to make decisions related to sexuality for another adult unless coercion, sexual use of children, or the high probability of an unwanted child are involved. Of course, that sounds great on paper, but what if you're confronted with a client whose sexual preferences you truly believe are abnormal, immoral, or harmful? In such a case, the client's wants and needs must be foremost in your mind. What *you* think the client *should* want or need is not necessarily relevant to the delivery of effective sex education/counseling services. It is not up to you—as a service provider—to impose moral standards and values on clients. Rather, the client should be helped to make his or her own informed decisions about sexuality, with realistic consideration of possible legal and social consequences. If you simply cannot maintain an open mind with a particular client, that client should be referred to someone who can be more objective.

6. **"How do I get more knowledge and skill in the area of sex and disability?"**

There are several ways to increase your information and skills:

a. Read relevant books, articles, professional periodicals, and reports. This material can be obtained from university libraries, medical libraries, bookstores, disabled consumer groups, other organizations concerned with disability, and organizations focusing on sexuality. A list of publications is provided in Appendix F of this handbook.

b. Rent or buy films and other audio-visual materials that deal with sexuality and disability. See Appendix G for a listing.

c. Talk with someone in your organization or community who has specialized information in this area. For example, set up an appointment with a Planned Parenthood counselor who works with mentally retarded clients, or ask representatives of the disabled community to come and speak to staff members at your facility.

d. Inquire about and attend workshops related to sex and disability at professional conventions, colleges and universities, and community meetings.

e. Contact a training program that can either provide direct training or can give other kinds of assistance. (See Appendix D.)

f. If no training program is available locally, get together with other professionals in your organization or community and take steps to form an effective program.

g. Discuss your need for training with your colleagues and supervisors. You may want to discuss the possibility of hiring a consultant to train staff members.

h. Form a discussion group of interested persons (service providers, disabled persons, parents, administrators, etc.) and share information, concerns, and ideas.

7. **"I don't provide sexuality-related services because my clients don't ask for them."**

Many service providers responding to our survey assumed that their clients didn't need sex education/counseling services because their clients never mentioned sexuality. Yet most rehabilitation counselors don't wait for a client to bring up vocational options. Nor does a physician expect a patient to initiate a discussion about all of his or her symptoms. These service providers ASK questions such as: "Have you ever thought about working as a computer programmer?" "What kinds of jobs have you liked?" "Do you feel any sensation in your arm?" "Does the medication relieve the pain?" etc. Why then should the subject of sexuality be treated as though only the client/patient can magically initiate discussion?

Place yourself in the client's position. Let's assume that you've been recently injured in a car accident and are now in a wheelchair. Let us further assume that during your hospital stay, much attention was focused on survival and mobility. Besides medical care, you received occupational and physical therapy, and were taught many skills for everyday living (how to use a catheter, how to transfer from a bed to a wheelchair, etc.). Later, at a rehabilitation facility you received further training and vocational counseling.

Throughout this entire process, however, no one ever mentioned sexual functioning. You have no idea whether you can ever be sexually active again. All you know is that you have very little or no sensation in your gential area. Your whole life has changed drastically, and you're trying to adjust to your disability. At this point, you're feeling confused and uncertain about sexual possibilities and options. Perhaps you assume that, since no one has talked with you about sexual functioning, maybe it's a dead issue because of your disability. In this state, how comfortable are you about bringing up the subject of sex? And, if you do have the courage to initiate discussion on this topic, how would you feel if service providers avoided your questions or told you that your concerns were irrelevant to their job roles?

Now consider an alternative. What if during your hospital stay, medical professionals brought up the subject of sexual functioning along with other functioning? What if you were encouraged to discuss your sexual concerns? What if sex were treated as an important and relevant concern? At the rehabilitation center, how would you feel if you were given the opportunity to discuss sexuality with other disabled people? What if couples counseling was provided for you and your spouse/partner?

Obviously, the second situation encourages a positive and open attitude toward one's sexuality *and* disability. The first scenario, however, blocks communication and spreads misconceptions and frustrations. A service provider, then, should attempt to put disabled clients/patients at ease about sexuality. One important way is to initiate the topic for discussion.

8. **"When is a good time to initiate a discussion about sexuality?"**

As early as reasonably possible. In many medical and counseling facilities, for instance, questions related to sexuality are included on the intake form. Depending on the type of services offered, this might involve a detailed sex history, or it might be limited to a few general questions. Not only do you as a service provider learn about client concerns, but, perhaps more importantly, the disabled person receives the message that sexuality is a valid concern.

Disabled children should have the opportunity to learn and talk about the many aspects of sexuality. Children—whether disabled or nondisabled—are curious about sex, and both informal and formal sex education should be provided. If parents and teachers avoid this topic, long-lasting misconceptions often result. A blind female adolescent in a residential school, for example, may have no idea what a penis looks like or how it functions. She may feel uncomfortable asking someone about it. As a result, she may avoid men and relationships with men because she fears the unknown. If discussions about sexuality had been initiated by a parent or teacher when she was a child, this situation could easily have been prevented.

After a traumatic injury, the initial priority is often on physical survival and the stabilization of medical conditions. Once a person has left the critical phase, however, sexual concerns resume their importance. Of course, all of this depends upon the individual. Some newly spinal cord injured people, for example, rate sexual functioning as high a priority as mobility. Others, on the other hand, consider sexuality a very low prioity.

The only way for you as a service provider to know whether or not a disabled person has sexual concerns is to ask. If the client/patient:

a. is not ready to deal with sexual issues,

b. has no sexual concerns to discuss, or

c. is not interested in the topic,

that person will let you know. Not every disabled person needs sex education/counseling services. It is, however, important to find out early whether a person does need some type(s) of services now or in the future.

9. **"How do I initiate a discussion about sexuality?"**

Sure, it's easy to say, "Talk about it. Find out what your client needs." But bringing up the topic can cause discomfort and awkwardness in a service provider who is not used to discussions of that nature.

There is no one right way to start talking about sexual concerns with your clients. It all depends on your personality and your relationship with each client. Below are a few suggested approaches. Some may sound comfortable and natural to you; others may be completely unsuited to your situation or your personality. You will need to experiment with different approaches until you find those which work best for you.

a. *The gradual approach.* Start with a relatively neutral topic. For example, you may open the conversation with:

—"Are you having any trouble finding accessible restaurants (bars, movie theaters, etc.)?"

—"It sounds as though your job is going well. How do you like the people that you work with?"

—"How is your husband/wife doing?"

—"What things do you enjoy doing for fun and recreation?"

—"It sounds as though you really (would) like to meet a lot of different kinds of people."

—"No matter how much parents love you, there comes a time when a young person wants to try his/her own wings."

Any of these questions or comments can eventually lead to a more specific and personal discussion about sexuality.

One progression might look like this:

acquaintances and work relationships—friendships—family and other close relationships—intimacy—sexual expression.

Another conversation might go from:

parents—growing up—need for more peer relationships—social skills—dating—contraceptives.

Still another:

desire to meet more people—shyness—feelings of inferiority—improvement of self-concept—acceptance of self (including sexuality).

b. *The strong possibility approach.* When talking with your client, assume that there is a strong possibility that the problem exists. When using this approach, you will probably start the discussion by acknowledging that many people in similar circumstances have certain difficulties and concerns. Then you can ask whether or not this particular situation exists for the client. For example:

—"After spinal cord injury, many people experience uncertainty about sexual functioning. Perhaps you've felt this way, too."

—"Although we live in a seemingly well-informed age, there is still a lack of education in the area of sexuality. Many people—including highly intelligent individuals—have questions about sexual concerns. Perhaps we can discuss some of these matters."

—"Some people feel shy about meeting strangers and making new friends. With all the recent changes in your life, perhaps you've been feeling somewhat uncomfortable in social situations."

—"Many people who have spent much of their lives in a residential facility tell me that it's sometimes difficult to start and maintain relationships with the opposite sex. I'd be interested in hearing your opinions."

—"When a disabled person and a nondisabled person marry, other people may react with prejudice and stereotyping behavior. Has anything like this happened to you and Tom?"

The advantage of using the strong possibility approach is that it establishes the existence of sexual/social concerns as a natural and normal occurrence. The client receives reassurance that (s)he is not a "weirdo," but rather has a concern shared by many others in similar circumstances.

c. *The multi-problem approach.* This approach places the topic of sexuality within a list of other—often unrelated—concerns. For instance:

—"While you're here at the center, we'll be meeting regularly to discuss a variety of topics such as vocational plans, family concerns, sexual issues, and economic aid."

—"The policy at this hospital is to view patients as human beings, not strictly as medical cases. for this reason we offer a variety of services such as vocational counseling, group discussions, couples counseling for you and your partner, audiovisual presentations dealing with sexual functioning, and other services based on individual need. Which services do you think would be most useful to you at this time?"

d. *The direct approach.* This approach may work fantastically or may drop like a cement cloud. It all depends on your manner and the personality of your client. Some clients may find this approach a refreshing relief from all the bureaucratic and medical jargon they've been hearing. Others may get blown away. Use this approach if it appeals to you, but use it with discretion. Examples:

—"How's your sex life going?"

—"Are you having any difficulties in the area of sexuality?"

—"We haven't talked much about sex during our meetings. Do you have anything you'd like to discuss about the subject?"

These approaches are just suggestions. As a service provider, you will need to experiment with what works best for you and your clients. Obviously, if you are a counselor in a residential school for mentally retarded adolescents, your way of initiating the subject of sexuality will differ greatly from that of a nurse at an acute spinal cord injury unit. Also, your personality will make a difference. Two counselors working in the same mental health center may have two totally different styles. Neither one is necessarily better than the other. Several hints, however, will help any approach:

1. Maintain eye contact. Shifty or downcast eyes communicate embarrassment. The client will pick up on this message and will shy away from the topic.

2. Speak as clearly as possible; don't mumble.

3. If you feel uncomfortable with the subject, move gradually.

4. Don't worry if you don't have all the answers. The client will probably be relieved just to have the subject brought up. If you don't know the answer to a question, don't panic. No one expects you to be a fount of omniscience.

5. Try to come to terms with your own feelings toward sexuality before plunging into those of your client.

6. Relax. Sexuality is a part of everyday living. It doesn't need to be treated like such a big and frightening production.

10. **"How many sexuality-related services should I provide before referring a client to someone else?"**

Obviously, the answer to this question depends on your knowledge, comfort, and skills. Review the material presented in Chapter 4 about the PLISSIT model. If you are not qualified or comfortable providing a certain service, refer your client to someone who is. Referrals can be made to: professionals within your facility, disabled peers, service providers in the local community (e.g., private physicians, sex therapists, and counselors), and resources outside your community (e.g., an out-of-state hospital program).

11. **"Where do I refer a person for these kinds of services?"**

The importance of *accurate* and *useful* referrals cannot be stressed enough. If clients are referred to four or five people before they find someone who can provide needed services, they may simply give up during the process. Also, it is unfair to waste clients' time and energy by sending them on a wild goose chase. It is essential, then, for service providers to have an accurate and up-to-date listing so that referrals can be made effectively. If no such sexuality service listing exists, it is up to you and your facility to develop one. Call service organizations in your community that deal with sexuality and/or disability services. Find out what they can and do provide. Make site visits. Contact disabled consumer groups and ask them what's available and what they recommend. Be sure that you check out services and get feedback from clients who have received those services. Sometimes an organization's PR is more effective than its services.

12. **"What should I do if I encounter resistance from my supervisors about providing these services?"**

This is a tough one. It is very difficult for a service provider to offer services which are considered inappropriate by supervisors. Some suggestions:

(a) Determine which sexuality-related services you think can and should be provided by your organization. Then find out if your organization has a formal policy about the provision of these services (see Section V). If no formal policy exists, ask that one be drawn up. Be prepared to offer your own suggestions. Once a formal policy statement is made, you will at least know what you're dealing with.

(b) Get together with other staff members who share your views and present a logical case for including specific sexuality services in your program.

(c) Ask disabled people and their families what needs exist in the area of sexuality services. Arrange to have their requests and recommendations presented to the top administrators.

(d) Find a sympathetic supervisor/administrator to help you in your attempts to re-educate other policy makers.

(e) Get permission to have an "expert" give a presentation to the staff about sexuality-related service needs and the capabilities of the organization to meet those needs.

(f) Conduct a literature search to find information about the sexuality services provided at facilities comparable to yours. Present this material to supervisors.

(g) Contact professional and consumer organizations and ask for their assistance.

(h) Include sexuality-related services in services which are already provided by your organization. For example, if you are teaching mentally retarded adults how to act in a job situation, you can also include social skills training that will be applicable to personal as well as on-the-job relationships.

(i) Try to determine costs, time, and human resources involved in providing recommended services. When approaching administrators about program changes, be specific and practical.

(j) Develop an accurate list of referral resources. In this way, you can still help your clients receive needed services.

(k) Give this handbook to your supervisor and ask him/her to read it and give you their reactions.

13. **"Is it better to have one 'expert' on staff to handle all sexuality-related concerns, or should all members know a little?"**

Ideally, all staff members should have some degree of familiarity and comfort with the subjects of sexuality and disability. In this way, if a client brings up a problem or question, the staff member present will at least be able to talk with him/her, and refer if necessary. If a staff member is unprepared for such a situation, the anxiety level in both the service provider and the client is likely to rise.

Of course, some staff members will be more likely to provide sexuality-related services than others. A counselor in a clinic will be far more likely to discuss serious sexual matters with a patient than will the receptionist. The counselor then needs more expertise. It is important, however, for the receptionist to have some awareness of the situation in case a patient does initiate a conversation about sexual concerns.

Having "experts" such as sex therapists on staff can be very useful, especially in settings where serious sexual problems and/or adjustments are common. Not all facilities, however, can afford or need to have sex "experts" on staff full-time. Part-time arrangements can be worked out, or an "expert" can be hired as a consultant for a limited time to teach other staff members needed skills.

14. **"I simply don't have time to provide these services."**

Reasons why you may not have time to learn about or provide sexuality-related services include:

—too much paperwork

—too few staff members for the number of clients served

—lack of organization

—a heavy schedule of activities

—lack of interest in making sexuality services a priority

Some of these time obstacles may be outside your control. If you are a VR counselor and are assigned a caseload of 300 clients, you will probably have trouble just doing the minimum for your clients in terms of vocational plans, let alone providing sexuality services. Sure you can try to change the system or look for another job, but you'll just do the best you can under the circumstances. Although you may not have time to provide sex education/counseling services, you can make available to your clients pamphlets and other publications about sexuality and disability. You might also help to organize a group of clients interested in discussing sexual concerns. In this way information can be presented and experiences can be shared without having to meet individually with each client. You can compile a community referrals list so that you can pass on at least that much information to an inquiring client.

Other time obstacles are within individual control. If you're disorganized you will undoubtedly waste a lot of time that could be put to more productive use. Also, you may have control over the number of clients you see. In such a case, don't overschedule yourself.

Lack of time is a real problem in the provision of services. Assess your situation. See if some changes can increase the time you have available. If not, do your best at least to touch base with clients about sexuality concerns, and to provide appropriate referrals.

15. **"Will clients think it strange that I consider sexuality-related services part of my job?"**

Most clients will not think it strange unless you do. It comes down to attitude and the manner in which you approach the subject. If you are embarrassed or ask for unnecessary details, the client will be understandably defensive. If, however, you broach the subject on a professional and matter-of-fact basis, your client will follow suit. Information can be exchanged and services can be provided without discomfort and confusion.

IV. Training

This section of the handbook is addressed primarily to three groups:

1) those who have had some training experience, but not necessarily in the area of sexuality and/or disability

2) those who have knowledge of sexuality and/or disability, and wish to initiate some training

3) those who are interested in the training process from an administrative point of view.

This section offers one perspective on human sexuality training, which relies on common educational practice. You can use this section as a framework around which to organize your ideas and goals. As you progress you will undoubtedly modify and expand our framework to suit your particular needs. We offer you this section not as a final, definitive answer to all your questions, but rather as a springboard for action!

To provide most sexuality-related services effectively, individuals need some level of special training. The training will be a series of organized activities aimed at improving the competencies of potential helpers. For the purposes of this handbook, the term "trainer" refers to the person who bears primary responsibility for this process. "Trainee" refers to anyone who—for a time—is participating in the process as a learner.

Training individuals in human sexuality is similar to other educational processes. The steps are the same and are applied to a core content of sexuality and disability. The process has eleven components:

- AWARENESS of the need for training related to sexuality
- training GOALS
- characteristics of trainee POPULATION
- NEEDS ASSESSMENT of trainees to determine present level of competency and required competency
- short-term and long-range training OBJECTIVES
- RESOURCES to help meet objectives
- FORMAT appropriate to objectives including learning activities
- LOGISTICS concerning:

  time
  place
  size of group
  cost
  publicity
  equipment
  handouts

- REHEARSAL of components
- IMPLEMENTATION of training
- EVALUATION and revision

AWARENESS

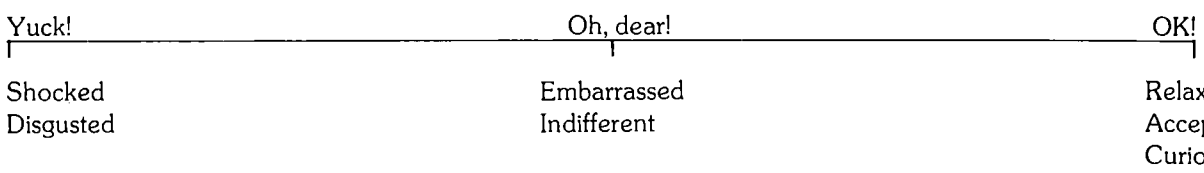
Someone has to take responsibility for initiating training. This person can be anyone, regardless of job title, who is aware of the importance of sexuality to rehabilitation. The initiator, for example, may be an administrator, counselor, parent, student, college professor, or disabled consumer. This initiator may be an individual or group, and may or may not have expertise in the core area. The initiator's role is to point out the need for and appropriateness of such training, and to offer support throughout the process.

GOALS

The goals of training can best be conceptualized by viewing them in relation to the PLISSIT model. In order to give permission, limited information, specific suggestions, or intensive therapy, a foundation of COMFORT, KNOWLEDGE, and SKILL is necessary for each PLISSIT level. (See Chapter 4 for more details on PLISSIT).

Comfort

Comfort is a prerequisite for the delivery of effective sex education/counseling services: comfort with the subject of sexuality, comfort with clients, comfort with one's own sexual behavior and value system, and comfort with a specific role. We can think of comfort along a continuum:

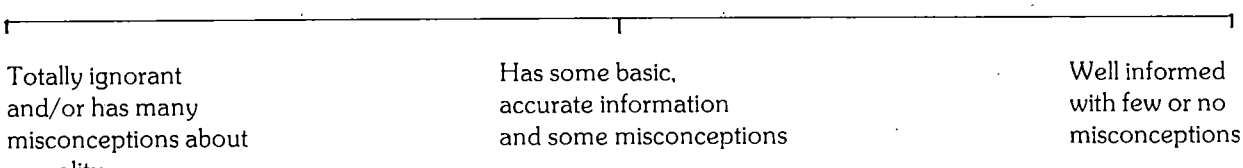


Because comfort is a prerequisite to learning PLISSIT skills, it is a fundamental core area in human sexuality training. Comfort should be commensurate with each level of helping.

Knowledge

Every provider of sex education/counseling services needs an information base. The base should include knowledge of physiological, behavioral, and psychological components of sexual functioning, the characteristics of the population to be helped, and the nature of appropriate helping techniques and strategies for each PLISSIT level. For instance, in order to give permission, the provider must understand the nature of the concern, must be free of myths associated with the subject, and must know any particular characteristics of the client that are relevant (e.g., usual concerns of adolescence).

The knowledge base, however, for intensive therapy includes much more detailed and thorough information than that for giving permission. When reviewed on a continuum, knowledge can be seen as:



Skill

A feeling of comfort with the subject of sexuality and a firm knowledge base are prerequisities in the delivery of sexuality-related services. The application of appropriate helping skills, however, is necessary in order to communicate this comfort and knowledge to the client. Helping skills are a set of behaviors and strategies applied to the needs of another person or group. Here is a partial list of helping skills:

listening
giving permission
instructing
suggesting
referring
comforting
empathizing

discussion leading
initiating
organizing
advising
recommending
creating awareness
facilitating
encouraging

When seen on a continuum, skills can be viewed as:



Manipulation for own purposes | Non-interference | Effective application of skills for helping

As we can see, the opposite of helping is manipulating. Skills are used for helping when they are applied to the needs of another person. We often think of manipulation in its most negative connotation—the sociopathic or psychopathic individual who manipulates, persuades, or intimidates others into doing what they want. Manipulation is often not intentional or cold-hearted. Frequently it arises from the provider's inability to judge which activities are beneficial. An example of this is the friend who tries to "cheer up" a depressed comrade by saying "look on the bright side." When someone asks another to behave in a way directly opposite to the way (s)he is feeling, the motive is usually to dismiss or eliminate an uncomfortable situation for the provider.

Skills, no matter how refined, are not helping skills if they are applied to the needs, concerns, or desires of the helper. Although there is nothing inherently immoral about taking care of one's own needs, it is improper to label self interest as "other's" interest. Consider the following example:

> Ellen is a 35 year old woman living in a small community. Recently disabled by an auto accident, she is receiving rehabilitation services on an outpatient basis at a local rehabilitation clinic. Ellen has asked for books on the sexual aspects of her disability and for an opportunity to discuss her concerns with someone. Her counselor tells her, "Everything will be OK. Don't worry about that." Ellen gets no books or further discussion on sexuality. It appears that this counselor is not helping Ellen, but rather helping herself avoid the issue.

Had the counselor asked Ellen what would be most beneficial, manipulation would not have occurred. Again, comfort is very important. When a provider is unable to respond in the best interest of the client because of discomfort or embarrassment, (s)he is unlikely to apply skills wisely. Some people don't want to provide sex counseling or education. The goal of training, in this case, will be to teach the skills of *referring*. In order for referral to be done sensitively and effectively, training is also required.

POPULATION

Anyone who can impact on the sexual well-being of other persons should be knowledgeable about and comfortable with sexuality. Various persons have different roles to play in supporting, maintaining, or providing services related to the sexuality of disabled persons. These people include:

parents of disabled individuals
teachers of disabled students
counselors
physicians
nurses

occupational therapists
physical therapists
social workers
attendants
administrators
psychologists
clergy
recreation specialists
trainers of rehabilitation professionals
peer counselors
hotline workers
allied health professionals
sex partners
house parents
friends

Some give direct services, such as teaching or counseling; some organize and plan such services; some motivate and initiate; some train. Here are two examples of different roles.

> *EXAMPLE 1:* Ms. Williams is the coordinator of community placement in a small residential center for mentally handicapped persons. Her job includes placement in community housing, job placement, and development of community living skills among her clients. She views her clients as whole persons and tries to develop rehabilitation plans that reflect that view. She has the *comfort* necessary to bring up the topic of sexuality with her clients, the *knowledge* to help her clients, and the *skill* to refer them for appropriate supportive services in the community (e.g., Planned Parenthood, family health services). She sees sexual well-being as part of total well-being.

> *EXAMPLE 2:* Mr. Franklin is a vocational rehabilitation counselor in a day-school for profoundly hearing-impaired students. Because Mr. Franklin believes that his clients will go on to live productive, active lives in the community, the individualized written rehabilitation programs (IWRP) he writes with his clients include the sexual aspect of personal adjustment. Mr. Franklin frequently finds that his clients have poor interpersonal functioning. Mr. Franklin asks the school's head administrator to call a meeting of all personnel to discuss this problem. Mr. Franklin is *comfortable* with the fact that deaf citizens are sexual persons, *knowledgeable* about their special problems in developing personal relationships and acquiring sexual information, and *skilled* in proposing a group problem solving approach to the issue.

The above examples demonstrate two ways that people can facilitate sexual well-being. Some people have developed a level of comfort, knowledge and training for this purpose *outside* a formal training structure, but these individuals are very rare. Most people need some kind of structured training to increase their abilities in one or more core area(s).

In spite of the tremendous need to train individuals to provide sex education/counseling services, human sexuality training should be *voluntary*. We can demand that an employee be punctual, responsible, and courteous in their dealings with others, but we can't insist that they deal actively with others' feelings and desires. Even the teacher, social worker, or parent who is understanding and helpful in relation to most areas of human concern may feel uncomfortable or have personal values which conflict with certain sexual thoughts and practices. These differences need to be respected. Not everyone in the helping professions needs or has the potential to deal effectively with all sexual concerns. However, we should not lose sight of the fact that sexuality is a legitimate health issue.

NEEDS ASSESSMENT

The next step in the process is needs assessment. Three basic questions guide this step:

What is the desired level of competency of the trainees?

What is their present level of competency?

Which competencies should be addressed first?

There are many ways to assess needs. Here are a few:

1. Have potential trainees brainstorm desired competencies.
2. Develop a questionnaire and distribute it to potential trainees.
3. Use an already developed questionnaire on sex knowledge.
4. Have trainees list issues of concern.
5. Consult literature on the PLISSIT model. Determine which levels are appropriate to the trainee population, and, therefore, which skills should be developed.
6. Obtain observations of potential trainees in their work settings.
7. Test existing skills through role-playing.

Identifying needs may not be as great a problem as deciding where to start. The issue of priorities (what is most important *now*) is always a thorny one. The best approach is to start with basic competencies and build toward more complex ones. For example, it is best to teach permission-giving skills first, then work on skills needed to give limited information, and so on.

On occasion, the trainer may have difficulty in prioritizing the training needs. Two problems are common enough to warrant consideration.

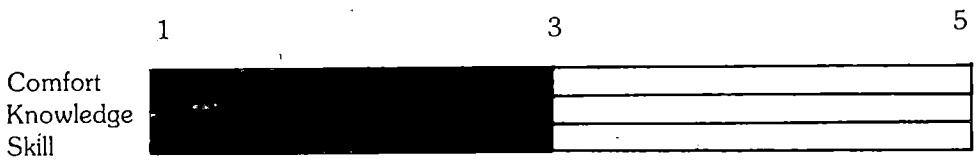
1. Often trainees will indicate that they need more knowledge and information. They may not recognize the necessity for developing a level of comfort which is appropriate to their roles. Although the KNOWLEDGE may be the expressed interest of a trainee group, the trainer may also need to consider COMFORT and SKILL.
2. Potential trainees may express confusion concerning their roles in providing sex education/counseling services. For a variety of reasons, they may not realize their potential to offer disabled citizens such services. The first step in the training process, under these circumstances, is to help trainees develop an awareness of their potential for providing services, referring clients for services, or offering administrative support for such services.

OBJECTIVES

A needs assessment has indicated the level of competency desired, present level attained by trainees, and the most important training priorities. The next step is to form specific training objectives from the needs. Objectives should be both long-term and short-term, the short-term ones relating to immediate training priorities and long-term ones addressing the ideal level. Let us consider the core areas—*comfort*, *knowledge*, and *skill*—in three examples.

> *EXAMPLE 1:* Let us say, for example, that the needs assessment indicated that a counselor population is mildly embarrassed by sexuality, is only

partially informed about sexuality and disability, and has a few skills. On a bar graph, the trainee profile would be represented as follows:



Training objectives in all three core areas, *comfort*, *knowledge* and *skill*, would be appropriate. Depending on the expressed problem areas of the trainees, emphasis could be placed on one or more areas. Some sample objectives for each area are:

Comfort

1. To desensitize trainees to emotionally-loaded topics such as homosexuality, incest, oral-genital sex play, abortion.

2. To clarify the role of parental values, present life status, and morality in forming judgments about sexuality.

3. To assist trainees in making informed choices about whether to provide services in a given situation, or to refer.

Knowledge

To present information about specific areas of concern such as:

a. Sexual development
b. Sexual response cycle
c. Effect of drugs on sexual response
d. Problems of disability associated with sexual functioning
e. Legal aspects of sterilization
f. Effects of institutionalization on sexual behavior

Skills

1. To suggest ways of initiating a discussion on sexuality.

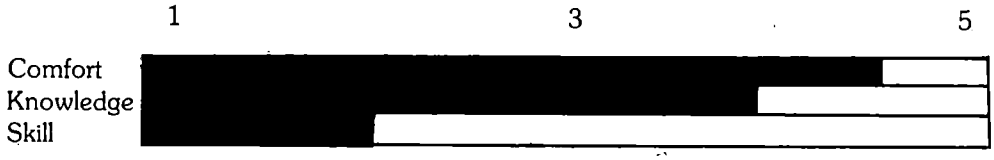
2. To demonstrate how to give permission appropriately.

3. To introduce basic problem-solving skills applied to sexuality.

4. To teach fundamental sex counseling strategies at different PLISSIT levels.

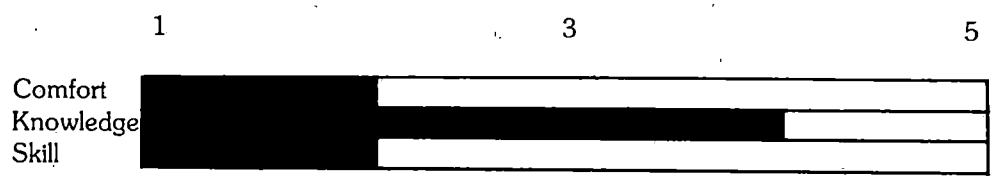
5. To give trainees the skills to plan a sex education/counseling program.

EXAMPLE 2: The trainees are very *comfortable* with sexuality and disability, somewhat *knowledgeable* about the facts and issues, but are not well trained in helping *skills*. The trainee profile looks something like this:



This group of trainees has the basic *comfort* and *knowledge* foundation for *skill* development. While increasing *comfort* and *knowledge* is important, the skill to apply present knowledge to actual situations would probably be the most important. Strategies and techniques of sex education/counseling should be the major focus, possibly using the levels of PLISSIT as a framework. Although a secondary consideration, attention to *comfort* and *knowledge* should also be included. (See skill objectives above.)

EXAMPLE 3: The trainee population is *knowledgeable* but lacks the *comfort* and *skill* necessary to apply this knowledge.



This trainee profile would guide the trainer to choose *comfort* and *skill* objectives. Early training efforts must come to grips with the integration of knowledge with personal values, attitudes, and prejudices. Skill development would be secondary because the basic foundation of comfort is absent. Some fundamental *comfort* objectives suggested by Cole (1975) are:

1. To examine one's own attitudes toward sexuality in order to deal more effectively with the sexuality of others.
2. To become aware of the various aspects of controversial sexual issues.
3. To increase tolerance of the wide variety of human sexual behaviors and responses.
4. To examine and discuss one's feelings about sexuality.
5. To realize the importance of initiating discussions about sexuality with clients.

RESOURCES

Once a list of objectives has been drawn up, resources needed to help meet those objectives must be located. We can divide these resources into four categories: PEOPLE, PROGRAMS, PRINTED MATERIALS, and AUDIO-VISUAL MATERIALS.

People

Many trainers have had limited experience in sexuality training. Other experienced people can greatly assist the training team in designing and implementing an effective program. PEOPLE resources can:

1. Help clarify goals, locate other resources, suggest formats.
2. Present material during training or actually conduct such training on a subcontract basis.
3. Be a panel of "experts," as when disabled adults present their own points-of-view.
4. Provide moral support and technical guidance.
5. Train the trainers.

Programs

Before starting a training program on sexuality and disability, trainers new to this area may want to attend existing similar programs. Appendix D is a partial list of training efforts, mainly over the last three years. Some programs are long-range, e.g., college or university programs toward degrees. Others are one, two, or three day workshops. Consultation with experienced trainers in sexuality and disability can be very beneficial.

Printed Materials

Five years ago, anyone seeking articles, books, curriculum guides, or films on sexuality and disability, was doomed to a futile search. Today a great store of information can be found that is pertinent to the understanding of sexuality and disability. Appendix F contains a partial listing of the material that may be particularly helpful in training.

Audio-Visual

During the last five years, the number of audio-visual materials produced on sexuality and disability has blossomed. Some materials are in video-tape format, such as the "Sexuality and Physical Disability" sequence developed at the University of Minnesota Medical School. Some are in film format, such as those developed by the Multi Media Resource Center in California. Appendix G contains a partial list of recommended films.

Some special consideration needs to be given to the use of audio-visual materials. Some contain lectures, panel discussions, or illustrations of helping techniques. Trainers can use them as a supplement to didactic presentations with optional group discussion. Other audio-visuals, however, require much more care and planning to be effective.

Sexually explicit films can have a powerful emotional effect on viewers. While many associate sexually explicit films with pornography, the films listed in Appendix G were made and are used *exclusively* for educational purposes. They are highly effective in presenting sexual behavior in an open way and have been used successfully in many training programs. Many viewers, however, have never had the experience of viewing sexual behavior and may find the explicitness more of a hindrance to learning than a help. This is especially true if the learners have not had time to become comfortable with the learning environment. **It is strongly recommended that participants be prepared in advance for the explicit nature of certain films. Further, sexually explicit films should only be used in training sessions that offer viewers an opportunity to discuss their reactions. Well-trained group leaders are essential to help put the films in perspective, to facilitate discussion, and to offer support.**

FORMAT

One's choice of a format should reflect an understanding of the trainee population, program objectives, and available resources. Limitations of time, place, and budget should also be considered. Some common educational formats are:

- lectures
- group discussions
- practicums
- role playing
- panel discussions
- programmed learning
- audio-visual presentations
- group exercises
- demonstrations
- reading
- tutoring
- question and answer sessions
- interviews
- simulations
- games
- site visits

Four common methods used in sexuality and disability training will be discussed here. They are the Sexual Attitudes Reassessment Seminar (SAR), didactic presentation, practice/feedback, and independent study.

The SAR

The SAR approach has been used primarily to achieve COMFORT objectives. Although it has been identified with the use of explicit sexual audio-visuals, some new approaches to the SAR use very little or none.

The SAR is a highly structured alternating sequence of large group presentations (many of which are audio-visual) and small group discussions. Each person is assigned to one group for the entire SAR. The goals of the SAR emphasize comfort, but may include knowledge and skills to a lesser extent. Many didactic programs are preceded by SAR's so that participants can examine their attitudes related to sexuality.

There are three types of SAR's:

1. The traditional SAR, originally developed by the National Sex Forum, makes primary use of highly explicit sexual materials and intensive group sessions. Participants are encouraged to reassess their attitudes toward sexuality. This process involves desensitization of emotional over-reactions toward sexual stimuli, while, at the same time, trainees are sensitized toward a more open-minded understanding of sexuality.

   Ted and Sandra Cole, along with their associates at the Minnesota Medical School, University of Minnesota, modified the SAR format in many ways, including the addition of a disability component. An instrument was developed to measure the effectiveness of this type of SAR. Results of this evaluation indicate that the SAR approach is effective as an intervention method and as a training tool (Cole, Chilgren & Rosenberg, 1973; Cole & Cole, 1976).

2. A different SAR approach, developed by Robert Wilson (1977), uses guided imagery instead of audio-visuals. In this type of SAR, trainees are led through a series of "fantasy" exercises, followed by small group discussions about these "internal movie" experiences. The major difference between this approach and the earlier one is that trainees use their own imaginations instead of relying on movies, tapes, or lectures.

3. The third SAR approach, often not called a SAR at all, relies on various presentations interspersed with group discussions. Stimulus materials may range from short lecture and panel discussions to role playing and simulations. Group processing focuses on the personal values and beliefs of trainees. When films are used, they often are not explicit, though they may be thought-provoking.

PRO's of the SAR Approach

* The SAR focuses on the individual trainee's own experience.
* The SAR has been highly effective in helping trainees dispel stereotypes and myths associated with sexuality.
* The SAR approach can be adapted for use with a wide variety of people.
* Most people have found SAR's to be beneficial.
* Through the process of desensitization and resensitization, trainees learn to approach the topic of sexuality with a more open-minded attitude.

CON's of the SAR Approach

* SAR's require well-trained leaders and group facilitators.
* If audio-visuals are used, rental (or purchase) of equipment can become expensive.
* The use of explicit films may cause controversy.

* Many small meeting areas are required (one per 7-12 persons).

* A SAR may require more time than a particular program allows.

DIDACTIC

Didactic sessions are appropriate when learning objectives focus on information giving. Lectures, panels, and films that present facts, outlines, statistics, research, conceptual models, or other information can increase the knowledge base of potential helpers. To a certain extent, better *knowledge* can increase *comfort* and improve helping *skills*.

An unfortunate association is sometimes made between didactically focused training and lecturing. Lecturing is only *one* type of didactic teaching. Knowledge and information may be presented in many different ways, the most effective of which encourage integration and application of information, as well as its acquisition. Learner participation in activities facilitates this synthesis of information. Good trainers will adapt their material to make didactic presentations interesting and meaningful to trainees.

PRO's of Didactic Sessions

* Didactic learning is an efficient means of meeting *knowledge* objectives.

* Didactic learning experience adapts well to short time frames, e.g., sessions at professional meetings.

* Didactic sessions can be interspersed within non-didactic formats.

* Didactic teaching is relatively inexpensive.

* Didactic sessions adapt well to large groups.

CON's of Didactic Sessions

* Didactic teaching addresses primarily one type of objective, *knowledge*.

* Didactic teaching is often too "trainer" centered as opposed to "trainee" centered.

PRACTICE/FEEDBACK

This category of learning/teaching formats includes such activities as group exercises, role playing, demonstrations, practicums, supervisory conferences, and simulation. The objectives most suited to these types of activities are *skill* objectives, i.e., the actual behaviors and strategies associated with education/counseling. In some cases, basic skills are the focus of teaching, e.g., listening, eye contact, lesson planning, problem solving, group leadership. In other cases, trainees are taught to apply already existing skills to the area of sexuality and/or disability. PRACTICE/FEEDBACK is necessary to insure that trainees can *use* information and feel comfortable providing needed services.

PRO's of Practice/Feedback

* Practice/Feedback includes important *skill* objectives.

* Practice/Feedback answers the question most often asked: "How do I help in this situation?"

* Practice/Feedback emphasizes the practical "reality" of sex education/counseling.

CON's of Practice/Feedback

* Practice/Feedback is not usually well adapted to short time frames or large trainee groups.

* Practice/Feedback formats require highly trained leaders.

INDEPENDENT STUDY

Independent study is suited to trainees from a variety of backgrounds and can be adapted to a variety of objectives. The availability of books, articles, monographs, and films establishes this format as a viable one. The ever-increasing volume of material being published encourages service providers to update and broaden their knowledge. Some materials are useful in increasing understanding of variations of sexual expression (*comfort*); some are excellent sources of information on this topic (*knowledge*); some focus on sex education/counseling strategies (*skill*). Independent study can be used as a supplement to other formats or as a free standing format. A well stocked specialized library would, of course, greatly enhance such an effort.

PRO's of Independent Study

- Independent study can be designed to meet a variety of objectives.
- Independent study involves a minimum of trainer time.
- Independent study proceeds at the learner's pace.
- Independent study is relatively inexpensive.

CON's of Independent Study

- Independent study cannot meet all objectives. It is particularly inappropriate for *some comfort* and *skill* objectives.
- Independent study requires access to appropriate materials, e.g., books, articles, journals, etc.
- Independent study reduces contact between trainee and trainer to a minimum.

Summary of Formats

The formats discussed above represent those commonly used. Frequently, the formats are used in combination (e.g., one workshop which includes didactic presentations, practice/feedback sessions, and guidelines for independent study). The core areas of *comfort, knowledge,* and *skill* are themselves interactive. An increase in one area is likely to spark an increase in the others. Training, while focusing on specific objectives, should allow for the integration of learning into other areas. Formats should reflect:

1. Present needs of trainees
2. Types of objectives for training
3. Available resources
4. Inherent restraints such as time, cost, skill of trainers

LOGISTICS

Setting up the learning environment is an important aspect of training. Training must be planned well enough in advance to assure that location, facilities, publicity, equipment, budget, and other components are managed efficiently and productively, Barrier-free environments and the modification of learning activities for some disabled trainees (perhaps blind or deaf) should receive considerable attention, since equal participation for all is essential (see Chapter 6).

In order to organize and plan a program, a trainer often relies on multiple checklists which detail the tasks that precede training. Davis & McCallon (1974) in their book, *Planning, Implementing and Evaluating Workshops*, provide clear and usable planning checklists.

REHEARSAL

Rehearsal before training begins is important because it:

1. Provides all principal program participants with an overview of the entire training plan.
2. Reinforces responsibility for individual activities.
3. Recognizes and corrects any oversights or problems.

Rehearsal should include the following activities:

1. Review the schedules with all program presenters and assistants.
2. Check to be sure that presenters, speakers, handouts, and audio-visuals are at the training site.
3. Review the site; make sure equipment is set up, enough seating is arranged, necessary keys are on hand.
4. Check and trial run all equipment including: lighting, air conditioning or heat, projectors, audio-playback, recording devices, and microphones.
5. Correct any problems *now*!

IMPLEMENTATION

Training people to provide sex education/counseling is an exciting task. By the time training actually begins, whether the training is a one-time presentation or a year-long seminar, much thought and work has already occurred. The actual implementation is the trainers' reward—the opportunity to help people learn how to help others.

In implementing a training program, some difficulties may arise. Here are two examples:

1. Trainees may be unaware of training goals and objectives and therefore feel that learning activities and format are silly, irrelevant, or inappropriate.

Action: Early in each session, goals and objectives should be reviewed with trainees. Rationales for various activities should be given and the opportunity for discussion planned. Since training must be voluntary, those who find the goals incongruent with their own value system should be allowed to resign from the program.

2. Trainees may experience emotional discomfort. Some may avoid participation or attempt to redirect training activities. It is not unusual that individuals have ambivalent feelings toward human sexuality training.

Action: Trainers should reassure participants that initial discomfort is *normal* and arises from previous social taboos. Trainers may use a variety of approaches to help trainees become more comfortable: small group discussions, individual conversations, self-disclosure about own discomfort in the past, description of other groups' reactions, etc. It is essential, however, that ambivalent and negative feelings be discussed openly. Ignoring these feelings will only increase trainee resistance.

EVALUATION

For some, this word is a horror story. Gloomy visions of reports, forms, and questionnaires piling up in an endless sea of trivia emerge. Evaluation means determining the *value* of the training effort. It means answering the following questions:

1. Were the objectives met? Which ones? How well?

2. Were the trainees satisfied? With which components?

3. Is there any further training to be done? Toward which objectives?

A formal evaluation strategy using criteria-referenced tests, observation checklists, or standardized instruments can be designed. This type of evaluation can yield usable information on the effectiveness of the training effort. Informal methods such as group discussion, questionnaires, and trainer observation can also be used to determine the value derived from training.

Whatever the evaluation method chosen, the primary consideration is improving training. Evaluation is the *tool* by which the trainer determines the effectiveness of training as a whole and the value of the various components. Further training can be planned from this data and the process, beginning with *Needs Assessment*, can begin again.

REFERENCES

Cole, T.M. Sexual functioning of the physically disabled adult. Minneapolis: University of Minnesota Medical School, 1975.

A program handout.

Cole, T.M., Chilgren, R., & Rosenberg, P. A new programme of sex education and counseling for spinal cord injured adults and health care professionals. *Paraplegia*, 1973, *11*, 111-124.

This article discusses the effects of spinal cord injury on sexual functioning and describes the SAR program developed at the University of Minnesota. Results of the program evaluation indicate that participants benefited from the experience.

Cole, T.M., & Cole, S.S. *A guide for trainers: Sexuality and physical disabilities*. Program in Human Sexuality, University of Minnesota Medical School and Center for Continuing Education, Region V, Multi-Resource Center, 1976.

This is an excellent guide written by renowned experts on training and human sexuality. The guide is one component of an RSA funded project to "train the trainers" of rehabilitation personnel. Participants in the program received this volume and its companion (a guide for students). It is both theoretical and highly practical. It provides an excellent rationale for the "traditional" SAR.

Davis, L., & McCallon, E. *Planning, conducting and evaluating workshops*. Learning Concepts, 2501 N. Lamar, Austin, Texas 78705, 1974.

This is a workbook and text for the trainer. It is a *practical* guide to organize workshops and includes "how-to's" on almost everything from assessing needs to packing workshop materials. It is not geared toward sexuality, but is extremely useful.

Kempton, W. *Guidelines for planning a training course on human sexuality and the retarded.* Philadelphia: Planned Parenthood Association of Southeastern Pennsylvania, 1973.

This little volume is exactly what its title implies: a guide for planning training. It approaches training from a very

down-to-earth point of view. It is highly recommended to trainers of both rehabilitation and special education personnel.

Wilson, R. *Sex counseling skills workshop: A trainer's handbook*. Carolina Population Center, University of North Carolina, Chapel Hill, North Carolina 27514, 1977.

This handbook is a practical well-formatted training guide, with listings of further resources. Although Wilson's focus is on sexual counseling skills for the mentally retarded person, his approach and ideas are easily applied to other areas. The "imagery" SAR is outlined in detail.

V. Making Policy

Making sound policy decisions about the provision of sexuality-related services involves a multi-step process. This section is designed to offer some insights into that process.

1. **"What are policies as they relate to sexuality and disability?"**

Every agency has "policy" regarding sexuality and disability services. Here are a few:

- Education about human sexuality is a regular service.
- Reading material on sexuality is made available to all clients.
- Sexuality is considered an Activity of Daily Living (ADL).
- Our clients are not interested in sexuality.
- Sexuality-related services are included in the Individualized Written Rehabilitation Program (IWRP).
- Married couples may not cohabitate in this facility.
- Sexuality is not our business.
- Disability is not our business.
- Dating is discouraged.
- Clients have private rooms with locks.
- Contraceptive information is provided to all clients.

Some of the policies above are *formal*; they are stated orally and/or in writing. Others, however, are *informal.* Some clients and staff members can articulate them, but no one comes right out and says, "We will do such and such." Informal policy is extremely powerful because it reflects the collective attitude of a group of people. Its weakness is that ambiguity, confusion, and inconsistency may plague staff and clients. Without clear guidelines each individual acts alone, unaware of the consequences that may follow.

Agency policy, then, is a code of behavior delineating the rights and responsibilities of the individuals associated with the organization. Policy may be *reactive* (crisis-oriented, putting out fires) or *proactive* (planning and development). It may be *specific* (clients shall have sexuality-related services included in the IWRP) or general (clients shall receive whatever services are necessary to secure gainful employment).

2. **"Why have policies regarding sexuality services been slow to develop?"**

Informal policy has always existed. It has been reflective of general, often negative, attitudes toward sexuality and disability. In the recent past, however, attitudes have been changing. Deinstitutionalization, consumer activism, normalization, professional education, and media presentations have had a great impact on attitudes. Sexuality has entered the public forum as a legitimate human concern.

Formal policy development, however, has lagged behind. Reasons may vary, but some common themes have emerged:

- Sexuality is unrelated to our mission.

- Our staff is not prepared to deal with this issue.

- We do not know what our policy should be.

- This clamor about sexuality is a fad. It will eventually go away.

- Formal policy is not needed. Everyone understands our position.

- Our past policies have been adequate. There is no need to change now.

Because change is extremely difficult, some organizations have chosen not to change. Some have viewed change as a challenge and have begun to examine present policy and to plan for new developments. Overcoming inertia is no easy task!

3. **"Which kinds of policies should various agencies/institutions have regarding sexuality?"**

That, of course, depends on the type of setting. Those settings which provide services primarily to disabled people need policies regarding the provision of sexuality-related services, including appropriate referral strategies.

Facilities for disabled individuals may have policies that relate to:

- which sexuality services will be provided

- which services will be purchased

- who will provide these services

- how referrals and/or purchases will be handled

- how qualified providers will be obtained

- how funds for services will be allocated

Residential programs need policies related to sexuality services. They also have the added responsibility of providing an environment that encourages sexual development and supports appropriate sexual expression. Some residential facilities are unaware of this important responsibility, and, as a result, have not developed a positive formal policy. Instead, a negative policy or a vague, informal policy has been in effect. As we mentioned earlier, informal policy is often based on negative attitudes and tends to be inconsistent and crisis-oriented. Examples of formal policies which encourage sexual development and support sexual expression include:

- acceptance of heterosexual social contact

- opportunities to learn about sexuality

- privacy and non-interference with appropriate sexual expression

- support for age-appropriate sexual behavior, e.g., dating, marriage

- preparation for adult sexual roles, e.g., parenting, contraception

- acceptance of non-traditional sexual expression

In developing sexuality-related policies, residential programs can be guided by a basic question: Is our facility providing the type of environment that encourages sexual development and supports sexual expression?

Those facilities which provide sexuality-related services to the community (mental health centers, Planned Parenthood, etc.) need policies which delineate how they will serve disabled individuals. In addition to the issues discussed above, facilities which provide sexuality services to the community may have policies regarding:

- how present services will be made accessible to disabled people (see Chapter 6)
- who will be responsible for accessibility changes
- how outreach will be accomplished

4. **"How do we overcome staff resistence to a policy which increases agency emphasis on sexuality?"**

It's very possible that staff members are reacting to the ambiguity of the situation rather than to the policy itself. The results, for example, of the Sex & Disability Project survey of rehabilitation counselors (see Appendix A) indicated that the majority saw a need for sexuality-related services and were willing to provide them. Many, however, were concerned with administrative attitudes toward the inclusion of these services in their job duties. Some felt that the administration would openly condemn their involvement in sex education/counseling. Others indicated more subtle administrative sanctions against provision of these services (e.g., not being allowed the time to attend workshops on sexuality, or not being reimbursed for participation in training). Many said that their heavy caseloads did not allow them the time to discuss sexuality with their clients. Staff members may also be uncertain about their ability to provide adequate services. They may not understand what their role is to be, or they may feel that their training in sexuality is inadequate.

It's important, therefore, to determine if "staff resistance" is actually a communication gap. By clearly defining your policy on sexuality, you can eliminate much of the confusion; staff members will have a clearer understanding of what both the agency and their clients will expect of them. You can also assure them of official support in their roles as the providers of sexuality-related services: adequate training to meet their needs, resources to help them. and time enough to both receive training and provide services. By openly stating your policy and guaranteeing administrative support of staff efforts, chances are good that you'll achieve maximum cooperation.

5. **"How do we begin?"**

You have already begun! This handbook was prepared in order to assist you in developing services or service networks that are appropriate to your setting. Your interest in using it is the beginning.

We have outlined six basic components of a sexuality-related service system which can be used as a guide in planning:

1. *Awareness* - How do our attitudes and myths shape our responses to the sexual needs of disabled citizens?
2. *Client Needs and Services* - Which clients need which services?
3. *Settings* - How can our agency/institution participate in sexuality-related services?
4. *Human Resources* - Who should provide services?
5. *Training* - What training needs to be done?
6. *Access* - Are services and training accessible?

6. **"How much will this cost?"**

Well, we finally got to the BIG question - MONEY. One thing is certain: there's never enough of it, and everyone is willing to tell you how to spend what little you have.

Let's face it. Spending funds for sexuality-related services will mean that you have fewer funds for other activities. This is a priority crunch. Often when people refer to a money issue, they are actually talking about priorities. When

sexuality-related services are viewed as an integral part of regular programming, financial resources are not seen as stumbling blocks. When sexuality-related services for disabled people are seen as extraneous to regular programming, financial resources are often cited as a major deterrent to providing them. Perhaps the issue is more an issue of attitudes than anything else. Let's look at an example:

> Ms. Galvin is an adjustment specialist in a vocational rehabilitation work evaluation facility. Many of her clients have been, in their youth, isolated in special classes for persons with mental retardation. She is concerned that, on entering the world of work, they will be unprepared to handle personal relationships and may well jeopardize their jobs by inappropriate sexual behavior. She wants to begin a sex education class for her clients. The facility administrator says that there isn't enough money for that.

Ms. Galvin may be suggesting that a large array of expensive audio-visuals be purchased and that a full-time sex educator be hired. Or, more likely, she is asking for a reallocation of some of her duties, a small materials budget, and the funds to hire a consultant for a few days to help her plan the program. The initial cost would depend upon the nature of the request. The maintenance cost (i.e., providing such programming on a regular basis) would be negligible. The amount of money/time allocated will depend on how important sex education is to total program goals. An issue of money or of priorities?

7. **"How do we acquire** *competent staff* **to provide services or develop referral networks?"**

There are two basic methods: (1) train present staff, and (2) hire already trained persons. Training resources are many. We have devoted several sections of this handbook to training issues (Chapter 5, Section IV, and Appendix D). Attending workshops, participating in college-level course work, independent study, etc., are only a few of the many ways potential providers can be trained. See Appendix D for the names and addresses of specific on-going training programs.

MAKING POLICY IN THE VOCATIONAL REHABILITATION SYSTEM

8. **"What is the present policy of state rehabilitation agencies toward sexuality-related services?"**

The Sex & Disability Project conducted a survey to gather information on this question. Ten top administrators in two state agencies participated in "in-depth" interviews about policy in their agencies. Eight other state directors, chosen at random from HEW regions, responded to mailed questionnaires (see Appendix A for survey summaries). Six of the eight mailed responses cited no agency policy regarding sexuality services. This differs substantially from the response of the ten policy makers who were interviewed in person. Most of this latter group indicated that an "informal policy" existed. This difference is probably due to the use of clarifying questions on the part of the interviewer.

When state agency administrators were asked which services rehabilitation counselors *should provide*, those mentioned most often were:

- access to reading material
- social skills training
- access to audio-visual material
- individual counseling on sexuality

They indicated that counselors *should refer* clients for:

- sex therapy

- contraceptive/genetic counseling

- general sex education

On the whole, they envisioned the role of the state rehabilitation agency as one of referral to outside vendors. Inclusion of sexuality-related services in the IWRP was mentioned by five administrators.

In order for a referral system to work, community-based professionals must be prepared to accept referrals and provide services. Those professionals considered by policy makers to be the most likely providers of needed services were sex counselor/therapist, physician, social worker, and psychologist. In our survey of disabled citizens, these groups were also seen as likely providers, although there were also interest in peer counseling.

At this point in the service chain, however, a hitch develops. Clients have needs. There is agreement that rehabilitation counselors should provide some services and refer clients for others. But--

1) Are counselors prepared to provide some services?

2) Can they refer competently for services they are unable to provide?

3) Are the outside resources prepared to offer services?

9. **"What can be done to close this gap between a client's sexual needs and available services?"**

A. Provide needed services within your agency. Train in-house staff, encourage staff by allocating adequate time for these efforts, hire a specialist (as is done for medical consultation) or acquire sex educators/counselors from already existing programs (see question 7).

B. Express your agency's need for sexuality-related services by influencing VR training priorities, college and university counselor education programs, and research and training centers.

C. Form cooperative agreements with local school boards, Planned Parenthood, medical or psychological service facilities, and consumer organizations.

D. Conduct workshops, lectures, etc. to educate community-based service providers.

E. Advocate. Your agency can influence the community. In some instances you may have Section 504 on your side. In others, your role will be to educate and encourage. In many communities, services are lacking because needs are unrecognized.

F. Use your agency clout to obtain Federal Improvement Grants, short-term training grants, and/or private funds for training and services.

G. Encourage your own staff by making your priorities known, by offering encouragement to counselors to provide some services and develop referral networks, and by including sexuality-related services in programming decisions, including the IWRP. Use *all* your usual channels to support and encourage needed service delivery.

10. **"But won't it be considered 'strange' that a vocational rehabilitation agency is becoming involved in sexuality-related services?"**

Perhaps. Because of the previous negative attitudes, some people may view a state vocational rehabilitation agency's participation in this aspect of rehabilitation as unusual. But the scene is definitely changing. Many rehabilitation centers and RT centers have been involved in sexuality services for a long time. The recent Rehabilitation Act Amendments of 1978 indicate an expansion of the role of state agencies in providing a multitude of needed services. Adjustment services (training) have often included sexuality issues.

The message is: Sexuality relates to rehabilitation. Providing sexuality-related services is compatible with goals of vocational and social independence.

11. **"What role should rehabilitation counselors play in sexuality-related services?"**

Rehabilitation counselors vary in attitudes and skills. Their roles will, of course, be dependent on a variety of factors including expertise, type of caseload, agency policy, previous training, and opportunities to receive additional training. They may provide direct counseling services, refer clients to others for services, build referral networks, and advocate for better sexuality services. In some cases, counselors may feel comfortable providing some services directly. In other cases, the counselor can serve as a coordinator of services, through the IWRP.

Whatever the role, however, most rehabilitation counselors will need training in order to fill their roles effectively (see Chapter 5 and Section IV). Some counselors have already received training through the VR system (particularly RRCEP, Region V), college counselor education programs, agency staff development, and continuing education from a variety of institutions. Many others, however, have had little training in sexuality-related services. In order to provide some services and refer knowledgeably for others, counselors must be sensitive to client needs, aware of the variety of issues involved, skilled in counseling techniques and informed about referral sources. As with other services included in the IWRP, sex education/counseling services should be integrated into a total rehabilitation program, and the necessary competencies to do that must be developed.

Your agency can increase counselor effectiveness in the area of sexuality services by:

1. Clarifying the expected role of the counselor regarding provision of and referral for services.

2. Providing training to counselors in the area of sex education/counseling for disabled persons.

3. Offering administrative support to counselors for these activities.

4. Including rehabilitation, counselors, consumers, and community resource persons in the development of needed services.

APPENDIX A

Survey Summaries

CONSUMER SURVEY

A survey of disabled persons in two states was conducted by the Sex & Disability Project staff in early 1978. Responses were received from 97 individuals.

The survey form mailed to disabled consumers is reproduced below. Many of the results have been indicated on the form itself (e.g., for questions 4, 5, and 6). Those questions, however, requiring further clarification or more detail (e.g., questions 1, 2, and 3) are indicated by an asterisk (*) on the form. These results and explanations immediately follow the survey form.

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SEX AND DISABILITY PROJECT -- Consumer Survey

* 1. Specify disability _____

* 2. Age at onset of disability _____

* 3. Present age _____

4. Sex: 47% Male 53% Female

5. State of residence: 33% State I 67% State II

6. Is the area that you live in: ____Urban ____Small Town

____Suburban ____Rural

Note: Sex education/counseling services are given by a professional or peer in order to help a person with a disability achieve satisfactory sexual and personal relationships. Services may include education, counseling, group discussions, therapy, family planning, and/or obstetrical, gynecological and urological care.

7. Have you ever received sexual education/counseling services? 28% Yes 72% No
**NOTE: IF YOU ANSWERED "NO," GO ON TO QUESTION 11.

* 8. Check those services which you have received:

20% Social skills training

51% Access to reading materials on sexuality

26% Access to audio-visual materials

34% General sex education course

6% Sex and disability course

40% Group discussions on sexuality

17% Individual counseling on sexuality

11% Group counseling on sexuality

3% Sex therapy

26% Contraception/Genetic counseling

26% Obstetric/gynecological/urological care

14% Couples/family counseling on sexuality

9. Were the above services given by a:

3% Member of the clergy

21% Psychologist

32% Teacher

9% Other disabled person

15% Social worker

-0- Telephone hotline

-0- Other (specify): _____

32% Physician

24% Other medical personnel (specify):

_____

18% Rehabilitation counselor

6% Planned Parenthood staff member

9% Sex counselor/therapist

10. Did the services you received meet your needs? 58% Yes 42% No

*IF NOT, WHY? _____

_____

* 11. If the following services were available, which would you use?

29% Social skills development

39% Access to reading materials on sexuality

35% Access to audio-visual materials on sexuality

19% General sex education course

49% Sex and disability course

48% Group discussions on sexuality

40% Individual counseling on sexuality

30% Group counseling on sexuality

26% Sex therapy

28% Contraception/genetic counseling

30% Obstetric/gynecological/urological care

32% Couples counseling on sexuality

* 12. Who do you think should help you with a question or concern about sexuality? (Check all those which are applicable.)

11% Member of the clergy

51% Psychologist

16% Teacher

50% Other disabled person

25% Social worker

12% Telephone hotline

9% Other (specify):_____

64% Physician

15% Other medical personnel (specify):

_____

31% Rehabilitation counselor

20% Planned Parenthood staff member

55% Sex counselor/therapist

* 13. From the above list, which three do you think are the most suitable providers of sex education/counseling services to disabled people. (Please rank.)

First _____

Second _____

Third _____

* 14. Would you prefer to use sex education/counseling services specifically designed for your disability, or would you prefer to use the same services as other citizens in your community?

54% Special services 42% Same services

* 15. How do you think sex education/counseling services for disabled people could be improved? _____

_____

Further Analysis of Consumer Survey

1. Respondents to our survey were as follows:

   16% Hearing-impaired or visually-impaired
   23% Spinal cord injured
   34% Other mobility-impaired (including polio, MS, MD, and arthritis)
   27% Other disabled

2. Age at onset of disability:

   23% Birth
   12% 0 - 10 years
   28% 11 - 20
   21% 21 - 30
   9% 31 - 40
   6% 41 - 50
   1% Over 50
   (Mean average = 16.4 years)

3. Present age:

   5% 10 - 20 years
   38% 21 - 30
   25% 31 - 40
   19% 41 - 50
   13% Over - 50
   (Mean average = 35.7 years)

   A further analysis was made to determine length of disability. The results were as follows:

   8% 0 - 2 years
   9% 3 - 5
   18% 6 - 10
   8% 11 - 15
   11% 16 - 20
   13% 21 - 25
   32% Over 25
   (Mean average = 19.2 years)

8. Percentages given for questions 8, 9, and 10 represent a percentage of those who responded "yes" to question 7. (E.g., of the 28% who received *any* services, 20% received social skills training; however, only 7% of the total respondent population received this service.) A more detailed analysis of services received by members of specific disability groups may be found in Table C.

10. The 14 persons who had received services but indicated that these services did not meet their needs gave the following reasons: services were insufficient, there was no practical experience, services were not very technical, there should have been more counseling on the specific disability, more spouse counseling was necessary, discussions were geared toward persons without any sexual experience, and the respondent did not complete the program.

11. A more detailed analysis of services requested and received by members of specific disability groups may be found in Table C. A bar graph depicting a comparison of services received by respondents (Question 8) and services that they would actually use (Question 11) is found in Table A.

12. A bar graph depicting a comparison of actual providers (Question 9) and appropriate providers (Question 12) may be found in Table B.

13. The following percentages represent the percent of highest possible point count (total points, had the provider been indicated as the best possible provider by all respondents).

This question was asked only of State II respondents (n = 60).*

51% Physician
34% Psychologist
32% Sex counselor/therapist
29% Other disabled person
15% Rehabilitation counselor
13% Social worker
7% Teacher
7% Planned Parenthood
6% Other medical
3% Telephone hotline
3% Clergy

* (It was inadvertently omitted from the form mailed to State I consumers.)

14. In addition, 3% of the respondents indicated that they would prefer to use both types of services.

15. Responses to this open-ended question have been incorporated throughout the handbook.

TABLE C

PERCENT OF RESPONDENTS WHO HAVE RECEIVED SERVICES VS. THOSE WHO WOULD USE THESE SERVICES

(Number of respondents = n)	Communication Impaired n = 15		Spinal Cord Injured n = 22		Other Mobility-Impaired n = 32		Other Disabled n = 28		TOTAL n = 97	
	Rec'd.	Would Use	Rec'd.	Would Use	Rec'd.	Would Use	Rec'd.	Would Use	Rec'd.	Would Use
Social Skills Training	--	20.0	4.5	28.6	6.3	25.8	14.3	37.0	7.2	28.7
General Sex Education	--	26.7	9.1	9.5	15.6	19.4	17.9	22.2	12.4	19.1
Sex & Disability Course	--	20.0	4.5	57.1	--	51.6	3.6	55.6	2.1	48.9
Access to Reading Materials on Sexuality	6.7	20.0	22.7	57.1	21.9	41.9	17.9	33.3	18.6	39.4
Access to Audio-Visual Materials on Sexuality	6.7	40.0	18.2	52.4	3.1	22.6	10.7	33.3	9.3	35.1
Group Discussion on Sexuality	--	53.3	27.3	47.6	6.3	58.1	21.4	33.3	14.4	47.9
Individual Counseling on Sexuality	--	40.0	9.1	52.4	3.1	35.5	10.7	37.0	6.2	40.4
Group Counseling on Sexuality	--	26.7	9.1	28.6	--	38.7	7.1	22.2	4.1	29.8
Couples Counseling on Sexuality	--	33.3	4.5	42.9	6.3	29.0	7.1	25.7	5.2	31.9
Sex Therapy	--	33.3	--	23.8	--	25.8	3.6	22.2	1.0	25.5
Contraceptive/Genetic Counseling	13.3	26.7	--	38.1	12.5	29.0	10.7	18.5	9.3	27.7
Obstetric/Gynecological/ Urological Care	13.3	26.7	--	52.4	12.5	22.6	10.7	22.2	9.3	29.8

COUNSELOR SURVEY

A survey of state vocational rehabilitation counselors in two states was conducted by the Sex & Disability Project staff in early 1978. Responses were received from 156 individuals.

The survey form mailed to counselors is reproduced below. Many of the results have been indicated on the form itself (e.g., for questions 2, 3, and 6). Those questions, however, requiring further clarification or more detail (e.g., questions 1, 4, and 5) are indicated by an asterisk (*) on the form. These results and explanations immediately follow the survey form.

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SEX & DISABILITY PROJECT -- Counselor Survey

* 1. Age _____

2. Sex: 66% Male 34% Female

3. State in which agency is located: 49% State I 51% State II

* 4. Description of caseload: 62% General
36% Specialized (specify population)_____

* 5. Approximate number of clients: _____

6. Is your caseload predominantly: 40% Urban 19% Small town
23% Suburban 18% Rural

NOTE: Sex education/counseling services are given by a professional or peer in order to help a person with a disability achieve satisfactory sexual and personal relationships. Services may include education, counseling, group discussions, therapy, family planning, and/or obstetrical, gynecological and urological care.

---

7. Have you ever received specific training in the area of human sexuality? 29% Yes 71% No

8. (a) Do you personally provide sex education/counseling services to your clients? 28% Yes 72% No

* (b) If not, why? (Check all that apply.)

22% Lack of time
51% Lack of appropriate training
19% Lack of agency support
12% Other (specify):_____
70% Clients don't request this service
16% Not an agency function
14% Not part of my job

* 9. Do you refer your clients for sex education/counseling services? 1% Within the agency 57% Outside the agency 38% Don't refer.

* 10. INSTRUCTIONS: Mark a "P" beside those services which you, yourself actually provide to clients. Mark an "R" beside those services to which you actually refer your clients. If you neither provide nor refer a service leave the space blank.

____ Social skills training
____ Access to reading materials on sexuality
____ Access to audio-visual materials
____ General sex education course
____ Sex and disability course
____ Group discussions on sexuality
____ Individual counseling on sexuality
____ Group counseling on sexuality
____ Sex therapy
____ Contraception/genetic counseling
____ Obstetric/gynecological/urological care
____ Couples/family counseling on sexuality

* 11. In your caseload, who usually initiates discussions about sexuality?
20% Rehabilitation Counselor 37% Client 37% No one

12. Do you usually feel comfortable discussing sexual concerns with your clients? 84% Yes 16% No
COMMENT: _____

_____

_____

13. Who do you think should provide sex education/counseling services to disabled people? (Check all that apply.)
27% Member of the clergy
72% Psychologist
27% Teacher
58% Other disabled person
56% Social worker
14% Telephone hotline
66% Planned Parenthood staff member
73% Physician
27% Other medical personnel (specify):
_____
58% Rehabilitation counselor
82% Sex counselor/therapist
____ Other (specify): _____
_____

* 14. From the above list, which 3 do you think are the most suitable providers of sex education/counseling services to disabled people. (Please rank.)
First _____
Second _____
Third _____

* 15. In your opinion, what are the most effective ways to provide sexuality and disability training to rehabilitation counselors?
38% Human sexuality course work toward a degree in rehabilitation counseling
76% Agency staff development workshops
28% RRCEP workshops
34% University course paid for by the agency
27% More workshops at professional conventions (e.g., NRA)
35% Access to reading and A-V material within the agency
36% Agency consultant on human sexuality
____ Other (specify): _____
_____

*16. How else do you think sex education/counseling services to disabled clients could be improved? _____

_____

_____

Further Analysis of Counselor Survey

1. Ages of respondents:

   25% 20 - 29 years
   48% 30 - 39
   13% 40 - 49
   12% 50 - 59
    3% Over 59

4. In addition, 2% of the respondents indicated that their caseload was both general and specialized.

5. Approximate caseload:

   15% 1 - 100 clients
   66% 101 - 200
   17% 201 - 300
    2% 301 - 400

8.b. Nine percent of the 12% of respondents indicating "other" wrote in that they felt it was their job to refer rather than provide sex education/counseling services.

9. In addition, 3% of the respondents indicated they referred clients both within the agency and outside the agency.

10. Respondents indicated that they provide the following services:

    41% Social skills training
    15% Access to reading materials on sexuality
     7% Access to audio-visual materials on sexuality
     2% General sex education course
     2% Sex and disability course
     4% Group discussions on sexuality
    27% Individual counseling on sexuality
     3% Group counseling on sexuality
     1% Sex therapy
    14% Contraception/genetic counseling
     4% Obstetric/gynecological/urological care
     5% Couples/family counseling on sexuality

    Respondents indicated that they refer clients for the following services:

    59% Social skills training
    42% Access to reading materials on sexuality
    44% Access to audio-visual materials on sexuality
    46% General sex education course
    44% Sex and disability course
    44% Group discussions on sexuality
    44% Individual counseling on sexuality
    47% Group counseling on sexuality
    48% Sex therapy
    60% Contraception/genetic counseling
    65% Obstetric/gynecological/urological care
    55% Couples/family counseling on sexuality

11. In addition, 7% of the respondents indicated that both client and counselor initiate discussions about sexuality.

14. The following percentages represent the percent of highest possible point count (total points, had the provider been indicated as the best possible provider by all respondents).

    63% Sex counselor/therapist
    32% Physician
    21% Psychologist
    19% Planned Parenthood
    19% Other disabled person
    16% Rehabilitation counselor
    12% Social worker
     6% Other medical personnel
     2% Teacher
     2% Clergy
     1% Telephone hotline

15. There is a large discrepancy between respondents in State I and State II on the effectiveness of "RRCEP workshops." Respondents in State I gave this mode of training the second highest ranking, being indicated by 45% of all respondents; it was ranked last among State II respondents, being indicated by only 12%. The possibility exists that this discrepancy may result from the fact that "RRCEP" in State II is more frequently called "CCE," and counselors, therefore, may have been unfamiliar with the term "RRCEP."

16. Responses to this open-ended question have been incorporated throughout the handbook.

COMMUNITY RESOURCE SURVEY

The Sex & Disability Project staff conducted a telephone survey in early 1978 of community resources in two states. People at 45 resource locations agreed to respond.

The questionnaire utilized during the phone survey is reproduced below. Some of the results have been indicated on the form itself (e.g., for questions 3 and 6). All questions, however, require further clarification or more detail. These results and explanations immediately follow the survey form.

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SEX & DISABILITY PROJECT: Community Resource Telephone Questionnaire

* 1. Name of Organization _____

* 2. Location of Organization (city & state) _____

* 3. Type of Organization:

4% Planned Parenthood
13% Hospital
24% Community mental health center/family services
18% Consumer service organization (e.g., United Cerebral Palsy)
24% Physician (specify specialty) _____
7% Psychologist
0 Visiting nurse association
2% Residential institution
7% Other (specify) _____

* 4. Job title of respondent _____

* 5. Approximately what percent of your clientele is physically disabled or mentally retarded? MR _____ PD _____

* 6. What sex education/counseling services, if any, do you provide for physically disabled or mentally retarded persons? (Check all those mentioned.)

7% Social skills training
33% Access to reading materials on sexuality
11% Access to audio-visual materials on sexuality
7% General sex education course
-0-% Sex and disability course
13% Group discussions on sexuality
49% Individual counseling on sexuality
9% Group counseling on sexuality
7% Sex therapy
36% Contraception/genetic counseling
24% Obstetric/gynecological/urological care
29% Couples/family counseling on sexuality

16% Other (specify) _____

31% None (If checked, why not?) _____

(If "none" is the response, proceed to question 8.)

* 7. Who on your staff provides sex education/counseling services? Please specify job title(s).

_____

* 8. To whom do you refer clients/patients for sex education/counseling services?

_____

* 9. What resource in your community do you think should have primary responsibility for providing sex education/counseling services to disabled people?

_____

_____

* 10. What do you think is the role of your organization in providing sex education/counseling services to disabled people?

_____

_____

_____

Further Analysis of Community Resources Survey

1. All surveys were tabulated anonymously. Initial identification was solely for the purpose of avoiding duplication in survey efforts.

2. The locations of responding organizations were as follows:

Urban area, State I	36%
Rural area, State I	7%
Urban area, State II	40%
Rural area, State II	18%

3. Physicians surveyed were either gynecologists (18%) or urologists (7%).

4. Staff members who responded to the survey were as follows:

24%	Directors
24%	Clerical staff members
13%	Physicians
13%	Counselors
11%	Social workers
4%	Medical assistants
4%	Psychologists
4%	Other professionals

5. The percentages of mentally retarded clients served by responding community resources were:

84%	0 - 5% of clientele
7%	6 - 25%
-0-	26 - 50%
2%	51 - 75%
-0-	76 - 99%
-0-	100%
7%	don't know

The percentages of physically disabled clients served by responding community resources were:

64%	0 - 5% of clientele
9%	6 - 25%
-0-	26 - 50%
-0-	51 - 75%
2%	76 - 99%
18%	100%
7%	don't know

6. These percentages represent the number of respondents providing each service compared to total number of respondents (including those who provide no sex education/counseling services).

7. The following percentages represent the number of respondents indicating a particular staff member as the provider of sex education/counseling services compared to the number of respondents who provide any of these services:

32%	Physician
19%	Counselor
19%	Social worker

10% Psychologist
7% Nurse
7% Sex educator/teacher
7% Paraprofessional
7% Other
3% Psychiatrist
3% Physiatrist

8. The following percentages represent the number of respondents indicating referral to each particular resource compared to total number of respondents (including those who do not refer):

29% Counseling services
27% Medical clinics/hospitals
22% No one
13% Private physicians/therapists
9% Don't know
7% Universities
7% Other
4% Social services
4% Sex therapists
4% Planned Parenthood
4% Rehabilitation facilities

9. Respondents indicated that the following resources should have the primary responsibility for providing sex education/counseling services to disabled persons.

29% Don't know
20% Hospitals/clinics
20% Rehabilitation facilities
18% Medical professionals
11% Planned Parenthood/other family planning services
9% Health Department
9% Social services/family services
9% Other
7% Consumer groups
4% Department of Vocational Rehabilitation
4% Children's Center
4% Schools

Only 15% of all respondents indicated themselves as having a primary responsibility for providing these services.

10. The following roles in the provision of sex education/counseling services were cited by responding organizations. (Percentages are proportions of respondents giving any answer to this question.)

45% Direct service
45% Referral
17% Provide information/education
14% Nothing
7% Diagnostic
3% Advocacy
3% Public awareness
3% Training

TRAINER SURVEY

In early 1978 the Sex & Disability Project staff distributed surveys to state agencies and RRCEPs in each of the ten vocational rehabilitation regions. In addition, surveys were mailed to the colleges and universities in State I and State II which offer graduate training in rehabilitation counseling. Responses were received from 19 programs.

The survey form mailed to the training programs is reproduced below. Many of the results have been indicated on the form itself (e.g., for questions 2, 4, and 8). Those questions, however, requiring further clarification or more detail (e.g., questions 1, 3, and 5) are indicated by an asterisk (*) on the form. These results and explanations immediately follow the survey form.

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SEX & DISABILITY PROJECT -- Trainer Survey

* 1. Name of state:_____

2. Type of program:

37% State agency staff development
53% RRCEP
11% College or University

* 3. Approximate number of trainees taught within your program per year _____

4. Have you received training in human sexuality?

47% No 53% Yes (specify)_____

* 5. Does your agency/program offer any training in human sexuality and disability?

26% Yes (please attach course/program outline/agenda)
16% We sponsor trainees for such programs elsewhere (specify where)_____
_____
47% No, we neither provide nor sponsor such training. (Go to question 8.)

* 6. How many trainees have participated? _____

* 7. How was training course in human sexuality and disability initiated?

63% Recommendations from counselors
13% Recommendations from consumers
13% Recommendations from advisory committee
25% Recommendations from superiors
88% Recommendations from trainers
38% Other (specify):_____

8. If your agency/program were to initiate or continue training in sexuality and disability which of the following program aspects would you need help with?

59% Training of trainers
82% A-V materials
77% Training materials
47% Program content
41% Program objectives
24% Program format
18% Program evaluation
6% None of the above
12% Other (specify) _____
_____

9. In your opinion, has your agency/program adequately addressed the training of rehabilitation counselors in human sexuality?

11% Yes
89% No, because:
47% No administrative support for such training
6% Lack of trainee interest in area
35% Not our training mission
24% Inadequate preparation of training staff
12% Too controversial

NOTE: Sex education/counseling services are given by a professional or peer in order to help a person with a disability achieve satisfactory sexual and personal relationships. Services may include education, counseling, group discussions, therapy, family planning, and/or obstetrical, gynecological, and urological care.

10. What do you think is the role of state vocational rehabilitation agencies in providing sex education/counseling services to clients? (Check all that apply.)

42% Should be included in IWRP
79% Should refer clients
68% Should purchase services from vendors
58% Should provide services within the agency for clients
11% Should not become involved in this aspect of rehabilitation
___ Other (specify)_____

* 11. Comments:_____

_____

_____

_____

Further Analysis of Trainer Survey

1. Responses were received from trainers throughout the country (at least one response from each of the ten DVR regions).

3. The number of trainees each year within the programs varied considerably (from 20 trainees to 3,000). Number of trainees reported were as follows:

    17% 1-100
    17% 101 - 300
    22% 301 - 500
    11% 501 - 750
    17% 751 - 1,000
    17% over 1,000

5. In addition, 11% of the respondents indicated that they both provide and sponsor services.

6. Percentages given for questions 6 and 7 represent a percent of those programs which either provide or sponsor sex and disability training. The number of trainees participating in sex and disability training varied considerably (from 1 trainee to 400). Number of trainees reported were as follows:

    30% 1 - 25
    30% 26 - 50
    30% 51 - 75
    10% over 75

7. "Other" means by which sex and disability training was initiated were recommendations of the organization from which services were purchased and a student interest survey.

11. Responses to this open-ended question have been incorporated throughout the handbook.

POLICYMAKERS SURVEY

The Sex & Disability Project staff conducted a survey of state, regional, and federal rehabilitation agencies administrators in early 1978. Policymakers in State I and State II were personally interviewed. In addition, surveys were mailed to administrators throughout the country. A total of 18 policymakers participated in the survey.

The questionnaire used is reproduced below. Many of the results have been indicated on the form itself (e.g., for questions 7 and 8). Those questions, however, requiring further clarification or more detail (e.g., questions 1, 2, and 3) are indicated by an asterisk (*) on the form. These results and explanations immediately follow the survey form.

* 1. Position in agency _____

* 2. Agency is: 83% State 6% Regional 6% Federal

* 3. Approximate number of clients served in FY 77-78 _____

NOTE: Sex education/counseling services are given by a professional or peer in order to help a person with a disability achieve satisfactory sexual and interpersonal relationships. Services may include education, counseling, group discussions, therapy, family planning, and/or obstetrical, gynecological, and urological care.

* 4. How are your agency's funds being spent to provide sex education/counseling services to disabled clients?
18% No funds being spent for this purpose
24% In institutions
24% Through field rehabilitation counselors
47% Purchase from vendors
35% Other (specify)_____

* 5. Does your agency have a policy regarding sex education/counseling services to clients?
53% No
47% Yes:
13% Written policy
87% Informal policy
-0- Other (specify)_____

* 6. INSTRUCTIONS: Mark a "P" beside those services which you think counselors should provide to clients. Mark an "R" beside those services to which they should refer clients.

____ Social skills training
____ Access to reading materials on sexuality
____ Access to audio-visual materials
____ General sex education course
____ Sex and disability course
____ Group discussions on sexuality
____ Individual counseling on sexuality
____ Group counseling on sexuality
____ Sex therapy
____ Contraception/genetic counseling
____ Obstetric/gynecological/urological care
____ Couples/family counseling on sexuality

7. What do you think is the role of state vocational rehabilitation agencies in providing sex education/counseling services to clients? (Check all that apply.)

72% Should be included in IWRP
83% Should refer clients
72% Should purchase from vendors
44% Should provide services within the agency for clients
-0- Should not become involved in this aspect of rehabilitation
6% Other (please specify)_____

8. Who do you think should provide sex education/counseling services to disabled people? (Check all that apply.)

50% Member of the clergy
83% Psychologist
28% Teacher
28% Other disabled person
56% Social worker
17% Other (specify)_____

22% Telephone hotline
67% Physician
17% Rehabilitation counselor
39% Planned Parenthood staff member
56% Sex counselor/therapist
17% Other medical personnel (specify)

* 9. From the above list, which 3 do you think are the most suitable providers of sex education/counseling services to disabled people? (Please rank.)

First_____
Second_____
Third_____

10. In your opinion, what are the most effective ways to provide sexuality and disability training to rehabilitation counselors?

44% Human sexuality course work toward a degree in rehabilitation counseling
44% Agency staff development workshops
44% RRCEP Workshops
28% Agency consultant on human sexuality
44% University course paid for by the agency
17% More workshops at professional conventions (e.g., NRA)
33% Access to reading and A-V material within the agency
-0- Other (specify) _____

* 11. How else do you think sex education/counseling services to disabled clients could be improved?

Further Analysis of Policymaker Survey

1. All respondents to this survey were upper level administrators.

2. In addition, one respondent indicated the agency was both regional and federal.

3. The number of clients served during FY 1977-78 by the responding agencies were as follows:

7%	10,000 or fewer
7%	10,001 - 20,000
40%	20,001 - 30,000
13%	30,001 - 40,000
-0-	40,001 - 50,000
20%	50,001 - 60,000
13%	Over 60,000

4. 28% of the respondents indicated that agency funds were being spent on the training of staff in sex education/counseling. (These responses are included in "Other.")

5. There was a large discrepancy between responses by mail and those in interviews. 86% of those responding by mail indicated that their agencies had no policy regarding sex education/counseling; only 30% of interviewees indicated that their agencies had no policy. This may be due to the methodology used in the interview situation. The interviewer asked for clarification if the policymaker's initial response was that the agency had no policy.

6. Policymaker respondents indicated that rehabilitation counselors should provide the following services:

50%	Social skills training
61%	Access to reading materials on sexuality
33%	Access to audio-visual materials on sexuality
-0-	General sex education
6%	Sex and disability course
28%	Group discussion on sexuality
39%	Individual counseling on sexuality
22%	Group counseling on sexuality
-0-	Sex therapy
17%	Contraception/genetic counseling
11%	Obstetric/gynecological/urological care
28%	Couples/family counseling on sexuality

Respondents indicated that rehabilitation counselors should refer clients for the following services:

50%	Social skills training
33%	Access to reading materials on sexuality
61%	Access to audio-visual materials on sexuality
89%	General sex education
78%	Sex and disability course
61%	Group discussion on sexuality
61%	Individual counseling on sexuality
67%	Group counseling on sexuality
89%	Sex therapy
89%	Contraception/genetic counseling
83%	Obstetric/gynecological/urological care
72%	Couples/family counseling on sexuality

Please note that these responses are not directly comparable to those of the rehabilitation counselors surveyed. In the policymakers' survey, respondents were asked to indicate whether they think counselors *should* provide or refer clients for these services; counselors were asked to indicate which services they *actually* provide and for which they *actually* refer. This may account to a great extent for the higher percentages among policymakers.

9. The following percentages represent the percent of highest possible point count (total points, had the provider been indicated as the best possible provider by all respondents).

    50% Sex counselor/therapist
    35% Social worker
    30% Psychologist
    24% Physician
     9% Clergy
     9% Other medical personnel
     7% Planned Parenthood
     7% Rehabilitation counselor
     6% Other disabled person
    -0- Teacher
    -0- Telephone hotline

11. Responses to this open-ended question have been incorporated throughout the handbook.

APPENDIX B
Literature Summaries

Hearing Impairment: A Review of the Literature

SEXUAL PROBLEMS ASSOCIATED WITH HEARING IMPAIRMENT

According to Della and Max Fitz-Gerald, noted experts in the field of sex education for hearing-impaired persons, "Of all the problems that deaf people face in our society, those of a sexual and emotional nature are the ones least discussed." They state that deaf persons are often forgotten, or given low priority, within the milieu of disability groups. A pervasive attitude exists that deaf persons are not sexual beings and that the small amount of sex education which is necessary should be done in the home (Fitz-Gerald & Fitz-Gerald, 1977a). Unfortunately, only 2% of the parents of deaf children know manual communication. Therefore, most parents cannot communicate clearly with their deaf children regarding sexuality or social norms.

Lack of communication and information is the crucial sexual barrier to the hearing-impaired population. No physiological sexual functioning problems accompany deafness. But the inaccessibility of information on sexuality affects both sexual knowledge and sexual attitudes of hearing-impaired people.

Research indicates that deaf adolescents and adults have more traditional attitudes regarding sex roles than the average person in the U.S. (Cook & Rossett, 1975). A research study done in 1972 indicates that deaf teenagers often have active sexual experiences with very little knowledge about sexuality. The study also states that deaf teenagers are much more accepting of sexual myths than are hearing teenagers (Grossman, 1972). The obvious extension of these findings is that deaf teenagers are likely to experience a vast array of sexual identity problems and concerns resulting from their lack of information.

The literature is unanimous in its opinion that the most crucial barrier to deaf persons regarding sexuality is their inability to obtain information due to communication difficulties. The fact that many deaf individuals attend residential schools adds a dimension to the problem of obtaining information. Residential settings tend to isolate the deaf individual from hearing peers and sexual information, and they allow the deaf teenager no privacy in which to develop relationships (Fitz-Gerald & Fitz-Gerald, 1978a).

Social skills development is an area of sexuality which is apparently ignored in many cases. Marriage problems often result from the inability to communicate regarding sexuality and the marital relationship (Ellicott, 1974). Residential schools hinder social development due to: separation from home and from the hearing population, and strict behavior rules regarding socializing and dating. Twice as many deaf teens as hearing teens have never even had a date (Evans, 1975).

Information regarding contraception is often inaccessible to hearing-impaired persons with communication difficulties. Instructions on many birth control methods are written in a complex fashion, making them confusing to deaf persons unfamiliar with medical anatomical terms. Physicians usually have no interpreters available during physical examinations to explain side effects and proper use of contraceptives, or the purpose and procedures of a routine gynecological examination.

Lack of information, miscommunication, lack of privacy, and isolation from hearing peers sometimes contribute to a poor sexual self-concept in deaf individuals. Lack of communication at home intensifies this problem.

PROGRAMS AND INTERVENTION STRATEGIES

Most of the available literature on sexuality and deafness involves sex education. In a study conducted in 1976 with 112 residential facilities, 66% indicated that they had a formal sex education program. This figure is deceiving in that most programs ended at the primary grade level, and the amount of time devoted to instruction ranged from one to hundreds of hours per year (Fitz-Gerald & Fitz-Gerald, 1976). The programs offered are often crisis-oriented and run by unqualified, untrained staff members. Schools indicated a reluctance to teach sex education for fear of a parental backlash.

Research shows that communication is the biggest barrier in sex education (Fitz-Gerald & Fitz-Gerald, 1977b). Both at home and at school, deaf people find it difficult to communicate and understand information which must be obtained from non-sign language speaking family members and teachers. Grossman's study (1972) indicated that the home environment was a decisive factor in the shaping of sexual attitudes. If parents of deaf children cannot speak sign language, very little sexual information can be shared. Also, overprotectiveness on the part of some

parents of deaf children prevents appropriate association with peers and serves as an excuse for ignoring a child's sexuality. Many parents try to deny their child's sexuality rather than assuming their responsibility as sex educators.

Existing programs and intervention strategies are obviously inadequate and unable to meet the informational needs of hearing-impaired persons. Captioned audio-visual materials are not being developed to meet the programmatic need, and staffs are not being properly trained to meet the sex education/counseling needs of deaf individuals.

GAPS IN PRESENT KNOWLEDGE

The most striking characteristic about sexuality and deafness is the lack of professional literature available on the subject. In the area of counseling, very little information is available to help professionals train themselves in sexuality education of deaf persons. Ellicott states that there is no information available on marriage counseling for deaf clients (Ellicott, 1974). The literature states that health professionals are usually uninformed and unaware of the sexual implications of deafness, and therefore are often not suitable as counselors (Fitz-Gerald & Fitz-Gerald, 1978a). Often, the responsibility for sexual guidance falls to teachers. A 1978 study shows that in 70% of the instances where sex education was provided to deaf students in residential schools, teachers were asked to assume this instructional responsibility. Most teachers felt they were inadequately prepared to assume this duty and expressed a need for training and the development of audio-visual materials and curricula (Fitz-Gerald & Fitz-Gerald, 1978b).

RECOMMENDATIONS

Recommendations for improving the sexual knowledge of deaf individuals were made in the literature. In summary, they were:

1) Deaf adolescents need more contact with hearing peers.

2) Parents must learn manual communication to enable them to discuss sexuality clearly with their deaf children.

3) Residential schools must allow more interaction among deaf students.

4) Teachers, rehabilitation counselors, and health professionals must have specialized training in sexuality and disability, including specialized needs of deaf individuals.

5) Professional awareness and sensitivity needs to be increased regarding the sexual implications of deafness.

6) Highly visual and captioned audio-visual materials need to be developed and used in sex education programs for deaf individuals. Concrete concepts and non-technical language must be used in sex education curricula for deaf people.

7) Organized sex education programs should be established in all residential schools for deaf students, from the primary level through college; special needs of deaf students should be considered in public school sex education programs where deaf students are mainstreamed.

8) More research needs to be done to assess the sex education/counseling needs of deaf individuals.

References

Cook, L., & Rossett, A. The sex role attitudes of deaf adolescent women and their implications for vocational choice. *American Annals of the Deaf,* June 1975, *120,* 341-345.

The sex role attitudes of deaf and hearing-impaired adolescent women were investigated and compared. Using

a Likert scale in an attitude survey, the deaf women surveyed were found to be significantly more traditional in their perception of sex role attitudes than their hearing peers. The implication of sex roles as they influence vocational choices is discussed. Suggestions for learning opportunities designed to effect a less traditional sex role attitude in deaf women are made. (Abstract)

Davila, R.R. Sex education from the deaf perspective. *SIECUS Report,* 1977, *6*(2).

The author emphasizes a shared responsibility for sex education among home, school, and community. Discussion of sex in the media and miscommunication to hearing-impaired people (e.g., "sexy" commercials). The author asserts that efforts need to be made to produce largely self-explanatory media which includes disabled people.

Ellicott, H. Marriage counseling with deaf clients. *Journal of Rehabilitation of the Deaf,* 1974, *8*(2), 29-36.

Article discusses the communication barrier in marriage counseling of deaf clients. Author states that there is a void of information in the literature on marriage counseling for deaf clients, and states that it is vital that the counselor see deaf individuals in all developmental stages in order to better understand the marital relationship. Similarities and differences regarding marriage are discussed as they relate to deaf vs. hearing populations. Deaf-hearing marriages are discussed.

Evans, D.A. Experimental deprivation: Unresolved factor in the impoverished socialization of deaf school children in residence. *American Annals of the Deaf,* Dec. 1975, *120*, 545-552.

A survey of socialization problems of 123 deaf teens (with a control group of 321 hearing teens) was undertaken at a state residential school for the deaf. Analysis of data showed that social development was hindered by a restricted type of communication at home, separation from hearing peers and from the opposite sex, strict dating rules, and lack of freedom to leave campus. Twice as many deaf as hearing teens have never had a date. Suggestions are that school officials and parents must permit increased contact with the outside world, parents must learn manual communication, and deaf teens must be allowed more freedom to interact with hearing peers.

Fitz-Gerald, D., & Fitz-Gerald, M. Sex education survey of residential facilities for the deaf. *American Annals of the Deaf,* Oct. 1976, 480-483.

A sex education survey within residential facilities for the deaf was conducted in 1974. 112 facilities were surveyed, with 88% responding. 66% reported having a formal program, with little sex education done at the primary level. It was offered as a separate course in 60% of the facilities. The amount of time devoted to instruction varied from one hour to 720 hours per year. Many programs seemed to be crisis-oriented. Many respondents requested more information, referred to lack of qualified staff, or indicated a fear or misunderstanding about sex education in their schools.

Fitz-Gerald, D., & Fitz-Gerald, M. Behind the times. *SIECUS Report,* 1977, *6*(2), 3-5, a.

The authors state that "of all the problems that deaf people face in our society, those of a sexual and emotional nature are the ones least discussed." Why? 1) deaf people are victims of prioritizing, 2) attitude that sex education should be done in the home (many parents can't communicate clearly with their deaf children), 3) attitude that disabled people are not sexual beings. The authors state that the overall goals for sex education don't differ with deaf individuals. Discussion of the role of parents, house parents, school administrators, and classroom teachers. Deaf persons require highly visual materials.

Fitz-Gerald, D., & Fitz-Gerald, M. Deaf people are sexual too! *SIECUS Report,* 1977, *6*(2), 1, 13-15, b.

This article discusses types of deafness and modes of communication for the deaf as well as psychosocial aspects of deafness (such as isolation). The authors assert that communication and language handicaps impose barriers to receiving sex education among deaf people and to receiving medical and counseling services.

Fitz-Gerald, D., & Fitz-Gerald, M. Sexual implications of deafness. *Sexuality and Disability,* 1978, *1*(1), 57-69, a.

The article discusses the fact that health professionals are usually uninformed and unaware of the severe educational, vocational, and social implications of deafness and sexuality. The authors stress lack of communication as a deterrent in the gathering of sexuality information by deaf persons and discuss the problems of residential settings (re: privacy), understanding of abstract concepts, and isolation. Implications for residential schools and agencies include increased professional awareness regarding sexuality and deafness. Suggestions for sex education programs include use of highly visual materials and concrete concepts. The sex educator for deaf persons, the role of the sex counselor, and sex counseling are discussed.

Fitz-Gerald, D., Fitz-Gerald, M., & Williams, C.M. The sex educator: Who's teaching the teacher sex education? *American Annals of the Deaf,* 1978, in press, b.

In 70% of the instances in which sex education is provided to deaf students in residential schools, teachers are asked to assume this instructional responsibility. This article addresses the fact that teachers are usually inadequately prepared to assume sex education responsibilities and discusses teacher preparation. The authors conducted a survey of 71 teacher training programs for deaf persons in 1977. Results indicated that only 2 schools provided a sex education course, although 83% expressed a need for more teacher preparation. Many respondents saw a need for producing A-V materials and curricula. The article includes a list of resources for parents and teachers and children, a suggested curriculum, and a list of interested professionals.

Grossman, S.K. Sex knowledge, attitudes, and experiences of deaf college students. Unpublished Master's Thesis, George Washington University, Washington, D.C. 1972.

Conclusions of this study of 108 Gallaudet students are: students at Gallaudet have a definite lack of sex information (using SKAT), are more accepting of sexual myths than hearing students, have had active sexual experience without adequate sexual knowledge, that home environment plays a decisive factor in sex education, that more sex education needed to be included in school curricula. Recommendations are: organized sex education program at the school should be established, counselors should provide sexual guidance, rehabilitation counselors need to become more aware of sexuality issues, further research in sexuality and deafness is needed.

Hill, A. Some guidelines for sex education of the deaf child. *Volta Review,* 1971, *73*(2), 120-125.

The author discusses stages of sexual development, parent/child roles, communication about sex, and emotional values.

Miller, A.S. "If I Have A Daughter..." The sex education program for teen-agers at Clarke School. *Volta Review,* Nov. 1973, *75,* 493-503.

Article describes a 16 year old program at Clarke School for the Deaf of sex education, social skills, and personal hygiene. The program covers such basic areas as how to manage sexual urges between adolescence and marriage, sex roles, reproduction, veneral disease, and drug addiction. Boys' and girls' classes are segregated. There is a bibliography of references on sex education which includes publications for adults, young children, and teenagers; films; magazine articles; and pamphlets.

Visual Impairment
A Review of the Literature

SEXUAL PROBLEMS ASSOCIATED WITH VISUAL IMPAIRMENT

Too often the assumption is made that visually-impaired people have no special sex education/counseling needs, since the disability itself does not inhibit genital functioning. Only recently has there been stated recognition and discussion of the specific difficulties encountered by visually-impaired persons.

The visually-impaired individual is frequently stigmatized as an asexual being, as a perpetual child, or as a person handicapped in all areas of his or her life. In addition, the visually-impaired individual frequently suffers from communication problems which affect both the social integration and the gaining of experience and knowledge necessary to a satisfactory social/sexual adjustment.

Congenitally blind persons are particularly likely to lack adequate sex knowledge. Being deprived of the ability to see the many shapes of the human body in various stages of dress and undress, and being inhibited culturally from gaining this information by touch, the congenitally blind person frequently suffers from a serious lack of sexual information.

Cataruzolo and Enis (1971, 1972) emphasize the importance of seeing the human body in such settings as the home, on the beach, and in shower rooms as well as in magazines, in the movies, and on television. Pornographic literature is also cited as a source of visual sex information.

Morse (1970) emphasizes the social inhibition against gaining such information by touch. He describes a teacher who became extremely embarrassed when a blind student tactually explored a statue's body during a museum visit. The teacher's willingness to let the sighted children visually examine the work of art and her unwillingness to let the blind child gain the same information by touch accentuates this inhibition.

Torbett (1974) states that exploration of the body by touch, which might be most appropriate in the home, often conjures up concerns about incest or simple parental embarrassment. In many residential settings, the early exploratory sex play of children is also stringently repressed, and the privacy which may be available to a sighted child is frequently denied. Often, institutions practice careful segregation of the sexes. In addition, situations have been cited in which blind children discover to their horror that their exploratory sex play (e.g., playing doctor) is being conducted in front of an open window or under a bright light (Barnett, 1974; van 'T Hooft & Heslinga, 1975).

A related difficulty emphasized by Scholl (1974) and Knappett and Wagner (1976) is the inability of a visually-impaired child to compare his or her physical appearance to that of others. Denied the visual sight and tactile exploration of others and of self, the visually-impaired child or adolescent is often unable to develop the positive self-concept so important to successful social interaction. This situation may produce long-lasting negative consequences (Vogel & Muxen, 1976).

Cataruzolo and Enis (1971, 1972) emphasize that such deficits in learning frequently result in misconceptions about the size and location of body parts. Foulke and Uhde (1974, 1976) interviewed a group of blind adolescents and discovered that traditional sex education had improved their knowledge of sexual functioning and terminology, but had not given them a comprehensive knowledge of sexuality. One child, for example, gave an acceptable definition of the term "intercourse," but, under further questioning, indicated that "the vagina is located under a woman's right breast." (Foulke & Uhde, 1974, 1976). Cataruzolo and Enis (1971, 1972) cite instances in which blind women are fearful of intercourse because of misconceptions about the size of a man's penis.

Visual cues are also a significant factor in social interaction, and, lacking these, a visually-impaired person may be awkward in social and sexual situations. Sighted individuals learn the use of appropriate eye contact, facial expressions, and body cues visually. People with visual impairment, however, must be taught these same skills verbally. These are important skills for successful social interaction (Scholl, 1974). Elonen and Zwarenstein (1975) describe the serious dangers inherent in this deficit. They report the disproportionately high incidence of sexual abuse of visually-impaired children and attribute this in part to the child's being unaware of dangerous visual cues. In addition, it is possible that the child may be unintentionally giving what are interpreted as provocative visual cues.

Visually-impaired people are subject to many of the same attitudinal barriers encountered by persons in other disability groups. They may be perceived as asexual, perpetually child-like and in need of protection, unattractive.

discomforting, bitter, or handicapped in all regards. In addition, a congenitally disabled child's sexuality may be denied because of the parents' feelings of sexual guilt.

In addition to these attitudinal barriers toward disabled people in general, visually-impaired persons may face other difficulties related to their specific disability. Scholl (1974) and Knappett and Wagner (1976) emphasize the particular sexual connotations of blindness: blindness as a result of sexual evil (e.g., Oedipus), masturbation, or venereal disease; and Freud's equation of blindness and castration. These myths may be internalized by family members, service providers, the general public, and blind individuals themselves. Additionally, the myth that blindness begets blindness may dissuade people from forming potentially close relationships with visually-impaired individuals (Knappett & Wagner, 1976).

As a result, even though a visually-impaired person may have no physical difficulties in expressing sexuality, the lack of sex knowledge and experience, and the attitudes of others toward the visually-handicapped person may cause a poor adjustment to self and sexuality.

PROGRAMS AND INTERVENTION STRATEGIES

Attention to the special sexual needs of visually-impaired persons has generally focused on the development of sex education programs and audio-tactile resources to supplement these programs. Two surveys were conducted in the early 1970's to determine the availability of sex education for visually-impaired children and adolescents. SIECUS and the American Foundation for the Blind jointly surveyed public schools, residential schools for the blind, and agencies dealing with visually-impaired persons to determine the availability of sex education programs and the facilities' willingness to offer such programs. Sixty-one percent of the organizations surveyed indicated that sex education was already available; another 17% indicated that a program was being developed. Only 12% of all respondents indicated that they did not consider sex education to be their responsibility. (This 12% represents approximately 2% of the public schools surveyed, 13% of the residential schools, and 21% of the consumer organizations.) Program content generally emphasized body image, hygiene, and reproduction. The scarcity of training resources was frequently mentioned (Bidgood, 1971; Burleson, 1971).

Cataruzolo and Enis (1971, 1972) surveyed all residential schools for visually-impaired people in the U.S. and found that 64% had sex education programs. The age group to which training was offered varied considerably. The program content also varied, although social skills and biological/hygienic information were included in most programs. These results are consistent with the SIECUS survey findings.

A more recent survey was conducted in 1975 of educational agencies serving the deaf-blind population (Davis, 1975). Only 8% of all respondents indicated the availability of sex education for this particular disability group. Furthermore, 68% of all respondents indicated that implementation of such a program in the near future was not intended; 17% of these respondents added that no program was being considered at any time. Of those providing sex education, all included biological aspects, and most included psychosocial factors.

More recent statistical information on the availability of sex education for the visually-impaired population is unavailable. However, the literature now seems to be focusing on existing program formats and model formats for such training. (Other than the survey by Davis *[cited above]* and a brief paper by Jan Neff (n.d.) defending the rights of all disabled persons, including deaf-blind individuals, to have access to sex education, this particular disability population has been largely ignored in the literature.)

Residential schools have been the most active in developing (or at least reporting on the development of) comprehensive sex education programs to meet the needs of visually-impaired people. Bartimeus (Institute for the Blind in Zeist, The Netherlands), Illinois Braille and Sight Saving School (Jacksonville, Illinois), Governor Morehead School (Raleigh, North Carolina), California School for the Blind (Berkeley, California), and Perkins School for the Blind (Watertown, Massachusetts) are examples of programs addressing these needs.

The Bartimeus program (van'T Hooft & Heslinga, 1975) emphasizes sexual awareness within a residential setting and deals with both social and biological aspects of human sexuality. A sincere effort is made at this school to establish a life style for the children as similar as possible to a family situation. Married supervisors live together in an apartment within the facility, thus allowing them to be "mother" and "father" without restricting their privacy. Co-education is stressed in daily life skills as well as in formal education. Older girls are allowed to help in the bathing of little boys, and social interaction with opposite sex peers is encouraged.

At Bartimeus, biological information is relayed both verbally and tactually. Torso models used in medical training are utilized and are available during non-school hours to the children. Van 'T Hooft and Heslinga (1975) strongly recommend the use of live nude models, although they admit that there frequently are social and legal restrictions on this practice. Other sexuality-related articles are also presented for tactual "seeing" by the students—sanitary napkins, condoms, and birth control pills.

Group discussions are encouraged at Bartimeus, as are private conversations with teachers and physicians. An attempt is made to deal openly and completely with both social and biological issues raised by the children.

A more formally-structured program was instituted by Illinois Braille and Sight Saving School in 1965 (Holmes, 1974, 1976). Elementary through senior high school students are given formal co-educational sexuality training which utilizes films, tactile life-sized models, and books transcribed into Braille by the school. Parents and staff are completely briefed on format and content prior to initiation of the program. Student evaluations at the end of each year are used to make any necessary changes or additions to the program. The major emphasis of the training is on interpersonal relationships, self-awareness, and body processes, including reproduction and heredity. Group discussion of these topics is encouraged. Sex education at the Illinois school is considered to be the communal responsibility of all staff members (teachers, social service providers, supervisors, doctors, and psychologists) and is specifically intended to extend beyond the classroom experience.

The Governor Morehead School offers a six-week course each year, entitled "Marriage and Family Life," to all high school students (Moore, 1969). Both social and biological aspects of sexuality are presented, and students are encouraged to participate in group discussions following each presentation. In addition, students are invited to raise questions or present discussion topics. These suggestions may be verbal or submitted anonymously in writing. Talking tapes and life-sized anatomical models are frequently used as teaching resources.

At the end of the program's first year, a formal research study was conducted to determine whether the students' sex knowledge had increased. A significant gain was found, and this finding encouraged the continuation of the program in succeeding years (Moore, 1969).

The well-developed and organized curriculum for sex education at the California School for the Blind has been published as a suggested format for similarly comprehensive programs in other residential schools (Neff, 1975). The program of study is designed according to developmental level and is intended for students ranging from 5-21 years of age. Although emphasis is on the needs of visually-impaired students, the needs of multiply-handicapped individuals were taken into consideration when preparing the curriculum.

Each level of instruction in the curriculum contains three components: self-understanding and emotional development, social and cultural development, and biological development. Topics include self-awareness and self-concept, various family life styles, human and animal reproduction, social skills, sexual expression, birth control, and genetics.

The most recently published residential program format for visually-impaired youths is the updated curriculum for the Sex Education and Family Life program at Perkins School for the Blind (Perkins, 1977). This curriculum also takes into account *both* chronological age and developmental age, thus allowing an even greater flexibility in the selection of topics and modes of presentation to meet the individual needs of students. The program is designed for visually-impaired children and adolescents (including those with learning disabilities) from pre-school age through high school. Major themes presented to all age groups and ability levels include self/other awareness, masculinity/femininity, physical and emotional development, sexual terminology, modes of sexual expression, varying life styles, interpersonal relationships, and health.

An extensive literature search has uncovered only two documented sex education programs for visually-impaired persons in non-residential facilities. One of these programs is located at the Rehabilitation Center for the Blind in Sioux Falls, South Dakota (Vogel & Muxen, 1976) and is specifically geared toward the sex education needs of visually-impaired adults. The three to four week classes concern both the social and biological aspects of sexuality. The instruction is supplemented by such tactile objects as models of the human body, articles of clothing, and contraceptive devices.

Major topics covered in the program are anatomy, intercourse, pregnancy and childbirth, contraception, varying life styles, and health. Sessions include group discussion. Participants are encouraged to determine for themselves the appropriateness of varying life styles and modes of sexual expression.

A second documented program of sex education in a non-residential setting is a summer workshop for visually-impaired youths at the Grand Rapids Association for the Blind (Karpen & Lipke, 1974). The goals of the program are to help the child or adolescent understand physical and emotional changes during puberty and develop the skills to communicate with others as a sexual adult. Emphasis is on enabling the youth to determine for himself or herself the appropriateness of different types of sexual expression. Topics covered include social interaction and communication, sexuality-related terminology, body changes during puberty, varying life styles, modes of sexual expression, intercourse and reproduction, and hygienic and grooming needs. Braille and talking books are used extensively.

As a result of this workshop experience, one of the developers of the program and an associate created a self-teaching resource for visually-impaired children and adolescents (Allen & Lipke, 1974). This resource is the first of two excellent self-education programs intended to give visually-impaired children much of the same sex knowledge gained visually by sighted peers. The resource packet developed by Allen and Lipke, entitled "Your

Changing Body: A Guided Self-Exploration" (1974), includes two tapes and a written guide for parents and teachers. Although parents and teachers are carefully informed of the contents of the teaching tapes, the tapes are designed to be utilized by the child individually, in privacy. The visually-impaired person is encouraged to explore his or her own body while the tape describes the various body parts for both sexes, the changes that occur during sexual maturation, and the similarities and differences between the male and female body.

A second resource designed for individual use by visually-impaired youths is one created by Tait and Kessler (1976) to explain sexual intercourse in a private, non-threatening setting. Several male and female dolls are utilized, including a child, females at varying stages of pregnancy, a male with an erection, and a couple during intercourse. Tapes are presented simultaneously which direct the visually-impaired person's exploration of these dolls.

Other than the sex education programs described above, little in the literature reports social or sexual counseling programs developed for visually-impaired people. The one notable exception is a model program of genetic counseling for persons considering parenthood (Zimmerman, 1977). Zimmerman relates the great strides made recently in research on congenital blindness and encourages the utilization of these findings in a comprehensive genetic counseling program for prospective parents, including visually-impaired individuals.

GAPS IN PRESENT KNOWLEDGE

As seen above, programs do exist which meet some of the sexual developmental needs of certain sectors of the visually-impaired community. For the most part, however, these programs are sex education programs in residential settings and are geared toward children and adolescents at these facilities. The only sex education program for visually-impaired adults reported in the literature is the one at the Sioux Falls rehabilitation facility. Vogel and Muxen (1976) note the great needs of these adults, who, for the most part, had no opportunity to take advantage of the type of training now available to some visually-impaired youths.

In addition, as can be seen from the reported programs, very little exists in sex education/counseling services for visually-impaired people outside of residential settings, in spite of the fact that a large proportion do not live in such facilities. With the exception of the Sioux Falls and Grand Rapids programs, little attempt seems to be made to impart even the most basic sex information to non-residential visually-impaired persons. This oversight is generally based on the assumption that sex education will be given in the home, yet findings indicate that parents are frequently unwilling to discuss sexual concerns with their visually-impaired children. This, in addition to the frequent social isolation of the disabled person from peers and the sex knowledge gained from them, often leads to naivete and a feeling of insecurity in social and sexual situations.

Another major sex education deficit for many visually-impaired persons results from a lack of accessible programs within the community. General sex education, where it exists, is not denied to the visually-impaired person, yet social mores may inhibit the modes by which this information is gained. As an example, a blind child mainstreamed into a school system will certainly not be barred from a sex education course available to his or her sighted peers. However, a teacher may be reluctant to allow a tactile examination of a nude mannequin by this child, even though the same teacher may have no qualms about allowing a visual examination by a sighted child. The teacher's reaction to the blind child touching a nude work of art in a museum, cited above (Morse, 1970), illustrates this discrepancy quite clearly.

As a result, visually-impaired persons who participate in programs primarily intended for sighted persons may show a significant increase in the ability to repeat definitions of sex-related terms, yet gain no true understanding of sexuality. This is portrayed excellently in Foulke and Uhde's (1974, 1976) previously cited example of the well-versed adolescent who believed a woman's vagina is located under her breast.

It is absolutely necessary that more self-help resources be created by which visually-impaired persons can gain a knowledge of sexuality. Sexuality is still a topic which may arouse anxiety within our society, and an individual's lack of sex knowledge may cause him or her embarrassment. Therefore, it is mandatory that visually-impaired persons be allowed access to materials equitable to those available for private, non-threatening, self-instruction for sighted persons.

Sex education, however, is not enough. Counseling services must also be initiated for visually-impaired people. Community service organizations which deal with the sexuality-related questions and concerns of the general population should also be equipped to deal knowledgeably and in an attitudinally positive way with the concerns of this specific disability population.

Facilities concerned with the other counseling needs of visually-impaired individuals should also be equipped to deal with and be agreeable to discussing the sexual concerns of these persons. Even those residential facilities which have developed or are developing sex education programs must be constantly aware of the comprehensiveness of sexuality—the subject must not be treated as a "classroom only" topic.

Zimmerman's suggestions for genetic counseling (1977) only scratch the surface. Genetic counseling is, indeed, a valuable service for visually-impaired as well as sighted people. However, genetic counseling is an advanced step in social/sexual counseling; it implies prospective parenthood. There are many stages prior to this state of mind which may necessitate counseling: self-esteem, interpersonal relationships, dating behavior, and courtship, to name just a few.

In order to establish appropriate sex education/counseling services, more research must be done on the specific needs of the visually-impaired population. It is anticipated that needs will vary according to age group, situation within the community (e.g., resident in a facility, rehabilitation client, community member with little or no particular facility ties, etc.). Concurrently, information should be solicited on possible sources for these services—appropriate providers and settings. In addition, the willingness of these providers and organizations to deal with the sex education/counseling needs of the visually-impaired population must be ascertained.

Lastly, there must be a comprehensive collection of resources (programs and materials) accessible to visually-impaired people and service providers dealing with this population so that referrals may be made on an individualized basis to meet the specific needs of the person involved.

RECOMMENDATIONS

1) Visually-impaired people must be more fully integrated into the sighted community.

2) Persons within the community dealing with the sexual concerns of sighted people should equip themselves to deal with these same concerns, and the specialized concerns, of visually-impaired persons seeking their assistance.

3) Organizations for both the visually-impaired population and the general population should research their own capabilities and determine for themselves whether it is most feasible to train all persons in educational/counseling positions to deal with the concerns of this specific disability group or to assign these duties to a specialist.

4) Persons dealing with visually-impaired individuals must re-examine their own attitudes toward tactual acquisition of sex-related information.

5) More audio-tactile resources must be developed for use in sex education of visually-impaired people, and these resources should be made available to persons wishing to examine them further during "out of school" hours.

6) More audio-tactile resources, which may be utilized in privacy, should be developed for self-taught sex education.

7) All persons dealing with the visually-impaired population in a professional position (medical personnel, counselors, etc.) should have at least a basic understanding of sex and disability and should be aware of resources available for visually-impaired people.

8) Resource listings of sex education/counseling programs, literature, and materials should be expanded, updated, and made known.

9) Residential facilities for visually-impaired persons must allow more interaction between the sexes.

10) Residential schools should assure themselves that the sex education/counseling needs of the students are dealt with, both in the classroom and in daily life.

11) There should be a system within all sex education programs by which questions or topics of concern may be raised anonymously (e.g., written suggestions).

12) More programs of sex education and counseling for visually-impaired people should be developed, particularly in non-residential settings.

13) More research must be done on sex education/counseling needs and program possibilities for the deaf-blind population.

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Bidgood, E. A study of sex education programs for visually handicapped persons. *New Outlook for the Blind*, 1974, *65*(10), 318-323.

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Burleson, D. A survey of sex education programs for the blind. Report by SIECUS (Sex Information and Education Council of the U.S.), May 6, 1971.

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Davis, C.J. Sex education of the deaf-blind. A survey report. Undated. (Perkins School for the Blind, Watertown, MA)

The results of a survey of educational agencies serving deaf-blind children on the availability of sex education programs or intention of creating such a program and program content. Included is a discussion of the need for sex education for this disability population and the specific problems which must be addressed.

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A brief discussion of five major factors which may inhibit normal sexual development in visually-impaired people. These needs should be considered in comprehensive sex education and counseling for this population.

Foulke, E. Sex education for the blind. In Report of the Perceptual Alternatives Laboratory for the period July 1, 1972 - June 30, 1973. *American Foundation for the Blind Research Bulletin*, April 1974, *27*, 296-297.

And,

_____. The blind child's knowledge of the anatomy and functions of sex. In Report of the Perceptual Alternatives Laboratory for the period July 1973 - June 1974. *American Foundation for the Blind Research Bulletin*, June 1975, *29*, 181-182.

Both of these report subsections describe the need of visually-impaired children for specialized training in sexuality. A project was initiated in which blind adolescents were interviewed to ascertain their sex education needs, and parents or other persons in close contact with visually-impaired people were surveyed to determine their attitudes toward sex education/counseling for blind children. These reports present little in the way of results of the research (see Foulke & Uhde, 1974, 1976, for results), but rather the rationale behind the creation of the study.

Holmes, R.U. The planning and implementation of a sex education program for visually handicapped children in a residential setting. *New Outlook for the Blind*, 1974, *68*(5), 219-225.

Description of the rationale behind and the implementation of a sex education program for visually-impaired adolescents at the Illinois Braille and Sight Saving School. The experience gained from this program (which had been in existence for seven years at the time the article was written) is utilized to recommend methods by which a similarly comprehensive program may be established. Teacher selection and training, resources, and program format are extensively discussed.

_____. A sex education program for the visually-impaired in a residential school. *SIECUS Report*, Special Issue on the Handicapped, 1976, 4.

A very brief summary of the Illinois Braille and Sight Saving School program described above (Holmes, 1974).

Karpen, M.L., & Lipke, L.A. Sex education as part of an agency's four-week summer workshop for visually impaired young people. *New Outlook for the Blind*, 1974, *68*(6), 260-267.

After a brief discussion of the role of community service organizations in the sex education of disabled children, the authors describe the groundwork and implementation of a summer workshop on sexuality for visually-impaired adolescents, including planning, program content, and resources.

Knappett, K., & Wagner, N.N. Sex education and the blind. *Education of the Visually Handicapped*, 1976, *8*(1), 1-5.

This article is an excellent summary of special difficulties in sexual development encountered by visually-impaired persons. Lack of visually-gained information during childhood, overprotectiveness, and attitudes toward the disability itself and the sexuality of visually-impaired people are discussed. Recent increased attention toward sex education for visually-handicapped persons is seen as a result of a general tendency toward sexual liberalism in society as a whole.

Moore, D.D. Sex education for blind high school students. *Education of the Visually Handicapped*, 1969, *1*(1), 22-25.

Discussions of a sex education course offered to visually-impaired high school students at the Governor Morehead School. Emphasis is on the resultant increase in sex knowledge rather than on the program format.

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This brief paper defends the rights of all disabled persons, including deaf-blind people, to gain both social and biological knowledge of sexuality.

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A detailed curriculum for the Sex Education and Family Life course offered by the Perkins School for the Blind. Program content is organized according to both chronological age and learning ability. An extensive list of resources is included.

Scholl, G.L. The psychosocial effects of blindness: Implications for program planning in sex education. *New Outlook for the Blind*, 1974, *68*(5), 201-209.

The specific sex education needs of visually-impaired people are discussed, and recommendations for attention to these specific needs in programs designed for them.

Tait, P.E., & Kessler, C. The way we get babies: A tactual sex education program. *New Outlook for the Blind*, 1976, *70*(3), 116-120.

A presentation on intercourse and childbirth designed for visually-impaired children. Complete transcripts of the tapes and directions for making the dolls utilized in this instruction are included.

Torbett, D.S. A humanistic and futuristic approach to sex education for blind children. *New Outlook for the Blind*, 1974, *68*(5), 210-215.

The specific sex education needs of blind children are discussed, and recommendations are made to enable blind children to acquire sex knowledge equivalent to that of their sighted peers. The reluctance of parents and teachers to discuss sexuality with visually-impaired people is presented as well as appropriate means by which this obstacle can be overcome.

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Vogel, D.S., & Muxen, M.J. A sex education program for congenitally blind adults in a rehabilitation center setting. *New Outlook for the Blind*, 1976, *70*(3), 104-108.

This article presents the process by which a sex education program for blind adults was instigated and conducted at the Rehabilitation Center for the Blind in Sioux Falls in response to the apparent unfulfilled sexual needs of

visually-impaired persons. Teacher training, resource selection, course format, program results, and evaluation are discussed extensively.

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A technical and statistical summary of recent advances in genetic research relating to congenital blindness, and the implications of this research for genetic counseling.

Cerebral Palsy: A Review of the Literature

SOCIAL-SEXUAL PROBLEMS ASSOCIATED WITH CEREBRAL PALSY

Although cerebral palsy does not usually restrict genital functioning, there are many possible effects of the condition which may interfere with a cerebral palsied person's social and physical expression of sexuality. Due to the wide diversity of symptoms and degrees of disability associated with cerebral palsy, it is difficult to discuss the specialized needs of persons within this disability group. The following, therefore, are simply suggested areas of consideration when analyzing the needs of a particular individual. The basic rule of thumb in choosing appropriate sex education/counseling services holds true for individuals with cerebral palsy: services should be selected on the basis of the recipient's individual needs, abilities, and desires.

For the sake of analysis, we may divide possible effects of cerebral palsy into three major areas: physical, communication, and psychological considerations.

PHYSICAL CONSIDERATIONS. Physical problems which sometimes accompany cerebral palsy include spasms, paralysis, muscle and bone deformity, muscular weakness, and balance difficulties. These conditions may affect social and sexual activities, contraception, pregnancy, and childbirth.

Mobility-impairment may inhibit a person's social interaction by lessening his/her opportunities for meeting other individuals and participating in couples or group activities. Architectural and environmental barriers, for example, may limit places to go on a date. In addition, a cerebral palsied person with visible symptoms of the disability may encounter attitudinal barriers which may further segregate her or him from other members of society.

Sexual activity may also be severely affected by these physical difficulties. Petting, masturbation, and mutual masturbation may be restricted by paralysis, stiffness, or deformity of the hands and arms. Spasms and athetoid movements are often accentuated by emotional excitement, thus making these sexual activities difficult.

Coitus may also be affected by these same physical problems. Reflexes may be heightened or retarded by athetosis. Spasms can cause involuntary muscular contractions which make intercourse extremely difficult. This is particularly true of adductor spasms in the groin, which may make it impossible for a woman to successfully separate her legs (Heslinga, 1974). Paralysis or spasms in the hips and knees can inhibit the range of sexual positions available to a person with cerebral palsy. In addition, premature ejaculation might occur, thus frustrating the gratification of one's partner. As Poling (1974) points out, certain symptoms of cerebral palsy may even interfere with a person's ability to get into bed without assistance.

The choice of a contraceptive method is also dependent on the abilities of the user (Task Force..., 1978). Paralysis, spasms, stiffness, deformity, or lack of manual coordination can make the use of a condom, foam, or a diaphragm impossible or impractical. Insertion of an IUD could be painful or difficult in cases in which the pelvic structure is deformed, and weak pelvic muscles may cause a diaphragm to slip out of position.

Pregnancy may be difficult for a cerebral palsied woman (Steinbock & Zeiss, 1977). Pregnancy can complicate existing balance problems, and low back pain might occur more frequently as the pregnancy advances. These difficulties can severely limit mobility during the latter stages of pregnancy.

Childbirth could likewise be problematic for a woman with cerebral palsy. Because of spasms, she may be unable to bear down during the birth. As a result, there is an unusually high incidence of caesarean births among cerebral palsied women.

COMMUNICATION CONSIDERATIONS. Cerebral palsy may also result in any of a number of disabilities which affect communication. These include speech problems, visual or hearing impairments, and mental retardation. These communication difficulties can have a damaging effect on the individual's social and sexual interactions.

Communication in one form or another is necessary for the formation of personal relationships. A cerebral palsied individual with a hearing impairment must obviously overcome the same communication barriers encountered by other hearing-impaired people. Alternate modes of communication must be found, and the person's social environment often is restricted to individuals familiar with these alternate modes.

In addition, the "spread effect" frequently encountered by people with other disabilities may be faced by communication-impaired persons with cerebral palsy. Social interaction situations are frequently frustrated by the as-

sumption, for example, that a mentally retarded person is also deaf, or a visually-impaired person is also mentally retarded.

Accurate knowledge of social skills and sexuality-related information might be lacking due to impairment of communication. Sex education may not have been available to the individual during childhood and adolescence, and informal learning could have been hampered by isolation during this same period, either within a residential school or in the home. Perhaps books, films, audio-visual materials, or tactile resources were not available to relay this important information in an accessible mode of communication. These deficits in social and sexual knowledge can have long-term effects on personal interaction.

Medical and counseling services should be available to all individuals. Frequently, however, these services are inaccessible to communication-impaired individuals. A sign language interpreter, for example, might not be available in a family planning center, and this will interfere with complete and accurate contraceptive counseling.

Although genetic research has advanced to a point at which the possibilities of an offspring inheriting cerebral palsy can be very accurately predicted, genetic counseling services might not be available to cerebral palsied individuals who happen to have communication problems. Lacking this important counseling, a couple may unnecessarily chose not to have children or even not to become sexually involved.

As stated above, a person with cerebral palsy who has one or more communication disabilities might encounter the same barriers to successful social and sexual interaction as those encountered by persons within those particular communication-impaired groups. The literature syntheses in this handbook on visually-impaired, hearing impaired, and mentally retarded individuals present these needs in greater detail.

PSYCHOLOGICAL CONSIDERATIONS In addition to the physiological effects of cerebral palsy on an individual's social and sexual life, we must also consider some of the attitudinal barriers that are encountered by people within this disability group. These psychological considerations are attitudes toward 1) cerebral palsy and disability in general, and 2) sexuality and varied forms of sexual expression. Psychological barriers may stem from the attitudes of others toward the disabled person or the attitudes of the disabled person toward himself or herself.

Attitudes Toward Cerebral Palsy and Toward Disability in General. As seen throughout this handbook, disabled people, regardless of the nature of their disabilities, are subject to many of the same negative attitudes. These can directly affect their social and sexual interactions. Disabled people may be looked upon as being either asexual or, when they do express a normal curiosity and interest in sexuality, as being oversexed.

The "Peter Pan" myth is frequently applied to people with disabilities, such as cerebral palsy, in which the individual may require a longer than average period of dependency on others. Parents or guardians may equate dependency with childhood and express shock when the disabled person exhibits any adult activities, i.e., smoking, having a drink, wanting to get an apartment alone (Morgan, 1971b). Obviously, mature sexual activity falls into this category.

Also related to this perpetual child myth and equally damaging is the attitude that sexuality is a reward to be meted out to the individual, rather than a basic right of all people (Morgan, 1971a). If the disabled person internalizes this perception of sexuality as a tantalizing prize that can be awarded or denied by others, the effects on his or her sexual adjustment can be disastrous.

Due to the dependency on others, a disabled individual may become extremely passive in her or his interactions with others. In situations in which the individual has both cerebral palsy and related communication difficulties, it might seem easier for the disabled person to become the passive partner.

Other barriers to the expression of sexuality by disabled people are particularly appropriate when discussing cerebral palsy. Cerebral palsy usually occurs during a person's early life (most frequently at or before birth). Because of this, a person with cerebral palsy has many difficulties in common with others who have congenital birth defects: those who are mentally retarded, congenitally blind, congenitally deaf, or have spina bifida.

Frequently, a child with one of these congenital or early childhood disabilities is isolated either in the home or in a residential facility. They may suffer from a lack of contact with peers, or, in the case of many residential settings, from a lack of contact with the opposite sex. Awkwardness in social situations, lack of informal sex education, and the development of overly conservative attitudes toward sexuality may all result from this social deprivation. The difficulties often caused by such isolated environments are discussed in greater detail in Chapter 2 of this handbook.

Other barriers frequently encountered by persons with cerebral palsy and persons in certain other disability groups are those related to the visible aspects of the condition. In this sense, people exhibiting the visible effects of cerebral palsy may face the same attitudinal barriers as people who have a spinal cord injury, the aftereffects of polio, spina bifida, or multiple sclerosis. Geiger and Knight (1975), for example, report that many people with vis-

ible disabilities suffer from a deprivation of touching. Hugging, kissing, and caressing are important in the normal development of an individual, both in attitudes toward the self and in attitudes toward others.

These same visible aspects of disability may even more directly affect the self-image of the disabled person. If others show repugnance toward the individual, it is likely that the person will internalize this disgust toward the physical self. Images encountered daily (in magazines, on television, etc.) frequently portray "beautiful people" in which the only criterion for beauty is physical attractiveness. This image is extremely detrimental to both disabled and nondisabled individuals.

Attitudes Toward Sexuality and Forms of Sexual Expression. Attitudes of others toward the sexuality of disabled people may have serious effects on a person with a disability. Barriers to expressing one's sexuality can be physical (segregation of the sexes in a residential setting), or they can be psychological (the negative attitudes of others). The person may have internalized the attitude that sexuality is not acceptable for a disabled person. As a result, he or she may feel guilty expressing sexuality in any form.

A further barrier to sexual expression by individuals with cerebral palsy might be society's definition of "acceptable" means of expressing sexuality. Frequently, a person with severe physical limitations is unable to "perform" in accordance with society's standards. A man with cerebral palsy, for example, may not be able to have intercourse in the "missionary" position (man on the top) because of muscular weakness in his arms. He may find a "woman superior" position far more satisfying both to himself and to his partner. However, if he has internalized a very conservative attitude toward sexual expression, the stigma associated with this mode of intercourse may inhibit his sexual activity.

Masturbation, with or without a sexual aid (e.g., vibrator), may also be affected by society's definition of "right and wrong." If a person with cerebral palsy finds these practices sexually satisfying, he or she should not be inhibited by the negative attitudes of others. People with cerebral palsy have the same basic right as do all other people—the right to express sexuality and achieve sexual satisfaction by any means which are agreeable to them and their sexual partners.

A further example of the need for an open and accepting attitude toward all non-detrimental forms of sexual expression deserves our attention, since it frequently applies to individuals with cerebral palsy. Society has traditionally taught that sexual expression is a private matter and that it should involve only the individual(s) participating in the activity. Many severely disabled cerebral palsied individuals, however, need assistance to perform daily activities of living. These same people may also require the assistance of another individual to make sexual activity possible. For example, a woman may need help in positioning herself for masturbation. A disabled couple may require an assistant to undress them and position them for sexual activity. This may pose a problem for the attendant. He or she may be embarrassed by the situation or may be concerned about the morality of the mode of sexual expression. Obviously, the assistant's feelings must be respected, yet the assistant must carefully examine his or her own attitudes and candidly communicate with the individual(s) involved. The privacy of sexual expression is not violated. Going to the toilet or bathing are also intimate and private activities, yet few aides have any qualms about assisting in these functions. Sexuality must be treated as a normal and necessary activity for all people.

PROGRAMS AND INTERVENTION STRATEGIES

In recent years, there has been an increased interest in the sexuality of people with cerebral palsy. Individuals within this disability group have been surveyed, and their needs have been researched, yet few sex education/counseling programs have resulted from these assessments. Those that do exist are, in fact, very comprehensive, yet they are few and far between. Much more needs to be done.

Great Britain seems to have been the first to take an interest in the sexuality of people with cerebral palsy. At least three surveys of cerebral palsied individuals were conducted during the 1960's in Scotland and England. The results of these surveys are carefully summarized by Margaret Morgan in two of her comprehensive papers on sexuality and cerebral palsy (Morgan, 1969; Morgan, 1971a). Unfortunately, however, the primary focus of these surveys is on the percent of respondents who had married or who had sexual experience, such as dating; the specific needs of the survey respondents are not reported.

Brant and Hansen (1972) also report results of a survey of individuals with cerebral palsy. In their survey, particular attention was paid to the sexual experience of the respondents, their needs for sexual expression, and their personal solutions to satisfying these needs. Although this survey addresses several important research points, little information was gained which could be directly applied to the establishment of sex education/counseling services.

United Cerebral Palsy (1972) also conducted a comprehensive survey which compared the sexual experience and sexual attitudes of cerebral palsied individuals and those of nondisabled peers. UCP found, as did Brant and Hansen (1972) and Morgan (1969; 1971a), that individuals with cerebral palsy have less sexual experience than do their peers. In addition, the UCP survey results indicate that their disabled respondents tended to have more conservative attitudes toward sexuality.

The above surveys produced valuable insight into the need for sex education/counseling for persons with cerebral palsy. Thus, they are extremely useful in encouraging increased attention to the sexuality of cerebral palsied individuals. However, they stopped short of pinpointing the specific service needs of people within this population. A cerebral palsied individual with a speech impairment might require different sex education/counseling than would a person with paralysis who has no communication problem. As a result, individual interviews with potential recipients of sexuality-related services will probably be more appropriate indicators of needed services.

United Cerebral Palsy (Weinrich & Sternfeld, 1973) used such an approach the following year. Individuals with cerebral palsy were questioned (using a structured survey form) about their sources of sex information, ages at which they gained this information, present needs for particular knowledge, and suggestions concerning the roles of UCP and their parents in filling these gaps. Based on their responses, action was taken on an individual basis. One man, for example, indicated a need for "dynamics of intercourse, counselling on masturbation, emissions." UCP scheduled him for sex and marital counseling to meet his requested needs.

Great Britain has also been a pioneer in dealing with some of the socialization needs of individuals with cerebral palsy. A club was founded in the Nottingham area (Morgan, 1969) to deal specifically with the independence goals of its members. Another group, the '62 Clubs, run by and for cerebral palsied individuals, also deals with the social needs of its members (Morgan, 1972).

An important sexuality-related course resulted from a Club '62 conference on marriage. At that conference, the 250 attendees discussed their needs for marital and pre-marital counseling. A course, based on these candid discussions, commenced in 1969 under the auspices of the Spastics Society. This weekend-long course is offered to cerebral palsied individuals who are married or are anticipating marriage. The course includes both the opportunity and the resources to discuss openly problems which may be encountered in a marriage in which at least one partner is disabled. The participants are encouraged to discuss their concerns with their partners, other couples, and available resource personnel. Topics include domestic skills, psychological adjustment to marriage, information on sexual expression, family planning, and child rearing. Special equipment that may prove useful is demonstrated, and the couples are given the opportunity to try out a wide range of daily living activities in a specially equipped flat at a London hospital (Morgan, 1972; Morgan, 1975).

Another early program which deals specifically with the sexuality-related needs of individuals with cerebral palsy is a comprehensive sex education/counseling program at United Cerebral Palsy of Denver (Cook, 1974). The program began in 1971 as a direct result of a stated need by women in the sheltered workshop for sexuality-related information. The women agreed unanimously to hold weekly group discussions. As a result of these early group discussions, United Cerebral Palsy instituted a comprehensive sex education/counseling program for adolescents with cerebral palsy. Parents and staff members were encouraged to participate in all stages of program planning. Trained facilitators were hired to meet with the staff; this was extremely helpful in reducing staff anxiety about the new program. Results have been extremely rewarding. An article by Rose Cook (1974) carefully summarizes the components necessary to the formation of such a program. Her article is a "must" for others anticipating the initiation of a comprehensive educational counseling program.

Another important program designed to meet the needs of disabled individuals, including those with cerebral palsy, is that created by the Human Sexuality Program at the University of California Medical School in San Francisco (Geiger & Knight, 1975). Participants are treated on an individual basis, and a comprehensive sex education/counseling program is designed to meet their stated needs. Whereas the Denver program proceeds from a base of generalized sex education, the San Francisco program is constructed on an individual counseling basis. Both, however, arrive at the same point: a comprehensive program which addresses both the general needs of the group and the specific needs of the individual participants. Both formats are excellent.

At least two other sex education/counseling formats for persons with cerebral palsy warrant our attention. Both are carefully constructed sex education/counseling plans which could readily be formalized into comprehensive programs.

A case report by Steinbock and Zeiss (1977) presents an individual counseling situation in which the sexuality-related needs of a young woman with cerebral palsy are ascertained and addressed. The woman was anticipating marriage and wanted counseling on sexuality and parenting. A multidisciplinary approach was used in which sex counselors, a gynecologist, an orthopedist, and a geneticist participated. The specific knowledge and counseling needs of the woman were determined during initial counseling sessions, and subsequent meetings with other members of the counseling team addressed these needs. Her concerns over positions for sexual intercourse, for

example, were treated both psychologically by the counselors and physically by the orthopedist and gynecologist. Such a multidisciplinary approach proved very favorable in this situation. It serves as an excellent format for the provision of services to disabled people.

A second important sex counseling/education format is presented by Carter (1972). He outlines the success of genetic research in predicting the likelihood of a cerebral palsied person's offspring inheriting the disability. He suggests a comprehensive program for family planning which would be particularly helpful for individuals with cerebral palsy. He stresses the predictive ability of genetic analysis and encourages the establishment of counseling services.

GAPS IN KNOWLEDGE AND PROGRAMS

Research has indicated that there is a need for sexuality-related services among people with cerebral palsy. As mentioned previously, the wide range of conditions produced by the disability makes it difficult to itemize general needs of people with cerebral palsy. More research must be done on the effects of speech impairment, muscular weakness, bone deformity, hearing impairment, and visual impairment on the expression of sexuality. This information can then be used to suggest possible areas of concern among clients with cerebral palsy.

Of prime importance is the creation of more programs to meet these needs. Programs such as the one developed by Rose Cook (1974) and the one initiated by Geiger and Knight (1975) are equally valuable in providing sexuality-related services to people with cerebral palsy. The multidisciplinary approach suggested by Steinbock and Zeiss (1977) is also an excellent model.

One very noticeable gap is in the availability of genetic counseling services. Carter's (1972) summary of research is an excellent tool in encouraging the initiation of counseling programs and the inclusion of genetic counseling on cerebral palsy in existing programs. Efforts must be made to develop formats in which available knowledge can be utilized in "real world" situations. Serious attention also needs to be given to the establishment of organizations and programs, such as those described by Morgan (1969, 1972, 1975), which allow increased socialization and sharing among individuals with cerebral palsy. In addition, efforts must be made to increase socializing and sharing opportunities with members of other disability groups and with nondisabled peers. There are far too few situations which encourage the integration of individuals with cerebral palsy into the larger society.

RECOMMENDATIONS

1) People with cerebral palsy must be integrated more fully into the community.

2) Service providers who come in contact with cerebral palsied individuals must recognize the wide diversity of effects of the disability. It must not be assumed, for example, that a person with cerebral palsy whose mobility is affected has the same sex education/counseling needs an one whose vision is impaired. Mobility impairment or visual impairment may *suggest* areas of possible concern. However, each person must be treated as an individual with individual needs.

3) Community service providers who deal with the sexual concerns of the general population should equip themselves to deal with these same concerns and the specialized concerns of individuals with cerebral palsy.

4) Organizations and facilities for people with cerebral palsy should recognize the need among this population for accurate and complete sex education/counseling.

5) Disability-oriented organizations and community organizations must assess their own capabilities and determine for themselves whether it is more feasible to train all staff members to deal with sexuality and cerebral palsy or to assign these areas to a specialist.

6) Persons dealing with cerebral palsied individuals must re-examine their own attitudes toward varying modes of sexual expression.

7) More resources must be developed which allow individuals with cerebral palsy to access information on sexuality. This would include audio/tactile materials for cerebral palsied individuals with visual impairments, simplified films and presentations for those with mental retardation, and highly visual materials for those with hearing impairments.

8) Facilities offering sexuality-related services must be accessible to individuals with cerebral palsy. This includes ramped entrances for cerebral palsied persons with mobility impairments, interpreters for those with hearing impairments, and typewriters or other means of communication for those with speech difficulties.

9) All providers of services to people with cerebral palsy (teachers, social workers, etc.) should have at least a basic understanding of sexuality and disability and should be aware of resources available to this population.

10) Resource listings of sex education/counseling programs, literature, films, and other materials should be updated, expanded, and made known.

11) Residential facilities for persons with cerebral palsy should allow more interaction between the sexes.

12) Residential schools should make sure that the sex education/counseling needs of the students are dealt with both inside and outside the classroom.

13) There should be ample opportunity within all sex education programs to raise questions or topics of concern anonymously (e.g., written suggestion).

14) Genetic research on cerebral palsy should be applied to family planning counseling, and these services should be available and made known to individuals within this disability group.

15) A multidisciplinary approach should be considered in sex education/counseling for people with cerebral palsy.

16) The privacy of sexual expression should not be used as an excuse to deny assistance to an individual who wishes to participate in sexual activity. An empathetic aide can give assistance discreetly without violating the privacy of the individual(s).

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A study which explores sexual experience of 22 moderately to severely cerebral palsied males and females in Denmark. Age of first intercourse was found to be later than the norm among their able-bodied peers. Although in 50% of all cases, first sexual experience was with an able-bodied partner, the few more lasting sexual contacts were with other handicapped persons. Among males, masturbation and sexual encounters with prostitutes were frequent sexual outlets; further information is not given for females interviewed.

Carter, C.O. Genetic counseling. In D. Lancaster-Gaye (Ed.) *Personal relationships, the handicapped and the community: Some European thoughts and solutions.* London: Rutledge & Kegan Paul, 1972, 144-150.

A rather technical summary on the probable occurrence of various types of cerebral palsy as a result of family history. The reported probabilities emphasize the need for careful family studies in genetic counseling for persons considering parenthood who have a family incidence of cerebral palsy.

Committee on Sexual Problems of the Disabled. Sexual implications of some typical disorders. Unpublished chart. Undated.

A well laid out chart which details sexual difficulties that are likely to accompany specific disabilities, including cerebral palsy. Physical problems related to the various phases of sexual intercourse and pregnancy are listed for both sexes.

Cook, R. Sex education program service model for the multi-handicapped adult. *Rehabilitation Literature*, 1974, *35*(9), 264-267 & 271.

An article which describes the origins of the sex education/counseling program at United Cerebral Palsy of Denver. The program began as a result of requests from adults in the workshop and was later extended to adolescents served by the agency. The article emphasizes the need for cooperation between staff members and parents, rather than the actual program content. It is stressed that each agency or organization should assess the needs of its clients, and the attitudes and abilities of its staff and its clients' parents, to ascertain the most appropriate program of sex education/counseling.

Freeman, R.D. Psychiatric problems in adolescents with cerebral palsy. *Developmental Medicine and Child Neurology*, 1970, *12*, 64-70.

A general discussion of the psychiatric problems which may be accentuated at adolescence. Included among these are the loss of self-esteem, due partially to the visibility of the handicap, and the difficulties experienced in sexual expression. Factors contributing to attitudinal barriers against the sexuality of cerebral palsied persons are discussed in some detail.

Geiger, R.C., & Knight, D.E. Sexuality of people with cerebral palsy. *Medical Aspects of Human Sexuality*, March 1975, 70-83.

An article emphasizing the special difficulties in sexual expression which may be encountered by persons with cerebral palsy. Overprotection by parents and by institutions, lack of social skills learning, and social isolation are cited as main causes for the frequent passivity of cerebral palsied individuals. Sex education proposed, therefore, by this article emphasizes psychological, rather than physiological considerations.

Heslinga, K. *Not made of stone: The sexual problems of handicapped people.* Springfield, IL: Charles C. Thomas, Publisher, 1974.

A general discussion of psychological and physiological difficulties encountered by physically disabled persons, including people with cerebral palsy. Possible solutions to these obstacles and alternative modes of sexual expression are suggested.

Liskey, N., & Stephens, P. *Cerebral palsy and sexuality.* Undated. Available from: Disabled Students Organization, c/o Handicapped Student Services, University of California, Fresno, California, 93740.

An interesting analysis of cerebral palsy and sexuality. Included are a general description of the disability itself, a brief statement of the effects of cerebral palsy on sexuality, and six case studies. Two single females, two single males, one married couple with children, and one married couple without children were the subjects for the research. Emphasis is on the social and psychological aspects of the disability as they relate to sexuality.

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An introductory article which raises significant questions regarding severely disabled persons who are institutionalized and the moral and social obligations of attendants to intervene or not intervene in their expressions of sexuality.

Morgan, M.R. Marriage and the handicapped. Paper presented at the 3rd International '62 Club Conference, Reading, England, July 1969.

A brief paper which cites several studies in which it was found that people with cerebral palsy are less likely to marry than the general population and which offers a few possible reasons for this low incidence of marriage. Discussion topics related to marriage of cerebral palsied individuals are raised including: the sex education/counseling needs of engaged couples; alternative marriage situations (e.g., trial marriages or companionate marriages); parenthood; finances; housing situations; domestic responsibilities; and marriage within a residential setting.

_____. Attitudes of society towards sex and the handicapped. Paper presented at the First Congress of the International Cerebral Palsy Society, Arnhem, the Netherlands, April 26-30, 1971, a.

A paper summarizing many of the attitudinal barriers to the sexuality of severely disabled persons. These attitudes are presented as those of the able-bodied population in general, those of able-bodied persons in close contact with the disabled (i.e., professionals and parents), and those of the disabled persons themselves. Included are results of sexual experience surveys of disabled persons, primarily persons with cerebral palsy, and reactions of cerebral palsied persons attending a 1969 conference to trial marriages, companionate marriages, marriages between severely disabled persons (where assistance in sexual gratification may be necessary), and sexual relationships without marriage.

_____. Sex, marriage and the adult spastic. Paper presented at The Spastics Society's Conference on "The Spastic Adult," Nov. 6, 1971, b.

A paper presenting the difficulties faced by cerebral palsied persons in their sexual expression. The major emphasis throughout is on the need for a greater degree of independence, which will allow disabled persons to choose for themselves the most appropriate life style, possibilities of parenthood, and modes of sexuality.

_____. Follow-up of cerebral palsied married and engaged couples who attended short residential group discussion courses between April 1969 and April 1972. Paper presented at the International Cerebral Palsy Society's International Symposium "Family and Society," May 16-19, 1972, Paris, France.

A report on results of questionnaries mailed to persons who had attended two-day courses at The Spastics Society. Course participants were married or engaged cerebral palsied couples. Courses included both group discussions and individual counseling, and some of the topics covered were sexual relationships, parenthood, mutual self help, independence, finance, living accommodations, and domestic work. Reactions to the course were generally very favorable, and evaluations by participants have served to further restructure the program format to the needs of other cerebral palsied couples.

_____. Marriage and handicapped people—Six years on. *Marriage Guidance*, May-June, 1975, *15*(9).

This article updates the results of the short-term residential course for engaged people with cerebral palsy, offered by The Spastic Society. Some of the modifications made as a result of participant evaluation are discussed. In addition, the questions of parenthood and of dependence upon each other are discussed in some detail.

_____. Problems facing people with cerebral palsy. *Nursing Mirror*, Feb. 5, 1976.

A frank discussion of psychological and physical difficulties encountered frequently in the expression of sexuality by persons with cerebral palsy. Such topics as attitudinal barriers, social isolation, dependence, and the effects of spasticity and/or motor control on masturbation and intercourse are discussed; and the need for sex education/counseling and genetic counseling is stressed.

Poling, D.A., II. *Socio-sexual distance: The emotional, social, and sexual obstacles the disabled encounter when interacting with the able-bodied.* New York: United Cerebral Palsy of New York City, June 15, 1974.

A personal account written by a man with severe cerebral palsy which relates his social and sexual development and the difficulties he encountered. Emphasis is on situations in which disabled and able-bodied persons interact socially and sexually. Included is an able-bodied woman's developing view of the disabled.

Richardson, S.A. People with cerebral palsy talk for themselves. *Developmental Medicine and Child Neurology*, 1972, *14*, 524-535.

A collection of comments from a group of cerebral palsied persons invited to speak about themselves and difficulties they have encountered as a result of their disability or attitudes toward their disability. Included are brief comments on social isolation, overcompensation in social situations, lack of sex education, and stereotypes of the disabled person as asexual.

Riley, J. The c.p. and sex education. *The Advocate,* 1972, *1*(9), 2-3.

A brief article by a woman with cerebral palsy in which she expresses the attitudinal barriers which prevented her from obtaining information on sexuality as an adolescent and which she later encountered when she married. A plea is made to parents to reassess their attitudes toward the sexuality of their cerebral palsied children.

_____. Sex: The human need. Unpublished paper. Undated.

A brief paper in which the author discusses sexual expression outside of marriage (masturbation and pre-marital sex) and the feelings of guilt and frustration imposed on these expressions by religion. She relates this specifically to persons with cerebral palsy since marriage is sometimes improbable or impractical for this population.

Siepp, J. Assessment Inventory. Questionnaire by United Cerebral Palsy. Undated.

A very detailed inventory of sexual attitudes and sexual experience which assesses both psychological and biological factors of the individual's sexuality, specifically designed for persons with cerebral palsy who are either married or involved in a long-term sexual relationship.

The Spastics Society. *Love matters.* London: The Spastics Society. Undated.

A pamphlet written for persons with cerebral palsy which discusses the rights of all persons to sexual expression. Specific difficulties, both psychological and physical, which may be encountered in various phases of sexual intimacy are candidly discussed, and suggestions are made on ways to overcome these obstacles. The emphasis is on the rights of persons to express themselves sexually by any means which are acceptable to those involved.

Steinbock, E.A., & Zeiss, A.M. Sexual counseling for cerebral palsied adults: Case report and further suggestions. *Archives of Sexual Behavior,* 1977, *6*(1), 77-83.

A case study in which a multidisciplinary approach was utilized in pre-martial counseling for a mildly cerebral palsied woman. Sexual counselors, a gynecologist, a geneticist, and an orthopedic surgeon participated in the sessions which included individual and couples counseling and general and disability-related individual sex education. Both psychological and biological factors were discussed, and topics covered included sexuality, modes of sexual activity in relation to the individual's disability, genetic counseling, pregnancy and birth, and child care.

Sutton, A.H. Marriage and the handicapped. In D. Lancaster-Gaye (Ed.), *Personal relationships, the handicapped and the community: Some European thoughts and solutions.* London: Rutledge & Kegan Paul, 1972, 109-118.

A personal recounting of the difficulties encountered by a severely cerebral palsied man in his educational, social, and sexual pursuits. Some of the attitudinal barriers in socialization and his own unpreparedness for social integration are discussed as well as the difficulties faced by him and his disabled wife during their engagement and marriage. The author presents important considerations prior to marriage and his and his wife's individual solutions.

The Task Force on Concerns of Physically Disabled Women. *Toward intimacy: Family planning and sexuality concerns of physically disabled women.* New York: Human Sciences Press, 1978.

A general book written for physically disabled women on the psychological and biological concerns of disability and possible solutions to these difficulties. Included are comments of cerebral palsied women and a brief discussion of physical difficulties specific to persons within this disability group.

United Cerebral Palsy Task Force. A comparative study of attitudes of handicapped and non-handicapped concerning sexuality. Unpublished paper. Undated.

The methodology and results of a sex attitudes and experience survey given to persons with cerebral palsy and nondisabled persons. Topics included in the survey were masturbation, homosexual and heterosexual experience, pre-marital sex, modes of sexuality activity, contraception, and sex-education.

Weinrich, E. & Sternfeld, L. Preliminary sexuality survey on cerebral palsied adults. Questionnaire by United Cerebral Palsy, August 6, 1973.

A questionnaire on access to present sex knowledge (sources, age at which acquired, validity of information) and needs for further sex education/counseling (topics, sources, techniques). Preliminary results are given, including suggested role of UCP and parents in providing this information.

Williams, M.B. On growing up tight. *The Independent*, 1977, *3*(4), 18-19.

A brief personal account of the social isolation and parental overprotection of a cerebral palsied boy which resulted in a socially and sexually isolated man.

Sexuality and Spinal Cord Injury: A Review of the Literature

During the past decade, the literature related to sexuality and spinal cord injury has shifted from a preoccupation with physiological functioning to an increasing concern with psychosocial factors. The past emphasis on physiological limitations and capabilities has been noted extensively in the literature (Hohmann, 1972; Griffith, Tomko, & Timms, 1973; Crigler, 1974; Cole, 1975a; Cole, 1975b; Griffith & Trieschmann, 1975; Teal & Athelstan, 1975). Most pre-1970 studies deal with the SCI male's ability (or inability) to achieve and maintain an erection, ejaculate, experience orgasm, and produce offspring (Talbot, 1955; Bors & Comarr, 1960; Rusk, Covalt, Fisher, Marks, Sullivan, & Diller, 1967). The primary question considered is, "What can or can't he *do*?". Psychosocial aspects of sexuality are—for the most part—ignored.

By the early 70's, however, the trend begins to reflect a broadening definition of sexuality by society. Interpersonal communication and caring between partners are now considered important components of satisfying sexual expression (Berkman, Weissman, & Frielich, 1978). These changes have considerable impact on spinal cord injured persons: "Of great importance to the paraplegic and quadriplegic is the awareness that the satisfactions and sense of adequacy derived from one's sexuality may be quite independent of the presence or absence of bodily sensation." (Cole, Chilgren, & Rosenberg, 1973, 112).

This humanizing trend has also affected the attention given to cord injured women. Current writers comment on the scarcity of information before 1970 about the sexual functioning of SCI females. They point out that the little information given involves menstruation, fertility, pregnancy, and childbirth (Griffith, et al., 1973; Staff of Physical Therapy Dept. & Wagner, 1974; Cole, 1975b; Griffith & Trieschmann, 1975). Mention of female sexual response and psychological factors are noticeably absent. The recent literature, however, reflects a greater concern with the cord injured female and all aspects of her sexuality, not only her reproductive functioning (Bregman, 1975; Griffith & Trieschmann, 1975; Bregman & Hadley, 1976; Task Force..., 1978a).

Two other trends appearing in the current literature are: a more accepting attitude toward forms of sexual expression that differ from traditional sexual intercourse, such as oral-genital sex, masturbation, and non-genital erotic pleasuring (Cole, et al., 1973; Mooney, Cole, & Chilgren, 1975); and evidence that sexual well-being is related to adjustment and satisfaction in other areas of life, e.g., self-concept, vocational adjustment, etc. (Cole, 1975a; Hanlon, 1975; Singh & Magner, 1975; Teal, & Athelstan 1975; Bregman & Hadley, 1976.)

PROBLEMS ASSOCIATED WITH SPINAL CORD INJURY AND SEXUALITY

Access to Information

Most spinal cord injuries occur during early adulthood, (Crigler, 1974; Cook, 1976). As a result, almost all individuals with spinal cord injuries have acquired at least some sexual information and experience as able-bodied people. Social skills, for example, have often been learned and practiced with little or no thought to disability. A traumatic injury suddenly disrupts this learning process, and the individual begins to re-evaluate and re-define his/her capabilities, and sociosexual interactions.

This transition is made more difficult because of the attitudes and myths held by many members of the nondisabled population. Whereas, prior to injury, an individual may have been accepted as a sexually active being, he or she may now find that other people regard disabled individuals as asexual. It might be assumed, for instance, that a male in a wheelchair is necessarily impotent. Because of their physical limitations, persons with cord injury are sometimes viewed as passive, dependent, and no longer able to express themselves sexually (Cole, et al., 1973; Isaacson & Delgado, 1974). Some people assume that any sexual interest on the part of spinal cord injured individuals is excessive, perverted, and abnormal. (Cole, et al., 1973; Held, Cole, Held, Anderson, & Chilgren, 1975).

Due to society's negative attitudes and misconceptions, a newly injured person may find that channels for obtaining needed information are blocked. At the very time when individuals most need accurate and understanding

communication about their sexual potential, they often find that the subject is considered taboo, not only by the general public, but by health professionals as well.

Following cord injury, an individual usually assumes that health and rehabilitation professionals will provide information not only about bladder and bowel functioning, mobility, self care, vocational concerns, etc., but also about sexual issues. Questions may include: "What is my physical capability?" "What are my sexual alternatives?" "How do I approach a potential partner?" "What do I do with my urinary catheter during sexual activity?" Health and rehabilitation professionals, however, often avoid the whole issue of sexuality. Scott Luebking (1975, 20), a quadriplegic, comments: "At the rehabilitation center the doctors told me about skin care. The physical therapists explained to me about range of motion. The occupational therapists showed me how to eat. But as for sex... Well, I guess they didn't think that was an 'Activity of Daily Living.' " Other individuals with spinal cord injuries report similar situations (Paraplegics discuss..., 1972; Thomas, 1976).

One reason why some health and rehabilitation professionals avoid discussion related to sexuality is their own personal discomfort with the subject (Cole, et al., 1973; Isaacson & Delgado, 1974; Held, et al., 1975; Singh & Magner, 1975; Walker, Clark, & Sawyer, 1975; Evans, Halar, DeFreece, & Larsen, 1976). One way these professionals limit discussion about sexual concerns is to focus exclusively on procreation and fertility (Cole, 1975b). In this way the physician or other health professional avoids topics such as sexual options to intercourse, pleasuring techniques, the use of fantasy, etc.

Avoidance of the subject by professionals can also result from a lack of knowledge (Isaacson & Delgado, 1974; Cole, 1975b; Evans, et al., 1976; Mims & Swenson, 1978). For example, physicians are frequently ignorant about the sexual capabilities of their cord injured patients (Cole, et al., 1973; Crigler, 1974; Gregory, 1974). Even worse, some health and rehabilitation professionals provide incorrect information, e.g., that an individual's sex life is over, that an SCI woman should not have children because of her injury (Hohmann, 1972; Isaacson & Delgado, 1974; Cole, 1975a; Mims & Swenson, 1978).

Health and rehabilitation professionals can also impede the transmission of accurate and unbiased information in the following ways:

—imposing their own personal values and morality on the SCI individual (Crigler, 1974), and

—not dealing with sexuality-related concerns because they consider them irrelevant to their job roles (Cole, 1975b).

Misconceptions and resistance on the part of health/rehabilitation personnel, coupled with the disabled person's own ambivalent attitudes toward sexuality and/or disability, can lead to the mistaken conclusion that sexual concerns after injury are inappropriate. This situation often results in the SCI individual unnecessarily limiting his/her sexual functioning, hesitating about experimentation, and/or experiencing interpersonal/marital difficulties (Paraplegics discuss..., 1972; Cole, et al., 1973; Singh & Magner, 1975; Thomas, 1976).

Some spinal cord injured persons have access to health and rehabilitation professionals who are knowledgeable and open about sexual concerns. These professionals either provide direct services or referrals to appropriate services. Some spinal cord injury units and rehabilitation centers offer a variety of sexuality-related services as part of their comprehensive programs. Only a minority of cord injured people, however, have reported access to these kinds of services (Paraplegics discuss..., 1972; Cole, et al., 1973; Isaacson & Delgado, 1974; Cole, 1975b). This access depends primarily on geographic location, knowledgeable referral, funding provisions (e.g., insurance policies, VR budget), and just plain luck.

Once outside the hospital/rehabilitation facility environment, a cord injured person encounters many obstacles in obtaining information about sexuality. As noted in Chapter 6 of this handbook, attitudinal, architectural, and transportation barriers often prevent community services (e.g., mental health centers, gynecologists, sex education classes) from providing adequate sexuality information and services to spinal cord injured persons (Ryan, 1976; Task Force..., 1978b).

Spinal cord injured people report that they receive most of their sexuality-related information either from other disabled individuals (self-help groups, group counseling as part of a formal program, informal communication with disabled peers) or by trial and error (Paraplegics discuss..., 1972; Luebking, 1975; Thomas, 1976).

Opportunities to Develop Partnerships

Within hospitals and rehabilitation facilities, a cord injured person may experience a lack of privacy. This hinders the development of new relationships and the re-affirmation of existing ones (Griffith & Trieschmann, 1977). There is often no opportunity to have a private conversation with another person, or to experiment sexually either alone or with a partner.

Once outside of the institutional setting, an individual with a cord injury finds that architectural barriers prevent him or her from beginning and/or developing relationships (Cole, et al., 1973). A spinal cord injured man or woman may be unable to go to a place of employment, private home, bar, theater, recreational facility, or church because of stairs, inaccessible bathrooms, and/or narrow doorways. Accessible transportation may be unavailable or too costly. These conditions curtail opportunities to meet new people and to form partnerships.

The negative attitudes of other people frequently inhibit the cord injured individual's ability to form interpersonal relationships and experience satisfying sexual expression. Many nondisabled persons assume that spinal cord injured people are not sexual beings (Cole, et al., 1973; Isaacson & Delgado, 1974; Cole, 1975b; Held, et al., 1975; Luebking, 1975). This misconception may result in the following behaviors by nondisabled people: condescension, distancing, the expectation of exclusively platonic interactions, avoidance, and insensitivity. Other persons may be repulsed by physically disabled persons, and may view sexual relationships with them as a perversion (Cole, 1975b).

When a spouse or other family member harbors inaccurate assumptions about the sexuality of a cord injured person, conflict and misunderstanding are likely to occur. With correct information and improved communication, however, many negative and frustrating situations can be alleviated. Deyoe (1972), in a study on marriage and family patterns among spinal cord injured persons, reports that the divorce rate is not exceptionally high, that most couples enjoy marital satisfaction, and that family units usually remain intact. After reviewing the literature on marriage/divorce statistics among cord injured persons, Teal & Athelstan (1975, 267) conclude that, "preinjury marriages are approximately normal with regard to stability, and that the likelihood of a post injury marriage ending in divorce is even less than for the general population."

Attitudes of the cord injured person may also inhibit interpersonal relationships. If an individual has not accepted his or her disability, or has a poor self-concept, he or she will experience difficulties forming and maintaining satisfying sexual relationships (Miller, Wolfe, & Spiegel, 1975; Mooney, et al., 1975; Singh & Magner, 1975; Teal & Athelstan, 1975). In his introduction to *Sexual Options for Paraplegics and Quadriplegics* (1975), Alex Comfort discusses the need for "self-deprogramming," i.e., rejecting the idea that one is asexual and unlovable. To accomplish the "deprogramming" an individual must re-evaluate several societal myths related to sexuality:

—that only "normal," able-bodied people are sexual beings
—that penile-vaginal intercourse equals sexuality
—that there are only one or two appropriate positions for sexual activity
—that the male must have an erection, ejaculate, and experience orgasm to have a satisfying sexual encounter
— that orgasm is the goal of sexual activity
—that "performance" is all-important
—that the male must assume the more active role in sexual activity
—that, in order to be sexually attractive, a woman must be slim, pretty, and perfectly proportioned

A cord injured person may also limit opportunities for establishing satisfying sexual relationships through: ignorance about own physical capabilities, lack of information about sexual options and techniques, self-consciousness about bladder and bowel functions, and inability to accept a new role (Sex and the Paraplegic, 1972; Singh & Magner, 1975; Teal & Athelstan, 1975; Thomas, 1976; Luebking, 1975).

Functional Capabilities and Limitations*

All individuals with spinal cord injury are capable of some form of sexual expression (Cole, et al., 1973; Cole, 1975b; Singh & Magner, 1975; Berkman, et al., 1978). Sexual capabilities are affected by both physiological and psychological factors. Level and extent of cord injury determine an individual's physiological response to sexual stimuli (Hanlon, 1975; Singh & Magner, 1975). Generally, the less complete the lesion, the more physiological functioning remains intact (Comarr & Gunderson, 1975; Singh & Magner, 1975). With a complete lesion, sensation in the genital area is lost. Sexual arousal, however, is not dependent on sensation in the genital area (Cole, et al., 1973). A male quadriplegic, for example, may achieve and sustain an erection despite loss of sensation in the pelvic area. Intact areas above the level of lesion, such as the breasts, neck, ears, and back often become increasingly sensitive to erotic stimuli (Cole, 1975a; Griffith & Trieschmann, 1975; Mooney, et al., 1975; Task Force..., 1978a).

Psychological factors contribute heavily to sexual functioning. For example, some cord injured persons report that they are able to experience orgasms by reassigning a sensation existing above the level of lesion to their genitals (Money, 1960; Romano & Lassiter, 1972; Cole, 1975a; Griffith & Trieschmann, 1975; Luebking, 1975; Teal

*Refer to Tables D and E for more detailed information.

& Athelstan, 1975). Due to individual differences, the literature stresses the importance of not trying to predict exactly what a person may be capable of experiencing sexually (Rusk, et al., 1967; Crigler, 1974; Singh & Magner, 1975). Although some prediction is viewed as useful, it should not limit a person's experimentation.

The belief by some that a cord injured person can only *give* sexual pleasure to his or her partner, but not *receive* it has been refuted in the literature (Luebking, 1975; Mooney, et al., 1975). Sexual satisfaction can be achieved by both partners through the use of various positions, aids, and techniques. Oral-genital sex play* and mutual masturbation, for instance, are recommended by both health professionals and spinal cord injured persons as viable alternatives to penile-vaginal contact, which may be difficult for some individuals (Paraplegics discuss..., 1972; Cole, 1975a; Mooney, et al., 1975; Bregman & Hadley, 1976). Many other possibilities for enhancing sexual activitiy are discussed (Rusk, et al., 1967; Romano & Lassiter, 1972; Bregman, 1975; Cole, 1975a; Griffith & Trieschmann, 1975; Mooney, et al., 1975; Sandowski, 1976).

Special considerations related to the cord injured male: the majority of spinal cord injured males are able to have erections of some kind.** Most, however, are unable to ejaculate or experience genital orgasm. A small percentage can produce offspring.

Special considerations related to the female: most spinal cord injured females can participate in coitus. Unfortunately, little research is available concerning actual sexual response. Ability to conceive and give birth to children remains intact. Most of the literature emphasizes that spinal cord injury is not as traumatic for women as men, due to social acceptance of a passive role for females and the ability of cord injured women to have children (Anderson & Cole, 1975; Cole, 1975b; Singh & Magner, 1975; Teal & Athelstan, 1975). This situation may not be as relevant today, however, given the changing role of women in society.

*This form of sexual expression is considered illegal in some states. Professionals should be aware of local laws in order to avoid recommending an illegal activity to clients.

**Data vary greatly on the subject of physiological capability because important variables are not considered in many studies. These variables include: time since injury, medication, level and completeness of injury, marital status, availability of a partner, age, and pre-injury situation (Griffith, et. al., 1973; Teal & Athelstan, 1975).

TABLE D

Effects of Spinal Cord Injury on Sexual Functioning of Males

LIBIDO

- Survey findings vary from a sharp decrease of libido following injury (46)* to undiminished sexual interest (26).

ERECTION

- The majority (54%-87%) of cord injured males are able to achieve erections (1,3,6,14,22). This percentage varies drastically depending on the level and severity of injury. Factors that influence ability to have an erection include:

  1. *level of injury.* In general, the higher the injury, the more chances of achieving and maintaining a complete erection (14,17,21,35,39).

  2. *severity of injury.* If the lesion is incomplete, there is a better chance for a complete erection (3,18).

  3. *time elapsed since injury.* Men who are unable to have erections shortly after their injury may regain this capability during the first year (1,18).

  4. *medical complications, medication, and surgical procedures.* In some cases, these decrease an individual's ability to have an erection.

  5. *type of injury.* Spastic paraplegics, for example, have a much greater chance of achieving an erection than individuals with flaccid paraplegia (46).

- Two types of erection are described in the literature:

  Psychogenic erection occurs when messages are transmitted from the brain to the sacral area via the spinal cord. Stimuli may be visual (e.g., erotic reading material, films, another person), mental (e.g., sexual fantasy), etc. The SCI males most likely to achieve a psychogenic erection are those with incomplete lower lesions (9,22). The smaller the neurological deficit, the greater the chance for psychogenic erections (9).

  Reflexogenic erection occurs spontaneously or as a result of external stimulation applied below the level of injury. Possible stimuli include: pulling the pubic hair, stroking the abdomen or inner thigh, stimulating rectal area, slapping thigh, etc. (37). This type of erection may be of short duration or may be protracted (25).

EJACULATION

- Most spinal cord injured men are unable to ejaculate (1,6,14,37); the percentages of those who are able to ejaculate range from 3 percent to 20 percent (18). Most researchers indicate that ejaculation occurs more

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*Numbers within parentheses correspond to numbered citations in the reference section at the end of this literature search.

frequently among men with incomplete lower lesions (up to 70 percent) (9,14,18,22). Men with complete upper lesions rarely report ejaculation (1-14 percent) (9,12).

- SCI men who ejaculate may experience retrograde ejaculation, a backflow of semen into the bladder. This situation is seen repeatedly in low level lesions (1,25,37).

- Orgasm does not necessarily accompany ejaculation (8).

- Heightened spasticity has been experienced by some individuals before or at the point when ejaculation would have occurred (6).

- Medical techniques such as intra-rectal electrical stimulation (18) and the injection of the drug Prostigmin (14,18) have raised the incidence of ejaculation. These techniques, however, are still experimental.

ORGASM

- Only a very small number of cord injured males experience orgasm as it is usually defined (14). It occurs less frequently than ejaculation (18). Experiences labelled as "phantom orgasms" or "para-orgasms" have been described by cord injured persons even in instances of complete lesions (6,14). During non-genital orgasms, physiological and psychological changes associated with orgasm occur (14). An ability to "re-assign" sensation from a neurologically intact part of the body to the genital area and experiencing orgasm from that sensation has also been described (1). Spasms in the legs and localized sensation in the abdomen and inner thighs have been reported by some SCI men (17,37).

COITUS

- The percentage of SCI males who are able to achieve erection sufficient for coitus varies depending on level and severity of injury. Eighty percent or more of those men with incomplete lesions have been found to achieve successful coitus; only 25 percent of those individuals with complete lower lesions were able to have coitus. The data—as in other areas—vary considerably.

OTHER PHYSIOLOGICAL CHANGES RELATED TO SEXUAL FUNCTIONING

- Although the genital area usually loses most sensation as a result of cord injury, other body areas above the level of lesion may become increasingly sensitive to erotic simulus (6). Some male paraplegics, for example, have experienced increased sensitivity in their breasts, neck, and ears (32).

- Some quadriplegics experience autonomic hyperreflexia (a condition resulting in increased blood pressure, headache, sweating, and flushing) during genital stimulation. The headache may be relieved by stopping the specific stimulation that caused it (6).

- During sexual activity, breathing, pulse rate, and blood pressure increase in spinal cord injured men as they do in able-bodied men (7).

- Testicular atrophy (reduction in the size of testes) and changes in sperm number and motility may accompany spinal cord injury (12,34).

BLADDER & BOWEL CONTROL

- With spinal cord injury, loss of bladder and bowel control often occurs. Most SCI men follow regular bowel

programs and, thus, avoid problems of voiding the bowels during sexual activity.

- Spillage of urine during sexual activity is a possibility. Spasms, for example, may cause leakage. To prevent accidents, physical activities prior to sexual activity can be avoided (6). Fluids can be restricted (21,37). Bladder may be emptied before sexual activity by using the Crede method (hand pressure over bladder) (32). It is advisable to keep a towel or other padding available (6,32). A urinal, can, or bottle can be placed near the bed (32).

- Those SCI men who have had an ileostomy or colostomy may experience positioning problems during sexual activity. They may choose either to empty the collection bag and leave it on or attach a drainage tube and drainage bottle (21,32). To prevent leakage, it is recommended that chafing, rubbing, and pressing on the collection device be avoided (32,34).

- Communication with one's partner concerning possible urine leakage is vital in decreasing possible embarrassment and worry (6,14,32).

- A catheter can be folded over the penis and along the shaft. A condom may then be pulled over both penis and catheter, and lubricated (6). The catheter may also be removed prior to sexual activity (6,14,21).

EFFECTS OF MEDICAL INTERVENTIONS AND MEDICATION

- Surgical procedures such as alcohol washes to relieve spasms may reduce the possibility of erection and ejaculation (35).

- Some medications can decrease interest in sexual activity and impede sexual performance (14).

POSITIONS, TECHNIQUES, AND AIDS

- Some suggested positions for sexual intercourse:

  1. male in wheelchair, female on lap with back to him (6),
  2. male in wheelchair, remove arms of chair, female faces and straddles male (6),
  3. male on back, female on top (37),
  4. female on back, male on top (arm strength necessary) (21, 32, 37),
  5. both partners on sides (37),
  6. whatever imagination, preference, and functioning allow.

- Oral-genital stimulation is suggested in the literature (6, 21). Anal stimulation may also prove pleasurable (32).

- A technique called "stuffing" has been found helpful for individuals who have difficulty achieving and maintaining an erection (6,32). In this technique, the soft penis is tucked into the vagina, and the female thrusts with her hips and contracts her vaginal muscles. The advantages of this method include: a sense of penetration for the female and the possibility of a resulting reflexogenic erection (32).

- Other techniques and devices to enhance sexual activity: digital stimulation, manual massage, use of a vibrator, an artificial penis, use of fantasy, mutual masturbation, hugging, fondling of the genitals, use of oils, and other forms of sexual stimulation engaged in by able-bodied and disabled persons (6,21,26,32,35,37).

- Experimental medical procedures involving silicone rods and injections which leave the penis semi-rigid have been reported. There is some hesitation about the use of these procedures, however (32,37).

- A person may take advantage of muscle spasms to achieve more movement during sexual activity. Some partners have indicated that they consider spasms a turn-on. Other individuals, however, have reported loss of bladder control and loss of erection resulting from spasms (32).

- If the cord injured man and his partner have difficulty positioning and preparing for sexual activity, the help of a third person may be considered (32,36). An attendant may also be hired to help with bladder and bowel functioning, as well as other activities of daily living. This option may be chosen by couples who find that activities surrounding bladder and bowel control reduce sexual interest.

FERTILITY

- A very low percentage of spinal cord injured males are able to produce offspring (17,21,22,31,37). Statistics vary with level and completeness of lesion (1%-15%) (14). Even among individuals who are able to ejaculate without retroejaculation into the bladder, the sperm is often not viable.

- Artificial insemination is a possibility, although the results reported indicate that the sperm count is usually too low for this procedure to be successful (14,18,37,49).

- Adoption is a consideration for individuals who wish to have children despite infertility (14,37).

CONTRACEPTION

- For males who are able to produce children, the usual male contraceptive measures can be used, e.g., condom, vasectomy. Quadriplegics may have difficulty in using condoms due to impaired manual dexterity (32).

SELF-STIMULATION

- Masturbation or mutual masturbation is recommended for those unable to achieve erections, or for those who cannot or choose not to engage in intercourse (37). It is suggested as a way to learn about the capabilities of one's body, as well as for enjoyment (32).

SOME PSYCHOLOGICAL EFFECTS

- The sexual expression of SCI men can be unnecessarily restricted. The reasons may include:

  1. *Low self-concept and poor body image.* The cord injured male may have feelings of inadequacy and uncertainty about himself and his role in terms of sexuality. The newly injured individual may experience great difficulty in adjustment to his disability.

  2. *Attitudes of others.* Family, friends, and health professionals may directly or indirectly communicate to the SCI man that he is considered asexual.

  3. *Lack of information and experimentation.* A cord injured individual may not realize his sexual potential or may define sexuality as a strictly penile-vaginal occurence.

  4. *Avoidance by health professionals.* Health professionals (e.g., physicians, nurses, rehabilitation counselors) may avoid or ignore the subject of sexuality in dealing with their disabled clients. This may result

from discomfort with the topic, fear of not knowing the answers to all questions, or the attitude that sexuality is not relevant to their setting.

TABLE E

Effects of Spinal Cord Injury on Sexual Functioning of Females

LIBIDO

- Findings indicate that after cord injury, interest in sexual activity either remains unchanged (25)* or increases (48).

GENITAL RESPONSE

- Sensations around the labia and clitoris are often lost; limitation in movement of pelvis and hips accompanies cord injury (34).
- Vaginal secretions may be affected by spinal cord injury. In one survey, however, 27 out of 31 SCI women indicated that they had no difficulty with lubrication (4). Research is lacking in this area.
- If cord injury is complete, mental attitude is unable to affect moistness of the vagina. Vaginal lubricants are recommended in these cases (32).
- Swelling of the clitoris and labia is reported by women with spinal cord injury. Responses of vagina and uterus are not documented (7).

OTHER PHYSIOLOGICAL CHANGES DURING SEXUAL ACTIVITY

- Although the genital area often loses most or all sensation as a result of cord injury, other body areas above the level of lesion may become increasingly sensitive to erotic stimulus. Areas most frequently reported as particularly sensitive to sexual stimulation include: breasts, lips, ears, and neck (6,21,42).
- During sexual activity, breathing, pulse rate, and blood pressure increase in the spinal cord injured woman as they do in able-bodied women (7).

ORGASM

- Few cord injured women experience orgasm as it is usually defined (9,14,20). Non-genital or "phantom orgasms," however, have been reported. An ability to "re-assign" sensation from a neurologically intact part of the body to the genital area and experiencing orgasm from that sensation has also been described (1).
- Vivid fantasies and dreams (20,31) as well as tactile stimulation above the level of lesion (14) have resulted in orgasmic sensations.

*Numbers within parentheses correspond to numbered citations in the reference section at the end of this literature search.

- Generally, when both sensory and motor pathways are transected, there is no sensation of genital orgasm (42).

COITUS

- A vast majority of spinal cord injured females are able to have successful coitus.

BLADDER AND BOWEL CONTROL

- With spinal cord injury, loss of bladder and bowel control usually occurs. Most SCI women follow regular bowel programs and, thus, avoid problems of voiding the bowels during sexual activity. Some women plan bowel programs around sexual experiences (5).
- Spillage of urine during sexual activity is a possibility. Spasms, for example, may cause leakage (32). To prevent accidents, physical activities prior to sexual activity can be avoided (6). Fluids can be restricted (2,37). The bladder may be emptied before sexual activity by using the Crede method (emptying the bladder by applying pressure to abdomen) (4,32). It is advisable to keep a towel or other padding available (4,6,32). A can or bottle can be placed near the bed (32).

- Those SCI women who have had an ileostomy or colostomy may experience positioning problems. They may choose either to empty the collection bag and leave it on or to attach a drainage tube and drainage bottle (32). To prevent leakage, it is recommended that chafing, rubbing, and pressing on the collection device be avoided (32,34).

- Communication with one's partner concerning possible leakage is vital in decreasing possible embarrassment and worry (6,32).

- A catheter can be positioned and taped along the thigh prior to sexual activity (4,6,20,32). Many women prefer to leave their catheters in place in order to maintain spontaneity (4,5). However, if desired, a woman can remove her catheter before sexual activity (14,21). If the catheter is retained, the bladder should be emptied beforehand (21).

EFFECTS OF MEDICAL INTERVENTIONS AND MEDICATION

- Ablative procedures such as alcohol washes do not alter menstrual periods (20). These procedures, however, may decrease sensation below injury level.

- Some medications can decrease interest in sexual activity and impede sexual performance (14).

POSITIONS, TECHNIQUES, AND AIDS

- Some suggested positions for sexual intercourse:

  1. female on back, male on top. Pillows can be placed under woman's legs for support (37),

  2. both partners on their sides facing each other (37),

  3. both partners on their sides with the male entering from rear (37),

  4. female on back, holding legs up and back, male on top (5),

5. female on top pulling with arms and hands around partner's neck and shoulders. (In this way the female can supply most or all the movement) (32),

6. female on stomach, partner entering from rear (4),

7. female on male's lap, using a rocking motion (5),

8. whatever imagination, preference, and functioning allow.

- Oral-genital stimulation is suggested in the literature (6,21). Anal stimulation may also prove pleasurable.

- Other techniques and devices to enhance sexual activity: breast stimulation, manual massage, telling of erotic stories, digital stimulation, use of a vibrator, an artificial penis, use of fantasy, mutual masturbation, hugging, fondling of the genitals, use of oils, licking, sucking, and other forms of sexual stimulation engaged in by able-bodied and disabled persons (5,6,20,21,32,34,35,37).

- A person may take advantage of muscle spasms to achieve more movement during sexual activity. Some partners have indicated that they consider spasms a turn-on. Other SCI individuals, however, have reported loss of bladder control as a result of spasms (32).

- If the cord injured person and her partner have difficulty positioning and preparing for sexual activity, the help of a third person may be considered (32). An attendant may also be hired to help with bladder and bowel functioning, as well as other activities of daily living. This option may also be chosen for couples who find that activities surrounding bladder and bowel control reduce sexual interest.

FERTILITY

- Approximately 50% of newly injured women do not miss a single period. The other half usually resume their normal menstrual cycle within 6 months after injury (6,9,20,25).

- Fertility of spinal cord injured women is usually unimpaired (6,9,12,21). For this reason contraceptive measures should be taken if the woman does not want to become pregnant.

- Routine gynecological care is recommended for all women, including those with spinal cord injury (20).

CONTRACEPTION

- In choosing an appropriate contraceptive, an SCI woman needs to consider additional factors that relate to her injury:

1. The *pill* has already been linked with thrombophlebitis (inflammation and clots in a blood vessel). A spinal cord injured woman taking oral contraceptives is even more susceptible to blood-clotting than an able-bodied woman (6,32,34,37).

2. An *IUD* may cause problems for a woman who has lost sensation in her pelvis. If the IUD becomes loose, penetrates the wall of the uterus, or causes an infection, she may not be aware of the situation, and medical complications may arise (6,32).

3. *Diaphragm* insertion may be difficult for a woman who does not have full use of her hands (14,32,34).

4. Application of *foams and creams* may also be difficult for a woman with impaired hand dexterity (32).

5. *Tubal ligation* may be selected by a female who has decided not to have children (14,37).

PREGNANCY

- Regardless of injury level, the potential for pregnancy almost always remains unchanged (6,20,25). Most SCI women who become pregnant deliver healthy infants (20). Caesareans are no more common among women with cord injuries than among able-bodied women (6).

- During pregnancy, the SCI woman is more susceptible to urinary tract infections than are able-bodied women (9,20). Kidney functioning and blood pressure need frequent monitoring (25,32). There is an increased possibility of decubiti (18,20), anemia (20), balance and breathing problems (32), and premature or precipitous delivery (20). Pregnant quadriplegic women are increasingly likely to experience autonomic hyperreflexia (a condition resulting in increased blood pressure, headache, sweating, and flushing) (32).

- Women with no sensation in the pelvic area may not realize when labor pains begin. These same women, however, will not experience pain during delivery (32).

- When the lesion is low, a woman can assist in childbirth. With a high lesion, spasms or cramps may occur in the pelvic muscles. Special medical procedures may be required, such as the use of forceps at delivery (25).

- In general, breastfeeding is unaffected by spinal cord injury (37). Women with loss of manual dexterity will need to make adjustments for holding the feeding infant.

SELF-STIMULATION

- Masturbation or mutual masturbation is recommended for those who cannot or choose not to engage in intercourse (37). It is suggested as a way of learning about the capabilities of one's body, as well as for pleasure (32).

SOME PSYCHOLOGICAL EFFECTS

- The sexual expression of SCI women can be unnecessarily restricted. The reasons may include:

1. *Low self-concept and poor body image.* The cord injured person may have feelings of inadequacy and uncertainty about herself and her sexuality. The newly injured individual may experience great difficulty in adjusting to her disability. The first sexual experiences after injury may cause psychological discomfort; rejection may be feared (5).

2. *Attitudes of others.* Family, friends, and health professionals may directly or indirectly communicate to the SCI woman that she is considered asexual.

3. *Lack of information and experimentation.* A cord injured woman may not realize her potential to experience sexual pleasure because parts of her body lack sensation and motion (5).

4. *Avoidance by health professionals.* Health professionals (e.g., physicians, nurses, rehabilitation counselors) may avoid or ignore the subject of sexuality when dealing with their disabled clients. This may result from discomfort about the topic, fear of not knowing the answers to all questions, or the attitude that sexuality is not relevant to their setting.

PROGRAMS AND INTERVENTIONS

Several comprehensive programs addressing the sexual concerns of spinal cord injured persons have been described in the literature. Some of these programs, however, have changed or are no longer functioning. For a a current list of SCI sexuality programs, refer to Appendix C.

1. University of Minnesota Medical School, Program in Human Sexuality. One aspect of this program is the use of intensive 2 or 3 day Sexual Attitude Reassessment (SAR) workshops, based on a format developed by the National Sex Forum. A major goal of these experiential workshops is to desensitize participants to explicit sexual material (films, slides, tapes, presentations) in order to resensitize them to their own sexual feelings. Topics include: masturbation, homosexuality, fantasy, sex therapy, pornography, and sexuality and the spinal cord injured person. As a vital part of the SAR, small group discussions led by trained facilitators allow participants to share reactions and explore feelings related to sexuality. Self-acceptance and recognition that sexual expression can take a variety of forms are central (Cole, et al., 1973; Held, et al., 1975). Although this program is no longer functioning, the SAR format is widely used as a component of many other programs.

2. Spinal Cord Injury Service, Veterans Administration Hospital in Cleveland. This program includes individual and conjoint counseling, group discussion, and the use of films. The emphasis, however, is on highly structured group sessions in which didactic presentations precede group discussion. A booklet, entitled *Sex and the Spinal Cord Injured: Some Questions and Answers* (Eisenberg & Rustad, 1974), which summarizes the program content, is used as a reference both for patients and their partners. Eight weekly sessions are considered minimum. Topics covered include: anatomy and physiology; interpersonal considerations; female sexual response; techniques for preparation, relaxation, and arousal; and marriage, divorce, and children (Eisenberg & Rustad, 1976).

3. Department of Physical Medicine and Rehabilitation, University of Michigan Medical Center. This program relies extensively on the group approach, with less emphasis on individual or conjoint counseling. The group mode is considered preferable to other techniques for several reasons: economy of time, realization by patients that their problems and concerns are shared by others, satisfaction of patients gained through helping others find solutions, and a vehicle for safe rehearsal to establish a range of acceptable social/sexual behaviors. The use of didactic information on the anatomy and physiology of the human reproductive system is also included (Romano & Lassiter, 1972). The program as described in the literature is no longer in effect.

Other programs reviewed in the literature include: the Rehabilitation Institute of Chicago, Rancho Los Amigos Hospital in Downey, California, the Human Sexuality Program at the University of California in San Francisco, the Spinal Cord Injury Service at VAH-Long Beach, and the Spinal Cord Injury Center, VAH-Bronx (Isaacson & Delgado, 1974; Luebking, 1975; Eisenberg & Rustad, 1976).

Several intervention methods are mentioned repeatedly in the literature describing various programs. Group discussion and group counseling are considered essential by most writers (Romano & Lassiter, 1972; Cole, et al., 1973; Isaacson & Delgado, 1974; Held, et al., 1975; Miller, et al., 1975). The composition of groups varies according to the program (spouses/partners, other family members, same sex participants, professionals and cord injured persons together). In most cases, involvement of the spouse/partner is considered essential for optimal outcome (Cole, et al., 1973; Isaacson & Delgado, 1974; Evans, et al., 1976).

Evans, et al. (1976) describe the team approach, in which many kinds of health professionals (e.g., nurses, physicians, physical therapists, occupational therapists, social workers, and psychologists) join together to provide coordinated and comprehensive sex education/counseling services for cord injured patients. In this way, evaluations based on both physiological capabilities and psychological factors can be made.

Didactic presentations are included—to some extent—in almost all programs specifically geared to the cord injured and their spouses. This approach is most useful for providing information about anatomy and physiology, effects of injury on sexual functioning, birth control methods, sexual options, etc. (Romano & Lassiter, 1972; Eisenberg & Rustad, 1976).

The use of audio-visual material differs with each program. The Minnesota SAR approach, for instance, relies heavily on audio-visual stimuli as a primary component, whereas the Cleveland VAH program uses films, slides, and other visual aids to clarify, illustrate, and add depth to the presentation (Cole, et al., 1973; Held, et al., 1975; Eisenberg & Rustad, 1976). A list of relevant audio-visual materials is provided in Appendix G. Books and pamphlets written specifically for the cord injured person include:

Sexual Options for Paraplegics and Quadriplegics (Mooney, et al., 1975)

"Sexuality and the Spinal Cord Injured Female" (Bregman, 1975)

"Sex and the Spinal Cord Injured: Some Questions and Answers" (Eisenberg & Rustad, 1974)

Toward Intimacy (Task Force on Concerns of Physically Disabled Women, 1978). Other disabilities are also addressed.

Further printed resources can be found n Appendix F.

The importance of confidence, imagination, experimentation, relaxation, and—above all—open communication, are noted frequently in the literature (Romano & Lassiter, 1972; Anderson & Cole, 1975; Cole, 1975a; Mooney, et al., 1975; Evans, et al., 1976). Comprehensive programs often focus on improving verbal skills and providing a common vocabulary. In this way, not only is there better understanding between staff and client, but also between the cord injured person and his or her partner (Romano & Lassiter, 1972; Evans, et al., 1976).

Some disagreement still exists about the timing and quantity of sex education/counseling services. Recommendations to start discussing sexuality vary from, "almost immediately after injury" to "six or more months after the injury."' (Crigler, 1974; Isaacson & Delgado, 1974; Cole, 1975b; Hanson & Franklin, 1976). Almost all writers, however, agree that some type of sex education/counseling program should be incorporated into the overall rehabilitation plan.

GAPS

Topics identified in the literature as needing further investigation include:

1. **Sexuality and the spinal cord injured woman**

   --physiological sexual response, e.g., vaginal secretions

   --endocrinological reactions

   --contraceptive problems

   --incidence of various gynecological problems

   --psychological effect, e.g., role, self-concept, vocational impact, etc.

2. **Sexual options**

   --non-genital orgasm

   --various sexual positions in relation to reactivity of non-genital erogenous zones

   --use of various sexual aids, devices, and techniques

   --homosexuality

3. **Psychosexual considerations**

   --the relationship between self-esteem, sexuality, and disability

   --attitudes and feelings of both sexual partners toward their relationship and sexual activity

   --the relationship between the pre- and post-injury sexual functioning of each partner

4. **Other physiological considerations**

--influence of medication and/or medical procedures on sexual activity of cord injured persons

--occurrence and effects of spasticity, autonomic dysreflexia, and fractures during sexual activity

5. **Evaluation and intervention**

--optimal time to begin evaluation of sexual capabilities and intervention

--best methods of evaluation and intervention

--value of co-therapists

--methods of teaching the motor skills of sexual performance

--value of using surrogate partners

RECOMMENDATIONS

1. **Research**

a) Further research on issues listed in the previous "Gaps" section

b) Comprehensive follow-up studies to determine effectiveness of programs

c) Use of non-hospitalized subjects in research studies

2. **Policy and content of program geared toward newly injured SCI person**

a) Coordinated sex education/counseling services included as part of the overall rehabilitation plan, and offered to all newly injured persons within a hospital or rehabilitation setting

b) Use of group discussions and counseling

c) Inclusion of spouse

d) Emphasis on developing communication skills between partners

e) Encouragement of experimentation and exploration of sexual options

f) Thorough medical examination to determine functioning potentials

g) Use of SCI persons in program planning

3. **Program staff**

a) All staff of hospital or rehabilitation facility at least comfortable with discussions and questions re: sexuality

b) Team approach rather than the responsibility of a single staff member

c) In-service training for staff in the area of sexuality and spinal cord injury

d) Use of SCI individuals within the community as resource personnel

4. **Community involvement**

a) Sensitization of community health and counseling services (e.g., mental health centers, clinics, gynecologists, Planned Parenthood) to the needs of the SCI population

b) Availability of and accessibility to regular community services

c) More information available to general public about the capabilities of SCI individuals

d) Attitudinal and architectural accessibility of community activities and facilities (e.g., theatres, bars, schools, churches, restaurants, recreational areas, etc.)

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Sexuality and Mental Retardation: A Review of the Literature

The realization that mentally retarded people are human beings with individual personalities, preferences, and potential is relatively new. In the recent past, persons with mental retardation were considered by many "normal" people to be interchangeable "subnormals" who should be kept locked away in huge, grim institutions. Although this opinion is still heard, attitudes are changing, and the trend is toward normalization and mainstreaming into the community (Kempton, 1977). As parents, professionals, and the general public develop a more humanized image of mentally retarded individuals, increased attention is being focused on sexuality and sexual expression. Concern, fear, confusion, and resistance are common among all persons involved, including those who are retarded.

During the 1970's, much has been written about sexuality and mental retardation. The spotlight has been aimed at dispelling myths about both sexuality and the disability, assessing education and training needs, and initiating effective sex education programs for retarded adolescents and young adults.

PROBLEMS ASSOCIATED WITH MENTAL RETARDATION AND SEXUALITY

As increasing numbers of previously institutionalized mentally retarded people are (re)entering the community, the need for accurate sex education has become apparent (Kempton, 1975a). Sex-related behavior often tolerated in institutions (e.g., hugging strangers, masturbating in public) is unacceptable, dangerous, or even illegal in the community setting (Rosen, 1972). Kempton (1977) states that one third of the crimes committed by retarded persons are sex-related. Yet on closer examination, she notes that these "crimes" are due to ignorance and lack of training rather than perversion or malicious intent. An individual, for example, may urinate on the sidewalk because (s)he doesn't know how to find a bathroom; or a retarded young adult may attempt to express affection physically to passersby in a shopping center. People who are unaware of the sexual mores of our culture are also more likely to become victims of sexual exploitation than individuals who are aware of sexual cues and motivations (Kempton, 1975a, 1977, 1978; Kempton, Bass, & Gordon, 1978; Pattullo, n.d.).

Effective sex education increases a person's repetoire of social skills, which in turn develops self-confidence and an improved self concept (Kempton & Forman, 1976). As a result, retarded individuals become more independent and competent in all areas of their lives. Studies have indicated, however, that "...deficits in sociosexual functioning can quickly lead to job or community failure..." (Edmonson & Wish, 1975, 172).

In spite of all the positive effects of accurate sex education, many mentally retarded adolescents and adults often are still ignorant of the most basic sexuality-related information (Rosen, 1972; Rostafinski, 1972; Edmonson & Wish, 1975; Hall, 1975). What are some of the reasons for this lack of knowledge? Why is enlightened sex education still being neglected and even actively discouraged in many homes and institutions?

Access to information

Obstacles to gaining accurate and useful sex education can be divided into two categories: those resulting from characteristics associated with the disability itself, and those which are due to the negative attitudes and ignorance of nonretarded people. The two categories are not discrete, but, rather, overlap. Passivity, for instance, is considered a typical characteristic of retarded persons, yet this passivity is frequently due to the way the individual has been treated by nondisabled people.

The literature offers several reasons why retarded persons have difficulty gaining information about sexuality, and, as a result, need structured sex education even more than the general population. "The retarded...need sex education more than anyone else because they cannot readily learn about sexuality from friends, books, or from observing the behavior of others, and they have more than usual difficulty with sorting out reality from unreality" (Kempton, 1978, 138). Also, cause and effect relationships may be unclear, e.g., that having intercourse may result in pregnancy. As stated before, retarded persons are also more vulnerable to sexual exploitation because, without adequate training and experience, they may: respond indiscriminately, do what is asked of them, be unaware of appropriate behavior, possess poor judgment in sizing up the motivation of others, or act impulsively.

Also, because exploiters know that a person with mental retardation is less likely to be taken seriously when reporting an incident, they will often deliberately seek out a retarded individual (Kempton, 1975a; Kempton & Forman, 1976; Kempton, et al., 1978; Pattullo, n.d.).

Mental retardation, however, is not the main reason why retarded adolescents and adults are generally uninformed about sexual matters. The negative attitudes and misconceptions of nondisabled people are by far the major impediments in the acquisition of sex-related knowledge by retarded individuals.

The literature indicates that many people—including the parents of retarded children and professionals—believe that retarded people are lifelong children, whose innocence should not be threatened by exposure to sexual issues (Goodman, 1972; Lee, 1972; Hall, 1975; Kempton, 1977). One parent responding to a mailed questionnaire about sexuality and trainable mentally retarded young people wrote, "if they are innocent, let them stay that way. We hope no overzealous leader or teacher will try to put any "big ideas" into a sweet, child-like mind' " (Alcorn, 1974, 130). Although this type of comment does not represent a majority view, it is often the loudest and, as a result, it is influential in decisions related to the initiation of sex education programs (Kempton, 1975a).

It has been found, however, that withholding information does not deter sexual activity (Kempton & Forman, 1976). Rather, lack of information gives rise to false assumptions, confusion, needless fears, inappropriate behavior, and unwanted consequences. A girl who has not been told about menstruation, for example, may believe that she is bleeding to death when she has her first period (Kempton, 1975a). An adolescent couple, ignorant of the possible consequences of their sexual behavior, may act on an impulse which results in an unwanted pregnancy. "A child is more likely to have sexual problems when he *doesn't* know much about sex. Studies show there is less promiscuity and venereal disease among those with more information.... If you satisfy their curiosity about sex, they will have fewer sexual problems" (Kempton, et al., 1978, 4). Garber (1972) also notes that women who are unaware of their own needs during pregnancy contribute to a higher rate of retardation in their children. With adequate sex education, these women will receive proper prenatal care and will lessen the chances of having a retarded child.

Another obstacle to the provision of adequate sex education for retarded children and young adults is the myth that knowledge will trigger uncontrollable and insatiable sexual urges. Kempton (1978) writes that the fundamental question is: Are retarded students who participate in sex education courses more likely to act sexually irresponsible? She reports that an evaluation of 31 courses involving 430 retarded people indicates that sex education heightens the maturity level of student attitudes. In a 1972 article, Gordon states, "Do you know what stimulates acting out? Ignorance, curiosity, lack of knowledge, lack of alternatives.... Information inhibits behavior; knowledge causes people to be a little bit more introspective; it makes them think" (1972b, 125).

Closely linked to the misconception that sex education will cause promiscuity is the belief that, as a result of their sexual activity, retarded persons will produce large numbers of mentally impaired children (Lee, 1972). This myth originated during the eugenics movement (1890's to 1920's) when it was believed that all retardation is hereditary. At that time, retarded persons were confined to residential institutions where they were segregated according to sex in order to prevent any possibility of pregnancy (Wolfensberger, 1972). During the peak of the eugenics era, sterilization without consent was common. Later, consent for such an operation was the cost of freedom from some institutions. In interviews with individuals who were released from institutions many years ago on the condition that they be sterilized, the memory of the sterilization procedure remains vivid and is considered a permanent and humiliating stigma (Hall, 1975).

Two discoveries brought the "genetic scare" to an end. It was found that only a small proportion of mental retardation is caused by heredity. In the majority of cases, retardation occurs after conception, e.g., during birth, as a result of a deprived environment. The second discovery was the realization that people with mental retardation have a relatively low reproductive rate (Hall, 1975). In spite of these facts, however, the negative public image of sexuality and retardation persists even today (Goodman, 1972).

Negative attitudes and ignorance about sexuality itself also interfere with informative and useful sex education (Goodman, 1972; Hall, 1975; Kempton, 1975a). For example, if a woman who believes that sex for pleasure is sinful discovers her daughter masturbating, she will undoubtedly respond negatively. Sex education will occur, and the message communicated will be that sexual activity is dirty and unacceptable. The girl will probably continue to masturbate, but will do so with feelings of guilt and shame.

Restrictive definitions of sexuality can also limit an individual's psychosexual sphere. If a sex education program only deals with the physiological mechanics of sexual expression and hygiene, there will still be many unanswered questions in the minds of the students. Many retarded adolescent females know *how* a baby is made; what they may not know are the responsibilities that go along with "making a baby." Unless these other concerns are discussed, sex education is not only inadequate; it can also be harmful.

A limiting definition of sexuality may result in programs and informal sex education which emphasize the crisis aspects of sexual expression. Parents and professionals may attempt to prevent sexual experiences rather than

provide instruction that will help retarded persons choose appropriate ways of expressing their sexuality (Edmonson & Wish, 1975). This type of sex education is characterized by a "don't" approach, e.g., "Don't let a boy touch your genitals," etc. Although some "don'ts" need to be included, sex education which stresses these negative aspects of sexuality is not helping retarded individuals meet their sociosexual needs.

Another way that mentally retarded individuals are barred access to information is the belief that other people, especially parents, strongly oppose sex education for retarded children. Teachers and other professionals frequently use the possibility of parental opposition as an excuse to avoid sex education (Gordon, 1972a; Kempton, 1975a; Hamilton, 1976). The majority of parents, however, express relief—not outrage—when attempts are made to educate their retarded children about sex. This relief stems from confusion about how best to handle the whole area. One parent responded to the initiation of a sex education program with these words: "I didn't know how to handle this area with my child, so I haven't done much. I'm relieved that you will be taking the responsibility" (Kempton, 1978, 142). Parental concern focuses more on their children's sexual ignorance and inappropriate behavior (real or anticipated) rather than on education (Goodman, 1972; Kempton & Forman, 1976).

Some people are hesitant about providing sex education for retarded children and young adults because they fear that they may inadvertantly overwhelm or confuse the individual with too much information. Writers in the literature note that sex education cannot be premature. If a person can't understand something, he or she will tune it out. People learn what they are capable of learning. The danger is not too much information, but, rather, too little (Kempton, 1975a; Kempton & Forman, 1976; Kempton, et. al., 1978).

Opportunities to develop partnerships

> "...we want social training so as to be able to move out into society and manage on our own."
>
> "We want the right to move /in/ together with members of the opposite sex when we feel ready for it, and we also want the right to marry when we ourselves find the time is right."
>
> --from a policy statement formulated by young retarded adults

Most of the sociosexual needs and desires of retarded adolescents and young adults are typical of our society (Rostafinski, 1972). Yet, "behavior which is acceptable when practiced by a normal person sometimes becomes unacceptable when practiced by someone who is different" (Hall, 1975, 186). Although our "normal" sociosexual model is to find a mate, marry, and have children, when a retarded adolescent or adult expresses these desires, many people are surprised and shocked (Hall, 1975). Normal sexual behavior is frequently interpreted as excessive and perverted when a mentally retarded individual is involved (Goodman, 1972).

By the time they have reached adulthood, many retarded people have spent years in restrictive environments, such as overprotective homes and large institutions. Normal sexual development has frequently been suppressed. Retarded children who are raised at home frequently receive inordinate amounts of affection from their parents (Kempton, Bass, & Gordon, 1978). This situation may cause the retarded child or adolescent to expect excessive amounts of affection from everyone else as well. Because these expectations are unlikely to be met, the retarded individual may feel confused and rejected.

Parents may also extend the dependency period of their retarded children (Goodman, 1972). They may, for instance, keep the child at home rather than allow interaction with other youngsters. Without socialization experiences and some level of risk-taking, the retarded person will be ill-equipped to deal with the adult world. Not only will relationships on a mature level be difficult, the vulnerability to sexual exploitation will be increased. Ironically, by overprotecting, parents leave their children defenseless in the face of a threatening situation.

The effect of institutionalization on the sociosexaul development of retarded people is enormous, and—in most cases—damaging. For the convenience of staff and the efficiency of the organization, certain behaviors are reinforced and cultivated in residents. Rosen (1972) describes the "institutional personality" which develops in almost all individuals who are institutionalized over an extended period of time: "...tendencies toward acquiescent or overly compliant behavior, helplessness, inadequate self-concepts and the absence of assertive behavior, socially inappropriate behavior, and heterosexual inadequacies" (107). Retardation has little to do with the development of these characteristics. Considering the typical institutional environment, the sexual adjustment of the mentally retarded residents is probably as "normal" as that of nonretarded people in a similar environment.

In many institutions, privacy is a rare commodity. Residents typically live in dormitories, or at best, share rooms.

Public masturbation may result from a lack of privacy (Ginsberg, 1977). In some institutions masturbation under any circumstances is forbidden. Other facilities, however, may ignore masturbation, even if it is done in front of others (Rosen, 1972). Both reactions adversely affect healthy sociosexual development.

Staff members in institutions frequently complain about the homosexual activity of the residents. The high rate of homosexual behavior, however, is hardly surprising due to the fact that most institutions are segregated according to sex. Due to the changing times, some contact with the opposite sex is permitted. These interactions, however, are "...well chaperoned, closely structured and supervised" (Rosen, 1972, 102). Heterosexual acting out is severely punished (even to the point of expulsion), whereas homosexual behavior is often ignored because it occurs so frequently (Rosen, 1972; Kempton, Bass, & Gordon, 1978). Kempton and Forman (1976) observe that if a male is separated from females and is punished harshly for showing heterosexual interest, and if sexual advances to other boys are ignored by the staff, he will (logically) assume that homosexuality is more acceptable than heterosexuality. Hall (1975) adds that homosexuality will flourish where heterosexuality is forbidden. Although homosexuality may be a viable option for some individuals, it should not be a forced choice.

"The sexual drives of the retarded are often misdirected when there is a lack of companionship with the opposite sex and often from being institutionalized" (Kempton, Bass, & Gordon, 1978, 20). There is currently a trend to allow and even encourage activities in which both males and females participate. Some institutions have even integrated living quarters. Elwyn Institute in Pennsylvania assigns males and females to rooms on the same floor of its halfway house in order to approximate the living conditions in the community. In Scandinavia, where normalization is the rule, institutions often have a permissive and tolerant atmosphere in which couples are permitted to live together in small apartments (Wolfensberger, 1972). In 1970, 50 retarded delegates who attended a national conference of retarded young adults in Malmo, Sweden, formulated a policy statement which included this demand: "Even in institutions, we want to be able to go steady and live together with members of the opposite sex without having the personnel meddle in our private lives" (Nirje, 1972, 191). Some Americans find this approach shocking, yet many unmarried couples live together in the U.S. Why then shouldn't individuals who are institutionalized also have this option?

Many mentally retarded people—like their nondisabled peers—want to marry. Retarded individuals, however, face several obstacles which do not apply to most nonretarded people who choose to wed. Because many retarded persons have spent years in sheltered and/or institutionalized environments, the social skills needed to start and maintain a long term relationship may be lacking. The additional responsibilities inherent in marriage may cause psychological strain in an individual who is not used to dealing with such pressures. Without appropriate training and experience, the retarded person may act on impulse and lack understanding of another's feelings. Also, the severity of retardation may make a marriage relationship, on any level, improbable (Wolfensberger, 1972; Kempton & Forman, 1976; Kempton, et al., 1978).

Generally, however, the advantages of marriage far outweigh the negative aspects. "In most cases, marriage has proven to be a stabilizing influence and source of additional income" (Rosen, 1972, 106-107). Hall (1975) discusses the role that marriage serves in meeting needs for love, companionship, and affection. A marital relationship, she writes, helps to avoid "...one of the most devastating experiences of the usual life of the retarded--loneliness" (190). Other advantages of marriage include: freedom from family supervision, an outlet for sexual expression, a broadening of both lives with the addition of the spouses' families, and a sense of accomplishment and self-confidence (Kempton & Forman, 1976).

Nondisabled people often react negatively to the idea of retarded individuals marrying. Their disapproval frequently results from an inability to accept a marital relationship which may be markedly different from their own (Wolfensberger, 1972). It also may stem from any of the myths about retardation and sexuality which have already been discussed, e.g., retarded people are lifelong children.

The concern and controversy surrounding the topic of marriage and retardation is so great that standards are sometimes set to determine the "qualifications" of retarded people who wish to marry. Laws exist which prevent mentally retarded persons from marrying (Valente, 1975). Yet, as Wolfensberger (1972) points out:

> There are many nonretarded, physically healthy people who are sex driven, shallow, incompetent, unstable, and incapable of deep and perhaps even a sustained relationship; yet our political system accords them the constitutional right to enter a legal marriage. In our society, a citizen has the right to treat sex on the "itch-and-scratch" level, and to enter a legal marriage that does not rise above this level. Therefore, we should either apply more stringent criteria to *all* citizens, or cease applying them to the handicapped...if it *[marriage]* is an act available to citizens who are not impaired, it should also be available to those who are impaired. (172)

Probably the greatest reservation that nondisabled people have regarding marriage for retarded individuals revolves around the bearing and rearing of children. Several points need to be considered concerning parenthood and individuals with mental retardation.

(1) Although scientific findings show that most retardation is *not* hereditary, children of retarded parents are more likely to be retarded than those whose parents have normal intelligence (Hall, 1975). Environmental factors (e.g., lack of adequate social interaction) play a large part in this situation.

(2) The reproductive rate of retarded people does not exceed that of the general population (Rosen, 1972; Hall, 1975).

(3) Kempton, et al. (1978) recommends genetic counseling to determine if the disability is hereditary. Even if it is found to be genetically caused, however, a couple may still choose to have a child. With genetic counseling, however, they are both aware of the risks, possibilities, and probabilities.

(4) Hall (1975) indicates that training, supervision, and support (emotional and financial) are required to help many retarded people cope with the responsibilities of parenthood.

(5) With the development of effective contraception, marriage, sexual intercourse, and pregnancy are not as intertwined as in the past. The option of marriage without having children has been discussed in the literature (Rostafinski, 1972; Kempton, et al., 1978). Some retarded persons, for instance, may not have the capability to raise children; others may simply choose not to have children for the same reasons that nonretarded people remain childless.

(6) For those members of society who are still appalled by the idea of retarded people having children, Wolfensberger (1972) notes, "If unfitness for parenthood becomes a criterion, then it should be applied both to the retarded and nonretarded alike—and many bright, well-educated persons are unfit parents" (172).

Functional Capabilities and Limitations

The American Association of Mental Deficiency currently defines mental retardation as "...significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior, and manifested during the developmental period" (Hall, 1975). When considering sexuality, Hall observes, it is more important to look at "adaptive behavior" rather than at I.Q. An individual with a below average I.Q., but who has been raised in a normalized and supportive environment, will express sexuality far more appropriately than a person with normal intelligence who has spent his/her childhood and adolescence in an institution. Thus, although retardation itself may limit sociosexual functioning, external factors are usually far more significant.

There is agreement in the literature that, at least among those with mild to moderate retardation, sexual development and expression are generally similar to that of the "normal" population (Johnson, 1973; Hall, 1975). Those individuals who are severely retarded, however, are delayed in pubertal development (Alcorn, 1974; Hall, 1975). Wolfensberger (1972) and Alcorn (1974) state that sexual impulses and interest are less strong and less common among severely retarded persons.

Among profoundly retarded persons, impotence and sterility are more common than in the general population (Wolfensberger, 1972). Most people who are mentally retarded, however, have normal reproductive capabilities. Contraception, then, is an issue which must be realistically addressed. To prevent an unwanted pregnancy, there are several options available. Below is a brief discussion of these options:*

(1) *the pill* - Oral contraceptives are considered appropriate for mildly retarded women who are motivated, reliable, and capable of following directions over an extended period of time. Regular supervision is also a favorable condition for prescribing the pill (Hall, 1975; Kempton & Forman, 1976). Wood (1972), however, states that, unless a parent or an institution assumes responsibility, the pill is not a good choice because retarded women may forget to take it regularly. Opinions in the literature are widely varied concerning the use of the pill by retarded women.

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*The information provided relates specifically to mental retardation. General side effects are not necessarily included.

(2) *IUD* (intrauterine device) - Hall (1975) writes that the IUD is best suited for a sexually active woman who lacks motivation and supervision. Wood (1972) agrees that this method is perhaps the most satisfactory. He cautions, however, that some women may pull out the IUD. Kempton and Forman (1976) also state that the IUD is an effective contraceptive for many retarded women because little intelligence and motivation are necessary in its use. They note, however, that dislodgement of the device may not be recognized as such by some retarded women. They add that if a woman dislikes or is afraid to touch her own genitals, more frequent check-ups will be required to insure that the IUD is in place.

(3) *Depo-provera* - This contraceptive method is in the form of an injection which is administered approximately every three months. Highly effective, Depo-provera works similary to the pill by inhibiting ovulation. This form of contraception is suitable for women who lack motivation and reliable judgment, and who tend to act impulsively. Several serious side effects, however, make this method less than ideal. After stopping the injections, a woman may not get her period for up to 18 months. It may, in fact, cause sterility. In addition, Depo-provera has not yet been approved by the FDA (Wood, 1972; Kempton & Forman, 1976).

(4) *condom* - Gordon (1972b) states that if the technique for using the condom is described simply and clearly, some retarded boys and men will use it effectively. The condom, however, is generally considered too difficult for most retarded individuals to use (Hall, 1975).

(5) *diaphragm* - This method is rarely mentioned in the literature and is regarded as too complicated for use by retarded women.

(6) *foam* - This method is rarely mentioned in the literature.

(7) *sterilization* - This drastic and permanent contraceptive method is only recommended if an individual definitely does not want any more children (Wood, 1972). It should be available to men and women on a *strictly voluntary* basis. The problem with voluntary sterilization is that true informed consent is sometimes difficult to get. The retarded person is not always aware of the full consequences of the procedure. Also, he or she may be highly suggestible and easily influenced by authority figures. Parents are often too emotionally involved to be objective, and professionals may make a decision based on temporary adolescent behavior rather than on later maturity. For these reasons, Hall (1975) believes that, although sterilization should be available, other alternatives should be considered first. Kempton (1977) gives other reasons why sterilization is too drastic a step to take in most cases:

—With improved methods of teaching, it is impossible to tell what an individual's real potential is. A person who now seems incapable of responsible parenthood may, in the future, mature to a point where (s)he is able to handle the responsibilities involved.

—Many people who are labeled "mentally retarded" actually have emotional or physical disabilities instead (e.g., autism). Eventually, their conditions may be successfully treated, and they will then join the "normal" population.

—It is no longer necessary to sterilize people in order to avoid pregnancy. In the past, contraceptive methods required a certain level of intelligence, judgment, and control. The new methods, however, such as the IUD, Depo-provera, and even the pill can be used by a large number of retarded persons.

(8) *abortion* - Abortion is considered a last resort (Kempton & Forman, 1976). It is especially appropriate as a legal option in cases of sexual exploitation (Kempton, 1977).

PROGRAMS AND INTERVENTIONS

Several programs, developed to help retarded people achieve their sociosexual potential, are discussed in the literature. Those described below are only a few of the programs currently available to individuals with mental retardation.

(1) Ronald B. Nipon Association (1100 Oak Lane Avenue, Philadelphia, PA 19120) is a nonprofit organization serving a population of young retarded adults between the ages of 17 and 35. Most of the participants are referred by social agencies, schools, workshops, and word of mouth. The program offers evening and weekend activities and trips, as well as a social meeting place for retarded persons.

The Nipon Association also provides a day program for lower functioning adolescents and adults. Members are expected to travel independently on public transportation; plan their own activities with some staff supervision; prepare their own lunches; participate in community activities; and learn skills such as cooking, shopping, budgeting, writing, etc. Parental support is encouraged because it reinforces new learning and self-reliance (Segal, 1972; Kempton & Forman, 1976).

"The program...assists its members in becoming a part of the normal social environment of the community and utilizing vocational training for eventual employment and independent living" (Kempton & Forman, 1976, 103). Segal (1972) states that many of the members have expressed the fact that socialization opportunities and experience were most meaningful in preparation for eventual employment.

(2) Elwyn Institute, also located in Pennsylvania, is a facility with 1100 residential and 400 day students. Their program is designed to help retarded individuals counteract the "institutional personality" and learn how to adapt to community living. A program entitled "Personal Adjustment Training" (PAT) consists of five separate units to be covered in 12 to 15 sessions of group therapy:

—Self-evaluation, identity, and self-concept

—Acquiescence and exploitation

—Assertiveness training

—Heterosexual training

—Independence-leadership training (e.g., problem solving, decision making).

The underlying emphasis is that each group member is an independent person with individual preferences and aversions. The techniques used in this program include group counseling, videotape self-confrontation, and behavior modification. An increasing number of coeducational activities is also part of the program, and relationship issues are regarded as very important.

The development of a sex education training program at this facility has been gradual, and Elwyn has avoided controversy, e.g., by not promoting birth control methods. Referrals, however, are made to Planned Parenthood for those individuals who are leaving the facility (Rosen, 1972; 1973).

(3) Examples of programs within the Scandinavian system are described in the literature by Wolfensberger (1972). Because sexual relationships between unmarried consenting adults is culturally normative, the national mental retardation service system accepts and supports this occurrence in the retarded population. In one hostel for mildly and moderately retarded young adult women in Copenhagen, for example, residents learn about dating and how to relate to male peers. If contraception is needed, the housemother sees to it that counseling is provided and a choice of contraceptives is given. If a woman decides to live with a man, a small apartment may be provided. Unlike the U.S., marriage or living together does not adversely affect services.

Other housing options are available depending on needs, preferences, and capabilities. Two examples are: an apartment house for retarded residents with houseparents living in the same building; one or more retarded couples in an apartment building for the general public with staff dropping in every few days to provide minimal supervision.

CONCLUSIONS AND RECOMMENDATIONS

Sex Education

1. Sex education should focus on expanding the mentally retarded person's sexual alternatives and on teaching appropriate behavior. Sex education should not be approached as a way to inhibit sexual behavior.

2. Sex education should be part of the regular school curriculum. This applies to residential as well as public schools.

3. Extensive and specific social skills training should be provided to enable retarded individuals to develop and maintain satisfying relationships with others.

4. Retarded children and adolescents should be taught how to express love and affection appropriately. They should not, for example, be allowed to show affection indiscriminately to strangers.

5. Retarded youngsters should be given information about sexuality *before* puberty.

6. Retarded adolescents and adults should be made aware of the responsibilities, as well as the rights, that go along with sexual expression.

7. A childless marriage should be presented as a viable option for individuals who are either unable or unwilling to have children, but who desire a long term relationship. Having a family should not be equated with adulthood.

8. The pleasurable aspects of sexual expression should be presented in sex education programs. Many retarded young people equate sexuality with marriage and procreation; they often, however, are unaware of the other elements of sexuality.

9. Accurate information about contraception should be provided to retarded adolescents and adults.

10. Facts and instructions should be specific and concrete. Once an individual understands a simple concept, a more complex one may be introduced. A person should be given as much information as (s)he can comprehend.

11. The correct terms for body parts and sexual functioning should be taught and explained to the retarded person. In order to aid communication, however, the vocabulary of the peer group, e.g., slang words, should also be used.

12. Behavioral techniques have been used successfully in teaching retarded individuals about sexuality. Role playing, for example, is useful for learning specific behaviors. Acting out situations is usually far more effective than verbal methods.

13. Audio-visual and tactile aids should be used as often as possible when providing sex education. These aids can be handmade and simple. For a listing of A-V and tactile materials currently available, refer to Appendix G.

14. Parents of retarded children and adolescents should be included in planning and assessing sex education programs whenever possible. In this way, misgivings will be more easily dispelled, and the parents can reinforce at home behavior learned in school.

15. The majority of parents want effective sex education for their retarded children. Program developers and teachers should not be intimidated into inaction by the opinions of the dissenting minority.

16. Family values and standards should be respected when providing sex education to retarded children and adolescents.

Socialization and Sexual Behavior

17. The society in general needs to be educated about retardation and sexuality. Because of misconceptions about the disability, many people still exhibit negative attitudes toward retarded individuals.

18. Nonretarded people need to tolerate and accept relationships which may vary greatly from those they picture for themselves.

19. Marriage is culturally normative in our society. Normalization, then, includes the right for mentally retarded persons to marry if they choose.

20. Having children is the choice of a couple. No stricter standards should apply to retarded people who wish to have children than apply to nonretarded people.

21. Sterilization should only be performed with true informed consent, and if other, less drastic, methods of contraception are not appropriate.

22. Depo-provera injections are not usually recommended as a contraceptive method for the "normal" population because of the risk of sterility. Careful consideration should be given to the ethical implications of giving Depo-provera to retarded people.

23. Financial support should be available to help retarded individuals and couples live as independently as possible in the community. It should be remembered that the cost of institutionalizing a person is far greater than the cost of maintaining him/her in the community.

24. Having a community advocate to aid a retarded individual or couple is an excellent practice. These advocates can be especially instrumental in helping a person make the transition from institutional to community living.

25. Masturbation in private should be treated as a normal sexual behavior.

Parents and Professionals

26. Professionals and parents need to examine their own attitudes toward both sexuality and mental retardation.

27. Greater communication and cooperation is needed between parents and teachers.

28. Professionals in close contact with retarded people and their families should initiate the topic of sexuality as early as possible.

29. In-service training about sex-related matters (including attitudes) should be provided for houseparents, teachers,

(De)Institutionalization

30. Institutions should be training and education centers, not simply custodial facilities.

31. More education and counseling about psychosocial issues should be available *before* a retarded person is discharged from an institution.

32. Mentally retarded people living in institutions should have privacy. In facilities where residents live in dormitories, partitions (at least) should be put up so that a person can be alone.

33. Retarded adults living in institutions should be treated like adults, not as though they were children.

34. Staff members in an institution should handle matters such as masturbation, homosexual behavior, and heterosexual acting out rationally and consistently. If each staff member handles a situation differently, the retarded individual will probably become confused and unsure of what is appropriate.

35. As deinstitutionalization occurs, a residential service system should provide small, dispersed residences within the community. This system should include a variety of facilities to meet the individual needs of retarded people.

Research

36. Follow-up is needed to determine the long range effects of deinstitutionalization on retarded people and the community.

37. The relationship between vocational success and psychosexual behavior needs to be documented.

38. More evaluation is needed concerning the effects of sex education programs/intervention methods on the attitudes and behavior of mentally retarded persons.

39. More information is needed concerning *sex counseling* (e.g., marital counseling) with retarded clients.

40. Research needs to be done to determine which contraceptive methods are best suited for which part of the retarded population.

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APPENDIX C

Service Programs

Service Programs

Below is a partial list of programs which provide sexuality-related services to people with disabilities. The program descriptions were gathered from journal articles, brochures, books, telephone interviews, and site visits. The staff of the Sex & Disability Project does not necessarily endorse these programs. Rather, we are presenting the information we have gathered and hope it will prove useful to our readers. Please note that some of the programs are within residential facilities (hospitals, residential schools), while others are offered as community services.

- Bartimeus
  Institute for the Blind
  Zeist, The Netherlands
  Contact people: Dr. van 'T Hooft, Consulting psychiatrist
  Dr. Heslinga, Deputy-principal

This program emphasizes sexual awareness within a residential school setting and deals with both the psychosocial and physiological aspects of human sexuality. Efforts are made to provide an atmosphere as close to a family situation as possible. Co-education is stressed in activities of daily living training. Social interaction with the opposite sex is encouraged. (For further information, also see: van 'T Hooft, F. & Heslinga, K. Sex education of blind-born children. *Sex education for the visually handicapped in schools and agencies.* New York: American Foundation for the Blind, Inc., 1975, 1-7.)

- California School for the Blind
  Berkeley, California
  Contact person: Jan Neff

The program is set up according to developmental levels, and is designed for students ranging from 5 to 21 years of age. Although designed primarily for visually-impaired students, the needs of multiply-handicapped people are also considered. (For further information, also see: Neff, J. Behavior objectives and learning activities in sex education for the visually handicapped. *Sex education for the visually handicapped in schools and agencies.* New York: American Foundation for the Blind, Inc., 1975, 50-76.)

- Centre for Sexual Counseling, Therapy and Education
  Department of Obstetrics and Gynecology
  Rambam Medical Centre
  Haifa, Israel
  Contact person: Dr. Zwi Hoch

In this program, couples are treated in which one partner is disabled because of trauma, surgery, or neurological problems. The first session is a conjoint one with special emphasis on observing verbal and nonverbal communication. Individual sessions follow. Then, the couple is brought back together. "Sensate focus" techniques are used. (For further information, also see: Hoch, Z. Sex therapy and marital counseling for the disabled. *Archives of Physical Medicine and Rehabilitation*, 1977, *58*, 413-415.

- Clarke School for the Deaf
  Northampton, Massachusetts
  Contact person: Anne S. Miller, Guidance counselor

An 18 year old program of sex education, social, and personal hygiene. The program covers such basic areas as how to manage sexual urges between adolescence and marriage, sex roles, reproduction, venereal disease, and drug addiction. Boys' and girls' classes are segregated.

- Craig Hospital
  Rocky Mountain Regional Spinal Injury Center
  3425 South Clarkson
  Englewood, Colorado 80110
  (303) 761-3040
  Contact person: Dr. Scott Manley, Family and Patient Service Dept.

  This hospital-based program offers sexuality-related individual, group, and couples counseling to patients with cord or brain injury. SAR's are conducted regularly for patients, family members, and staff. Nearby family living units are available for patients and their families to aid in the transition from hospital to home.

- Dept. of Rehabilitation Medicine
  University of Washington Medical School
  Seattle, Washington 98195
  Contact person: Dr. Jo Ann Brockway

  The objectives of this four-week program for people with spinal cord injury are: (1) to introduce the topic of sexuality so that SCI patients regard it as a legitimate concern, (2) to provide information about sexuality and reproduction, and the effects of cord injury, and (3) to encourage an open minded attitude toward sexuality and sexual options. Two SCI "alumni" (one female, one male) participate in the program. (For futher information, also see: Brockway, J.A., Steger, J.C., Berni, R., Ost, V.V., Williamson-Kirkland, T.E., & Peck, C.L. Effectiveness of a sex education and counseling program for spinal cord injured patients. *Sexuality and Disability*, 1978, *1*(2), 127-136.)

- Illinois Braille and Sight Saving School
  Jacksonville, Illinois 62650
  Contact person: Ruth V. Holmes

  Formal co-educational sexuality training is provided for students from elementary through high school age. Parents and staff members are involved in this residential program. Group discussions are encouraged, and student evaluations are instrumental in making program modifications. (For further information, also see: Holmes, R.V. The planning and implementation of a sex education program for visually handicapped children in a residential setting. *Sex education for the visually handicapped in schools and agencies*. New York: American Foundation for the Blind, Inc., 1975, 43-49.)

- Institute of Rehabilitation Medicine
  Spinal Cord Injury Center
  400 East 34th Street
  New York, New York 10016
  (212) 679-3200
  Contact person: Dr. Joan Bardach, Director of Psychology Dept.

  Sexuality services for patients include: weekly classes about general functioning including sexual anatomy and physiology, discussion sessions, groups focusing specifically on sexuality concerns, and sex counseling.

- Kendall Model Secondary School
  Gallaudet College
  Washington, D.C. 20002
  Contact person: Max Fitz-Gerald

  Gallaudet provides sex education and counseling to secondary and college students as part of their services for hearing-impaired students. Referrals to other service programs for hearing-impaired people are available.

- Moss Rehabilitation Hospital
  12th & Tabor Rd.
  Philadelphia, Pennsylvania 19141
  (215) 329-5715
  Contact person: Dr. Dorothea Glass, Medical Director

  Group sessions to discuss coping problems with cord injured patients are held weekly. Sexuality-related counseling is available on an individual basis to patients and their partners/spouses. A sex therapist is available in case of serious difficulties. A cord injured patient advocate meets with each SCI patient individually to discuss specific concerns. Privacy rooms are available to patients and their visitors for a variety of reasons, including sexual activities. A SAR is available near the time of discharge. Sexuality-related programs for patients with other disabilities (e.g., arthritis) are also offered at Moss.

- Rancho Los Amigos Hospital
  Spinal Injury Service
  7601 East Imperial Highway
  Downey, California 90242
  (213) 922-7605
  Contact person: Dr. A. Estin Comarr

  Monthly lectures are held followed by "Coffee and Sex" group discussions. Family members are included in sessions comprised of the patient, physician, and psychologist/social worker.

- The Rehabilitation Institute of Chicago
  345 East Superior Street
  Chicago, Illinois 60611
  (312) 649-6179
  Contact person: Dr. Don Olson

  Educational sessions are conducted using a combination of lecture and discussion. A team is available including a social worker who deals with special problems.

- Rocky Mountain Planned Parenthood
  Center for Continuing Education
  2030 East 20th Avenue
  Denver, Colorado 80205
  Contact person: Roger Mellott

  Client services include workshops open to the public for disabled people, especially those with mental retardation. Individuals with cerebral palsy, hearing impairment, and cord injury are also participants. This Planned Parenthood also works with other agencies primarily in the Denver area, and tailors services for individual organizations. Services also include needs assessment, group sessions, and sex education for parents and staff.

- Santa Clara Valley Medical Center
  751 South Bascom
  Santa Clara, California 95128
  (408) 279-5116
  Contact Person: Dr. Dan Mayclin, Clinical psychologist and Co-Director, SAR program

  Sexuality concerns are discussed as part of individual and couples counseling. An educational group meets to discuss physiological information and emotional issues, including sexuality. A group for "significant others" is available, and a SAR is conducted a few times a year for interested outpatients and staff.

- The Sex and Disability Unit
  814 Mission Street-Second Floor
  San Francisco, California 94103
  (415) 666-1066
  Contact person: Mary M. Rodocker, R.N., M.S.

  As part of the Human Sexuality Program at the University of California, the Sex and Disability Unit provides sociosexual counseling services for disabled people, their partners, and family members. Education and counseling focus on: dispelling myths and misconceptions about the sexual functioning of disabled people, and helping individuals develop more satisfying and intimate relationships. An important component of this program is its referral service.

- Sex Education and Family Life Program
  Perkins School for the Blind
  Watertown, Massachusetts 02172

  The sexuality-related curriculum in this residential school is based on both chronological and developmental age, with the goal of meeting the individual needs of students. This program is designed for visually-impaired children and adolescents, including those with learning disabilities. (For further information, also see: Enis, C.A., & Cataruzolo, M. Sex education in the residential school for the blind. *Education of the Visually Handicapped*, 1972, *4*(2), 61-64.)

- Spastics Society
  Family Services & Assessment Centre
  16 Fitzroy Square
  London W1P 5HQ
  England

  Since 1969, the Spastics Society has conducted periodic short-term residential courses for disabled couples who are considering marriage. The couples have the opportunity to discuss with each other, with the group, and with trained professionals, areas of concern related to marriage. Recently, married disabled couples have been invited to some of the sessions as peer counselors. Topics generally include accommodations, finances, and day-to-day tasks, as well as mutual understanding, sexual expression, parenting, and contraception. Couples participate in such domestic tasks as shopping, cooking, and housekeeping; and a visit is made to an adapted flat so that couples may try out various types of specialized equipment. (For further information, see: Morgan, M. Follow-up of cerebral palsied married and engaged couples who attended short residential group discussion courses between April 1969 and April 1972. Paper presented at the International Cerebral Palsy Society's International Symposium, "Family and Society," May 16-19, 1972, Paris, France. Also see: Morgan, M. Marriage and handicapped people--Six years on. *Marriage Guidance*, 1975, *15*(9).)

- Special Education
  Grand Rapids Public Schools
  1753 Rosewood, S.E.
  Grand Rapids, Michigan
  Contact person: Lee Ann Lipke

  This sex education program was developed for visually-impaired youths and aimed toward helping the child or adolescent (1) understand the physical and emotional changes that occur during puberty, and (2) develop appropriate social skills. Emphasis is on individual assessment and decisions concerning the appropriateness of modes of sexual expression. This program is conducted in a non-residential setting. (For further information, also see: Karpen, M.L., & Lipke, L.A. Sex education as part of an agency's four-week summer workshop for visually impaired young people. *Sex education for the visually handicapped in schools and agencies*. New York: American Foundation for the Blind, Inc., 1975, 35-42.)

- Spinal Cord Injury Service
  Veterans Administration Hospital
  130 West Kingsbridge Road
  Bronx, New York 10468
  (212) 584-9000 (ext. 591)
  Contact person: Anne Berkman, M.A.

  Sexuality-related services are provided primarily by a sex counselor (Anne Berkman). These services include: individual counseling, a three-session group program, and couples counseling, if appropriate. (For further information, also see: Berkman, A.H., Weissman, R., & Frielich, M.H. Sexual adjustment of spinal cord injured veterans living in the community. *Archives of Physical Medicine and Rehabilitation*, 1978, *59*, 29-33.)

- Spinal Cord Injury Service
  Veterans Administration Hospital
  10701 East Boulevard
  Cleveland, Ohio 44106
  (216) 791-3800
  Contact person: Dr. M.G. Eisenberg

  Patients are invited to attend a series of eight weekly sessions which are a combination of didactic presentations and group discussions about the various aspects of sexuality and spinal cord injury. Individual sex counseling, couples counseling, and individual counseling for partners are available. (For further information, also see: Eisenberg, M.G., & Rustad, L.C. Sex education and counseling program on spinal cord injury service. *Archives of Physical Medicine and Rehabilitation*, 1976, *58*, 135-140.)

- Spinal Cord Injury Center
  Veterans Administration Hospital
  1400 V.F.W. Parkway
  West Roxbury, Massachusetts 02132
  (617) 323-7700 (ext. 210)
  Contact person: Kris Sherman, Occupational therapist

  A new sexuality program has been developed by three members of the rehabilitation medicine department, and includes four sessions over a two-week period for patients and their partners. Physiological information and psychological concerns are discussed. Input from SCI men with post-injury sexual experience is included.

- The Texas Institute for Rehabilitation & Research (TIRR)
  P. O. Box 20095
  Houston, Texas 77025
  (713) 797-1440
  Contact person: Joyce T. Salhoot, M.S.W.

  Weekly group "Sex and Coffee" sessions are held for patients and their partners. Individual and couples counseling are available, as well as a "maximum independence building" for patients near discharge and their families. Although many of the participants are cord injured, other disabled people are also involved, e.g., persons with visual impairment, stroke, cerebral palsy, multiple sclerosis, and muscular dystrophy. (For further information, see also: Halstead, L.S., Halstead, M.M., Salhoot, J.T., Stock, D.D., & Sparks, R.W. A hospital-based program in human sexuality. *Archives of Physical Medicine and Rehabilitation*, 1977, *58*, 409-412.)

- United Cerebral Palsy Association of Greater Hartford
  80 Whitney Street
  Hartford, Connecticut 06105
  (203) 236-6201
  Contact person: Susan M. Fleischmann, A.C.S.W.

This organization has conducted two courses about sexuality, one for adolescents and one for adults. Participants were individuals with mild to moderate cerebral palsy with limited sexual experience. The adult course ran 11 weeks, and was facilitated by both a male and a female. Topics discussed ranged from human anatomy to alternative sexual life styles.

APPENDIX D

Training Programs

Training Programs

The following is a list of *examples* of training programs that have been conducted on sexuality and disability. In addition, most service programs include in-service training for staff which you may be able to attend. See Appendix C for information on service programs.

Title: **Alberta Institute of Human Sexuality, Inc. (AIHS)**

Purpose: To promote the development of new programs, with special emphasis on sexuality in its relation to disability.

Format:
1) Sexual Attitude Reassessment seminars
2) didactic presentations to interested groups
3) provision of consulting services

Target participants: Medical and helping professionals

Length: Varies with format used

Sponsored by: AIHS
10420 - 54 Avenue
Edmonton, Alberta, Canada
T6H 0T5

Contact: Secretary-Treasurer, AIHS

Fees: Negotiable, based on expenses plus a professional fee, depending on type of program requested.

When given: Continuous. Staff available to take part in lectures, workshops or seminars throughout Canada.

Title: **Course on Sexuality and the Developmentally Disabled**

Purpose: To enhance basic knowledge of sexuality; to present resources, participant self-evaluation of attitudes and feelings about sexuality; to prepare participants for promoting and planning sex education programs.

Format: Films, tapes, discussion, lectures, role-play

Target participants: Course participants selected on interest, distribution among different counties or community groups, and ability to further programs directly or with other professionals.

Length: 8 days (sessions weekly)

Sponsored by: Southern Adirondack Planned Parenthood
135 Warren St.
Glens Falls, NY 12801

Contact: Joanne Gavin

Fees: $25

When given: On-going

Title: **Experimental Training Project in Sex and Disability**

Purpose: To train educators and counselors to help physically disabled persons achieve more satisfactory sexual functioning and personal relationships. Trainees receive preparation for dealing with disabled persons, family members of disabled people, and health care delivery personnel in the area of sexuality and disability.

Target participants: Sex and disability educators/counselors

Sponsored by: School of Medicine
University of California, San Francisco

Contact: Douglas Wallace
Ambulatory and Community Medicine
School of Medicine
University of California, San Francisco
San Francisco, CA

When given: July 1976-July, 1979

Title: **Family Life Education for Teachers and Parents of Students with Physical Disabilities**

Purpose: To increase the following: sex knowledge, comfort in discussing sexuality, knowledge of sexuality and disability, clarity of one's values regarding sexuality, awareness of social resources available to disabled persons, experience in designing curricula.

Format: Day 1: Didactic presentations, discussion, explicit films.
Day 2-4: Development of curricula, small groups.

Target participants: Special education teachers

Length: 4 days

Sponsored by: University of California, San Francisco
Department of Psychiatry
Human Sexuality Program
814 Mission Street - Second Floor
San Francisco, CA 94103

Contact: Carla Thornton, R.N., M.S.

Fees: Professionals not teaching - $100
Teachers - receive stipends for tuition and partial travel.

When given: March 19-22, 1978

Title: **Human Sexuality Education: Issues in the Workshop Setting**

Purpose: To explore strategies for developing a human sexuality course in a rehabilitation facility and resolve problems associated with such a program.

Format: Didactic, discussion, etc.

Target participants: Rehabilitation facility staff and others who work with disabled people

Length: 3½ hours

Sponsored by: National Rehabilitation Association

Contact: Chris Diprizio, Ph.D.
Rehabilitation Counseling Program
Illinois Institute of Technology
Chicago, IL 60616
(312) 567-3500

Fees: $5

When given: September 24, 1978

Title: **Human Sexuality for Teachers of the Hearing Impaired**

Purpose: To provide training and education in human sexuality of hearing-impaired children. Two graduate credit hours given.

Format: Ten workshops including didactic presentations, group discussions, films, and field trips.

Length: 30 hours (10 three hour sessions)

Sponsored by: Gallaudet College, Washington, DC

Contact: James C. Achtzehn
Dept. of Education
Gallaudet College
Florida Avenue and 7th Street, N.E.
Washington, DC 20002
(202) 447-0345

When given: July 10-August 4, 1978

Title: **Human Sexuality: The Handicapped, The Aging. A Search for Perspective**

Purpose: To raise awareness of participant attitudes toward own sexuality and sexuality of others; to explore sexual attitudes of disabled persons; to dispel myths and misconceptions about sex education; to increase understanding, knowledge, security, and skills for working with those with special needs; to share resource materials.

Format: Didactic presentations

Target participants: Professionals and paraprofessionals in health care, ministers, teachers, counselors, home economists, social workers, family life specialists, special education personnel, therapists, psychologists, rehabilitation personnel, physicians, disabled people, families of disabled people.

Length: 2 days

Sponsored by: On Your Own
Continuing Education in Home Economics
Division of Continuing Education
University of Alabama
P.O. Box 2967
University, AL 35486

Contact: Dr. Joseph S. Rowland

Fees: $35

When given: January 30-31, 1978

Title: **Human Sexuality: Personal Freedom vs. Institutional Necessity**

Purpose: To provide a public forum for discussion about how institutions deal with sexual needs and rights of people under their care.

Format: Keynote address, 6 workshops, panel discussions, 5 films, media resources presentations.

Target participants: Professionals

Length: Two days

Sponsored by: Drake University, Iowa Humanities Board

Contact: T. Nicholas Tormey, Conference Director
Suite 210, West Bank Bldg.
1601 22nd Street West
Des Moines, IA 50265
(515) 225-0932

When given: April 7-8, 1978

Title: **Sex and Disability Training Project**

Purpose: To develop a training packet containing course outlines, printed reports of trainee study groups on sexuality and specific disabilities, and project-related publications. To train persons having significant contact with disabled people as socio-sexual educator-counselors for disabled persons, their spouses, intimates, families, health care providers, and rehabilitation agencies.

Format: Both didactic and supervised practicum experience in counseling and education relating to sexuality and disability.

Target participants: Persons having significant contact with disabled people.

Length: One year (20 hours per week)

Sponsored by: University of California, San Francisco
Dept. of Psychiatry
Human Sexuality Program
Sex & Disability Unit
814 Mission St., Second Floor
San Francisco, CA 94103

Contact: Sue Knight

When given: On-going

Misc.: Stipends available

Title: **Sex Education for Persons with Communication Impairments**

Purpose: To enable participants to provide training in sex education to professionals who work with hearing-impaired or mentally disabled individuals.

Format: Didactic presentations, sexual attitudes reassessment (SAR), practice/feedback sessions, group discussion.

Target participants: Trainers, educators, and counselors

Length: Three days

Fee: $60.00

Sponsored by: Institute for Family Planning
Planned Parenthood of Southeastern Pennsylvania
1220 Sansom Street
Philadelphia, PA 19107
(215) 629-2835

Contacts: Winifred Kempton, Della Fitz-Gerald, Max Fitz-Gerald

When given: June 1-3, 1978

Title: **Sexual Attitude Reassessment (SAR)**

Purpose: To increase understanding of human sexuality; to increase comfort and knowledge about own sexuality; to increase sensitivity to sexual problems and needs of the physically disabled.

Format: Large group presentations, sexually explicit slides, movies, tapes, small group discussions.

Target participants: Health care professionals and students; disabled people, their partners, and parents.

Length: Two days

Sponsored by: Sunnyview Hospital and Rehabilitation Center
1270 Belmont Ave.
Schenectady, NY 12308

Contact: Robert J. Bylancik

Fees: $35 (includes meals); $20 - full-time students.

When given: February 17 & 18, 1978; On-going.

Title: **Sexual Attitude Reassessment (SAR)**

Purpose: To raise awareness of participants' attitudes and feelings about their own sexuality and the sexuality of others, with special emphasis on physically disabled persons. To provide an opportunity for participants to practice communication skills.

Format: Developmental. Intensive use of explicit audio-visuals depicting sexual activities. Small group discussion to discuss and integrate feelings and attitudes participants are experiencing.

Target participants: Physicians, nurses, therapists, counselors, clergy, disabled persons. Participants urged to come with spouse, close friend, or colleague.

Length: Three days

Sponsored by: University of Alberta
Faculty of Extension
Room 234, Corbett Hall
82 Avenue and 112 Street
Edmonton, Alberta
T6G 2G4

Contact: Mrs. Benita Fifield
President AIHS
10420 - 54 Avenue
Edmonton, Alberta, Canada
T6H 0T5

Fees: $95 - single; $175 for two.

When given: March 2-4, 1978

Title: **Sexual Counseling of Adults with Disease or Disability**

Purpose: To provide the information and skills necessary to handle sexual problems of disabled adults. To help participants become more comfortable with their own sexuality.

Format: SAR, didactic presentations, and demonstrations

Target participants: Health professionals

Length: 3 days

Sponsored by: Emory University
Center for Rehabilitation Medicine
1441 Clifton Rd., N.E.
Atlanta, GA 30322

Contact: Lawrence D. Baker, M.D.

Fees: $150 for physicians
$110 for other health professionals

When given: Scheduled March 1-3, 1978
Rescheduled for March, 1979

Title: **Sexuality and Physical Disability (SPD)**

Purpose: To increase counselor knowledge, skill, and comfort regarding problems related to the sexuality of physically disabled clients.

Format: Audio-visuals, didactic presentations, structured practice sessions

Target participants: Counselors and supervisors providing rehabilitation services to clients with physical disabilites.

Length: 2 days

Sponsored by: Program in Human Sexuality
School of Medicine
University of Minnesota
Minneapolis, MN

Contact: Gary A. Hines

Fees: $15 materials fee

When given: On-going on request

Title: **Sexuality and the Disabled**

Purpose: To help participants examine their feelings and attitudes on various points of view regarding conventional sexual issues. To offer professional guidance in developing counseling skills. To provide information regarding sexuality and disability.

Format: Speakers, panels, slides, group discussions, workshops, Sexual Attitude Reassessment seminar (SAR).

Target participants: Medical and other helping professionals

Length: SAR - one day
Workshops - one day

Sponsored by: University of Delaware
Division of Continuing Education
Wilmington, DE

Contact: Edith H. Anderson
College of Nursing
University of Delaware

Fees: $55

When given: October 27-28, 1977

Title: **Sexuality and the Disabled: Dealing with the Special Problems of the Physically and Mentally Disabled**

Purpose: To provide information on sexuality and disability. To train professionals to deal with client concerns regarding sexuality. To assist in the development of human sexuality programs in facilities providing services to disabled people.

Format: Didactic presentations, sexual attitude reassessment (SAR), practice/feedback sessions, problem solving in small groups.

Target participants: Physicians, rehabilitation counselors and therapists, mental health professionals, social agency personnel and administrators, education and training directors.

Length: Two days

Sponsored by: The Institute of Pennsylvania Hospital
Physician Education Project
P. O. Box 388
Philadelphia, PA 19105
(215) 829-2772

Contact: Winifred Kempton (seminar leader)

Fees: $200 tuition, plus $35 registration fee

When given:

Feb. 22-23, 1979	Phoenix
Mar. 19-20, 1979	Memphis
May 17-18, 1979	Boston
June 7-8, 1979	Chicago
Aug. 13-14, 1979	Toronto

Title: **Sexuality and the Psychiatrically Handicapped**

Purpose: Improve comfort and attitudes about sexuality, increase understanding of sexual needs of mentally ill people.

Format: Workshop

Target participants: Mental health professionals

Length: Three days

Fee: $50.00

Sponsored by: Institute for Family Planning
Planned Parenthood of Southeastern Pennsylvania
1220 Sansom Street
Philadelphia, PA 19107
(215) 629-2835

Contacts: Winifred Kempton, Mona Wasow

When given: April 27-29, 1978

Title: **Sexuality: Mental Retardation and Other Disabilities**

Purpose: Improve skills for professionals dealing with the sexual behaviors, decisions, and/or problems of disabled persons.

Format: Lecture and small group, audio-visuals, guest speakers and/or panels. Provision of handouts on research, workshops, audio-visuals, and bibliographies.

Target participants: Helping professionals

Length: 1 or 2 days

Sponsored by: Rocky Mountain Planned Parenthood
Center for Continuing Education
2030 East 20th Ave.
Denver, CO 80205

Contact: Roger Mellott, RMPP Training Consultant

Fees: $150 per day plus travel and boarding expenses

When given: Upon request, whenever possible.

Title: **Social Sexual Development of People Who Are Mentally Retarded**

Purpose: To identify people involved in social sexual curriculum development. To identify multi-media resources applicable to teaching human sexuality to severely and trainable mentally impaired students. To share new materials being developed. To assist people in seeking answers to questions about parents, staff, and student programming.

Format: Small group discussion, talk groups, multi-media resource display and film theatre, participant presentations.

Target participants: Teachers, professionals in the area of mental retardation, counselors

Length: One day

Sponsored by: Michigan Association for Retarded Citizens
Kent County Association for Retarded Citizens

Contact: Instructional Office
Grand Rapids Public Schools
143 Bostwick, N.E.
Grand Rapids, MI 49502
* Report available for $2.00

When given: April 22, 1977

The following organizations have also given training sessions on sexuality and/or disability. Write to them for details on their curricula.

Edwin K. Hammer
South Central Regional Center for Services to Deaf-Blind
Children in Arkansas, Iowa, Louisiana, Missouri & Oklahoma
c/o University of Texas at Dallas
Callier Center for Communication Disorders
Aram M. Glorig, M.D., Director
1966 Inglewood Road
Dallas, TX 75235

Craig Rehabilitation Hospital
3525 South Clarkson
Englewood, CO 80110

Walt Wilson
Spinal Cord Injury Project
Woodrow Wilson Rehabilitation Center
Fishersville, VA 22939

Cheryl LaPointe
North Carolina AASECT
Highland Hospital
Div. of Duke University Medical Center
Asheville, NC 28801

Bill Rockwood
Box J-233
J.H. Miller Health Center
Gainesville, FL 32610

American Association of Sex Educators, Counselors & Therapists
5010 Wisconsin Avenue, N.W.
Suite 304
Washington, DC 20016

Institute for Sex Research - Summer Program
416 Morrison Hall
Indiana University
Bloomington, IN 47401

Joan L. Bardach
Rehabilitation Medicine
School of Medicine, Post Graduate Medical School
New York University
New York, NY

American Personnel & Guidance Association
P. O. Box 3186
Washington, DC 20010

Eastern Association for Sex Therapy
c/o Lawrence Sharpe, M.D.
145 East 35th Street
New York, NY 10016

Dr. Stephen L. Sloan
New York University
Dept. of Health Education
South Bldg., Fifth Floor
Washington Square
New York, NY 10003

APPENDIX E

Consultants and Organizations

Consultants and Organizations

Below you will find some names and addresses of people and organizations dealing with sexuality and disability. Some names which have been previously mentioned in the handbook have not been duplicated here. In addition to the names listed below, you can contact service and training programs, and authors of books and articles cited in reference sections.

Some of the names listed below specialize in a particular field in sexuality and disability. The specializations are noted, either in the address or in parentheses at the end of the citation.

It is hoped that the people and groups listed here will be good sources of information and/or referral regarding your questions about sexuality and disability.

Virginia Aldape, Counselor
Rehabilitation Service
Southwest State University
Marshall, MN 56258
(507) 537-6296

American Association for Health,
Physical Education & Recreation
National Education Association
1201 16th St., N.W.
Washington, DC 20036

American Association of Marriage
and Family Counselors
225 Yale Avenue
Claremont, CA 91711

American Association of Sex Educators
and Sex Counselors (AASEC)
815 15th St., N.W.
Washington, DC 20005

American Association of Sex Educators,
Counselors & Therapists (AASECT)
5010 Wisconsin Ave., N.W., Suite 304
Washington, DC 20016

American Institute of Family Relations
5287 Sunset Blvd.
Los Angeles, CA 90027

American Association on Mental Deficiency
5201 Connecticut Ave., N.W.
Washington, DC 20015

Association for Voluntary
Sterilization
708 Third Ave.
New York, NY 10017

Joan Bardach
Institute of Rehab Medicine
400 East 34th Street
New York, NY 10016

Anne Berkman
Spinal Cord Injury Service
Veterans Administration Hospital
130 West Kingsbridge Road
Bronx, NY 10468
(212) 584-9000 (Ext. 591)

Rosie Bishop
Indiana University
School of Medicine
1100 West Michigan Street
Indianapolis, IN
(317) 264-7338
(spinal cord injury)

Mary Brassells, R.N.
Moss Rehabilitation Hospital
12th and Tabor Road
Philadelphia, PA 19141
(arthritis)

Joanne Brockway, Ph.D.
Dept. of Rehab Medicine RJ-30
University of Washington
School of Medicine
Seattle, WA 98195

Robert J. Bylancik, C.S.W.
Director, Dept. of Social Work
Sunnyview Hospital and
Rehabilitation Center
1270 Belmont Avenue
Schenectady, NY 12308
(518) 382-4500

Barbara Capell
Program in Human Sexuality
University of Minnesota
School of Medicine
2630 University Ave., S.E.
Minneapolis, MN 55414

Joseph Capell, M.D.
Dept. of Rehabilitation Medicine
6500 Excelsior Blvd.
St. Louis Park, MN 55426

Child Study Association of America
9 East 89th Street
New York, NY 10028

Sophia Chipouras
Route 2, Box 5BB
The Plains, VA 22171
(703) 253-5665

Sandra Cole
Dept. of Psychiatry
University of Michigan Medical School
Ann Arbor, MI 48104
(313) 764-5335

Theodore Cole, M.D.
Dept. of Physical Medicine & Rehab.
University of Michigan Medical School
Ann Arbor, MI 48104
(spinal cord injury)

Phil Colgan
Rehabilitation Counselor
208 Gelena
Wyoming, IL 61491

Dr. A. Estin Comarr
Rancho Los Amigos Hospital
Spinal Cord Injury Service
7601 East Imperial Highway
Downey, CA 90242
(213) 922-7605

Paul Corcran, M.D.
Boston University Medical Center
750 Harrison Street
Boston, MA 02118

Debra A. Cornelius
Regional Rehab. Research Institute on
Attitudinal, Legal & Leisure Barriers
George Washington University
1828 L St., N.W., Suite 704
Washington, DC 20036
(202) 676-6377

Council for Exceptional Children
Jefferson Plaza
1411 S. Jefferson Davis Highway
Arlington, VA 22202

Anne Cox
Community Education Specialist
Planned Parenthood, St. Louis
Administration & Education Office
2202 South Hanley Road
St. Louis, MO 63144
(314) 781-3800

Nancy Crewe, Ph.D.
Dept. of Physical Medicine & Rehab.
Box 297 Mayo
University of Minnesota
Minneapolis, MN 55455

Anne D. Crumpton
166 Western Plaza
P. O. Box 10964
Knoxville, TN 37919
(615) 588-3546

Ward Curtis, M.D.
Craig Hospital
3425 South Clarkson
Englewood, CO 80110

Jack Dahlverg
Craig Hospital
3425 South Clarkson
Englewood, CO 80110

Susan M. Daniels, Ph.D.
Dept. of Rehabilitation Counseling
Louisiana State University Med. Ctr.
School of Allied Health Professionals
1100 Florida Avenue
New Orleans, LA 70019
(504) 945-6028

Carl Davis
Perkins School for the Blind
Watertown, MA
(617) 924-3434

Bill DeGravelles, M.D.
Younkers Memorial Rehab. Center
1200 Pleasant
Des Moines, IA 50308

Jim Dillon
Craig Hospital
3425 South Clarkson
Englewood, CO 80110

L. Robert Dodge
65 Linaria Way
Menlo Park, CA 94025
(visual impairment)

John P. Donohue
Dept. of Urology
School of Medicine
Indiana University
Indianapolis, IN
(spinal cord injury)

Joan Donovan
Rehab 3
Tufts New England Medical Center
171 Harrison Avenue
Boston, MA 02111

Stanley Ducharme
Boston University School of Medicine
75 East Newton Street
New England Spinal Cord Injury Center
Boston, MA 02118

Yvonne Duffy
123 North Thayer, #1
Ann Arbor, MI 48104
(disabled women)

M.G. Eisenberg, Ph.D.
Coordinator of Psycho-Social Rehab.
Spinal Cord Injury Service
Veterans Administration Hospital
10701 East Blvd.
Cleveland, OH 44106
(216) 791-3800
(spinal cord injury)

Ginger Esler
124 East Lincoln St.
Bensenville, IL 60106

Family Planning Association
27 Mortimer St.
London W1
England
(mental retardation)

Fred Fay
171 Harrison Avenue
Box 1014
Boston, MA 02111

Benita Fifield
Div. of Occupational Therapies
School of Rehab. Medicines
University of Alberta
Edmonton, Alberta, Canada
T6G 2G4

Orville Fifield
Alberta Institute of Human
Sexuality
10420 54 Avenue
Edmonton, Alberta, Canada
T6H 0T5

Della Fitz-Gerald
Max Fitz-Gerald
Kendall Model Secondary School
Gallaudet College
Washington, DC 20002
(202) 447-0621
(hearing impairment)

Bob Flynn
Psychology Dept.
Indiana/Purdue University
1201 East 38th Street
Indianapolis, IN 46205
(317) 923-1321

Lockhart Follin-Mace
1011-D Hunting Ridge Rd.
Raleigh, NC 27609

Murray M. Freed, M.D.
University Hospital
75 East Newton Street
Boston, MA 02118

Michael F.X. Geraghty
Director
Collier Co. Mental Health Clinic
David Lawrence Ctr for Human Dev.
6075 Golden Gate Parkway
Naples, FL 33942
(community action)

T.G. Gibbs
Committee on Sexual Problems of the Disabled
49 Victoria Street
London SW1 H OUE
England

Dorothea Glass
Medical Director
Moss Rehabilitation Hospital
12th & Tabor Rd.
Philadelphia, PA 19141
(215) 329-5715

Richard Goldberg, M.D.
245 Hartman Road
Newton Center, MA 02159

Frani Goldman
Indiana Rehabilitation Services
1001 Illinois Bldg.
17 West Market Street
Indianapolis, IN 46204
(317) 633-5961

Sol Gordon
Director
Institute for Family Research & Education
760 Ostrom Avenue
Syracuse, NY 13210

George Gore III
Dept. of Elementary & Special Ed.
College of Education
Michigan State University
East Lansing, MI 48824
(visual impairment)

Debbie Gormally
F.A.M.E., Y.W.C.A.
26 Howard Street
Springfield, MA 01105
(sex education)

Ernest Griffith, M.D.
Box 148
Medical College of Virginia
Richmond, VA 23298

Judy Hall
99 Washington Ave., #1841
Albany, NY 12230
(mental retardation)

Lauro Halstead, M.D.
Texas Institute for
Rehabilitation and Research
Texas Medical Center
1333 Moursund Avenue
Houston, TX 77030

Marsha Hanack
Coordinator, SCI Project
Institute of Rehab. Medicine
Spinal Cord Injury Center
400 East 34th Street
New York, NY 10016
(212) 676-3200

Marjorie H. Handry
Montebello Hospital Center
2201 Argonne Drive
Baltimore, MD 21218

Peter Himmel, M.D.
18 Aldrich Terrace
Providence, RI 02906

Gary Hines
RRCEP Region V
1900 Chicago Avenue
Minneapolis, MN 55404
(612) 871-2402

Kathy Hix
Program in Human Sexuality
University of Minnesota
2630 University Ave., S.E.
Minneapolis, MN 55414

Peter Hofstra, M.D.
Spinal Cord Injury Service
Veterans Administration
Dept. of Medicine & Surgery
Washington, DC 20420

Dr. George W. Hohmann
Chief, Psychology Service
Veterans Administration Hospital
Tucson, AZ 85723

Ruth V. Holmes
Illinois Braille & Sight Saving
School
Jacksonville, IL

Guy Hudgins
Ebon Research Systems
1542 9th Street, N.W.
Washington, DC 20001
(202) 483-3306

Institute for Family Research & Education
760 Ostrom Avenue
Syracuse, NY 13210

Institute for Sex Education
22 W. Madison St.
Chicago, IL 60602

Institute for Sex Research
416 Morrison Hall
Indiana University
Bloomington, IN 47401

Jim Jackson
16 Laural Street
Arlington, MA 02174
(617) 648-9283
(tactile models)

Simi Kelley
Northeast Coalition on Sexuality & Disability
122 East 23rd Street
New York, NY 10010

Winifred Kempton
Planned Parenthood of SE Pennsylvania
1220 Sansom Street
Philadelphia, PA 19107
(215) 284-1613
(mental retardation)

Herbert Kent, M.D.
Chief, R.M.S.
Veterans Administation Hospital
5901 East 7th Street
Long Beach, CA 90801

Rosemary King
Asst. Director of Nursing
Rehabilitation Institute of Chicago
345 East Superior Street
Chicago, IL 60611

Sue Knight
Human Sexuality Program
Sex & Disability Unit
814 Mission Street, 2nd Floor
San Francisco, CA 94103
(415) 666-1066

Mike Kollar
Box 1-1701
Andy Holt Avenue
Melrose Hall
Knoxville, TN 37916

Carol Krueger, R.N.
4110 Beecher St., N.W., Apt. 1
Washington, DC 20007

Learning Systems
Sarah Strickland
Bill Norris
1675 Lakeland Drive
Jackson, MI 39216
(spinal cord injury)

James S. Liljestrand, M.D.
Med. Dir., Braintree Hospital
250 Pond Street
Braintree, MA 02184

Lee Ann Lipke
Health Ed. Consultant for Special Ed.
Grand Rapids Public Schools
1753 Rosewood, S.E.
Grand Rapids, MI
(visual impairment & learning disability)

Nan Loggins, R.N.
Cardinal Hill Hospital
2050 Versailles Road
Lexington, KY 40504
(spinal cord injury)

Elaine Makas
Regional Rehab. Research Institute on Attitudinal, Legal & Leisure Barriers
1828 L St., N.W., Suite 704
Washington, DC 20036
(202) 676-6377

Dr. Scott Manley
Family & Patient Service Dept.
Craig Hospital
3425 South Clarkson
Englewood, CO 80110
(303) 761-3040
(spinal cord injury & brain injury)

Dr. Don Mayclin
Santa Clara Valley Medical Center
751 South Bascom
Santa Clara, CA 95128
(408) 279-5116

Ron Mazur
University Health Services
University of Massachusetts
Amherst, MA 01003

Roger Mellott
Rocky Mt. Planned Parenthood
Center for Continuing Education
2030 East 20th Avenue
Denver, CO 80205

Jim Murphy
Dir. Consumer Activities Committee
United Cerebral Palsy
66 East 34th Street
New York, NY 10016

National Association for Mental Health
39 Queen Anne Street
London W1N OAU
England

National Assoc. for Retarded Children
2709 Avenue E East
Arlington, TX 76011

National Council on Family Relations
1219 University Avenue, S.E.
Minneapolis, MN 55414

Giovanna Nigro
United Cerebral Palsy
122 East 23rd Street
New York, NY 10010

Don Olson
Director of Training
Rehab. Institute of Chicago
345 East Superior Street
Chicago, IL 60611
(312) 649-6179

Chris Pfaffmann
Craig Hospital
3425 South Clarkson
Englewood, CO 80110

Planned Parenthood Association
of S.E. Pennsylvania
1220 Sansom Street
Philadelphia, PA 19107

Planned Parenthood Federation
of America
Alan Guttmacher Institute
515 Madison Avenue
New York, NY 10022

Planned Parenthood Federation
of America
Youth & Student Affairs
810 Seventh Avenue
New York, NY 10019

Planned Parenthood-World Pop.
810 Seventh Avenue
New York, NY 10019

Population Services, Inc.
c/o Phillip Harvey
P.O. Box 400
Carrboro, N.C. 27510

Ed Prenata
Program Division
UCP of Greater Hartford
80 Whitney Street
Hartford, Conn. 06105
(cerebral palsy)

Barry Ravin
Veterans Administration Hospital
5901 East 7th Street
Long Beach, CA 90801

Roy L. Raymond
Director, Xandria Collection
P. O. Box 31039
San Francisco, CA 94131
(sexual aids)

Regional Rehab. Research Institute
on Attitudinal, Legal, and
Leisure Barriers
George Washington University
1828 L St., N.W., Suite 704
Washington, DC 20036
(202) 676-6377, 676-6842

Glen G. Reynolds, M.D.
Director, Rehab. Medicine Service
Santa Clara Valley Medical Service
751 South Bascom Avenue
San Jose, CA 95128

Mary Romano
Social Services
Presbyterian Hospital
622 West 168th Street
New York, NY 10032
(212) 694-2553

Joel S. Rosen, M.D.
Rehab. Institute of Chicago
345 E. Superior Street
Chicago, IL 60611

Lynne Rustad, Ph.D.
Spinal Cord Injury Service
Cleveland Veterans Administration Hospital
10701 East Blvd.
Cleveland, OH 44106

Joyce Salhoot, A.C.S.W.
Program in Human Sexuality
Texas Institute for Rehab. & Research
1333 Moursund Avenue
Houston, TX 77031
(713) 797-1440

John Schatzlein
Dept. of Physical Medicine & Rehab.
Box 279, Mayo
University of Minnesota
Minneapolis, MN 55455

James P. Semmens, M.D.
Dept. of OB/GYN - MUSC
80 Barre Street
Charleston, SC 29401

Sex Information and Education Council
of the United States (SIECUS)
1855 Broadway
New York, NY 10028

Kris Sherman
Spinal Cord Injury Center
1400 V.F.W. Parkway
West Roxbury, MA 02132
(617) 323-7700 (Ext. 210)

David Shore
Suite 1102A
1525 East 53rd Street
Chicago, IL 60615
(312) 493-2968

Margie Sloan
4399 Tree Haven Drive, NE
Atlanta, GA 30342

Society for the Scientific Study
of Sex, Inc.
12 East 41st Street
New York, NY 10017

The Spastics Society
12 Park Crescent
London W1N 4EQ
England

Spina Bifida Council of MD
5709 38th Avenue
Hyattsville, MD 20782

W.F.R. Stewart
1 Woodcock Hill
Harefield Road
Rickmansworth
Herts. WD3 1PX
England

Helen Stonehill
Chief Librarian
ICD Rehab. & Research Center
340 East 24th Street
New York, NY 10010
(212) 679-0100
(printed materials)

Pearl E. Tait, Ph.D.
Associate Professor
of Special Education
Florida State University
Tallahassee, FL 32306
(visual impairment)

Jeannette Taylor
Dept. of Social Service
Rehab. Institute of Chicago
345 E. Superior Street
Chicago, IL 60611

Dr. Donald D. Thompson
Director of Research
Virginia Spinal Injury Systems
Spinal Cord Project
Woodrow Wilson Rehab. Center
P. O. Box 499
Fishersville, VA 22939
(spinal cord injury)

Roberta Trieschmann
P. O. Box 2465
Culver City, CA 90230

Douglas Wallace
Ambulatory & Community Medicine
School of Medicine
University of California
San Francisco, CA

Anne Welbourne, Ph.D.
Dept. of Psychiatry
State University of New York
Lab Office Bldg.
Stony Brook, NY 11794
(516) 444-2427
(visual impairment)

Charles B. White, Ph.D.
Assistant Professor, Gerontology Program
School of Allied Health Sciences
U. of Texas Health Sciences Center
5325 Harry Hines Blvd.
Dallas, TX 75235

Sharon Wilkin
Veterans/Handicapped Program
OFCCP
Room 3402
200 Constitution Avenue, N.W.
Washington, DC 20210
(202) 523-9494

Masters & Johnson Institute
4910 Forest Park Blvd.
St. Louis, MO 63108

APPENDIX F

Books & Journals

Books Related to Sexuality and Disability

AAHPER, & Sex Information and Education Council of the U.S. *Resource guide in sex education for the mentally retarded.* Washington, D.C.: AAHPER, 1971.

American Foundation for the Blind. *Sex education for the visually handicapped in schools and agencies—selected papers.* New York: American Foundation for the Blind, 1975.

Annon, J.S. *The behavioral treatment of sexual problems: Volumes 1 & 2.* Honolulu: Enabling Systems, Inc., 1974.

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Archives of Sexual Behavior
Plenum Publishing Corp.
227 West 17th Street
New York, NY 10011

Family Life
Edward Peacock, Ed.
5287 Sunset Blvd.
Los Angeles, CA 90027

Family Planning Perspectives
Planned Parenthood
Alan Guttmacher Institute
515 Madison Avenue
New York, NY 10022

Family Planning/Population Rptr.
Planned Parenthood
Alan Guttmacher Institute
515 Madison Avenue
New York, NY 10022

Forum: The International Journal of Human Relations
155 Allen Blvd.
Farmingdale, NY 11735

Getting It Together
Planned Parenthood Fed. of America
Youth & Student Affairs Program
810 Seventh Avenue
New York, NY 10019

Homosexual Counseling Journal
HCCC, Inc.
30 East 60th Street
New York, NY 10022

Information Service
Institute for Sex Research
416 Morrison Hall
Indiana University
Bloomington, IL 47401

Journal of Homosexuality
Haworth Press, Inc.
174 Fifth Avenue
New York, NY 10010

Journal of Marriage & Family
National Council on Family Relations
1219 University Avenue, S.E.
Minneapolis, MN 55414

Journal of Sex & Marital Therapy
65 East 76th Street
Suite 1A
New York, NY 10021

Journal of Sex Education & Therapy
AASECT
5010 Wisconsin Ave., N.W.
Washington, DC 20016

Journal of Sex Research
208 Daffodil Road
Glen Burnie, MD 21061

Medical Aspects of Human Sexuality
Hospital Publications
609 Fifth Avenue
New York, NY 10017

Newsletter
AASEC
5010 Wisconsin Ave., Suite 304
Washington, DC 20016

Sex News
7140 Oak
Kansas City, MO 64114

Sex Roles: A Journal of Research
227 West 17th Street
New York, NY 10011

Sexuality & Disability
Dept. of Rehab. Couns.
100 S. Derbigny
New Orleans, LA 70112

Sexuality Today
Atcom Building
2315 Broadway
New York, NY 10024

SIECUS Reports
137-155 North Franklin
Hempstead, NY 11550

Disability-Related Journals

Achievement
Achievement Disabled Action Group, Inc.
925 N.E. 122nd St.
North Miami, FL 33161

Accent on Living
P.O. Box 700
Gillum Rd. & High Drive
Bloomington, IL 61701

American Annals of the Deaf
5034 Wisconsin Ave., N.W.
Washington, DC 20016

American Foundation for the Blind Research Bulletin
15 West 16th Street
New York, NY 10011

American Journal of Public Health
1015 18th Street, N.W.
Washington, DC 20036

Archives of Physical Medicine and Rehabilitation
American Congress of Rehab. Medicine
30 North Michigan Ave.
Chicago, IL 60602

Clearinghouse Review
500 N. Michigan Ave.
Suite 2220
Chicago, IL 60611

Closer Look
1201 16th Street, N.W.
Suite 607E
Washington, DC 20036

Deaf American
5125 Radnor Road
Indianapolis, IN 46226

Disabled USA
President's Committee on Employment of the Handicapped
Washington, DC 20210

Education and Training of the Mentally Retarded
1920 Association Drive
Reston, VA 22091

Education of the Visually Handicapped
Assoc. for the Education of the Visually Handicapped
919 Walnut Street
Philadelphia, PA 19107

Exceptional Children
Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

The Exceptional Parent
PSY-ED Corp.
Room 708, Statler Bldg.
20 Providence Street
Boston, MA 02116

Focus on Exceptional Children
6635 East Villanova Place
Denver, CO 80222

Hearing Rehabilitation Quarterly
NY League for the Hard of Hearing
71 West 23rd Street
New York, NY 10010

Impact
North Carolina Rehabilitation Assoc.
P. O. Box 505
Henderson, SC 27536

Innovator
Cal. State Dept. of Rehabilitation
830 K Street Mall
Sacramento, CA 95814

International Journal of Rehabilitation Research
Neuburger Str. 13 a
7512 Rheinstetten-Neu
Germany

International Rehabilitation Review
Rehabilitation International
432 Park Avenue South
New York, NY 10016

Journal of Applied Rehabilitation Counseling
NRCA
1522 K Street, N.W.
Washington, DC 20005

Journal of Rehabilitation
National Rehab Association
1522 K Street, N.W.
Washington, DC 20005

Journal of Rehabilitation of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910

Journal of Special Education
Grune and Stratton
111 Fifth Avenue
New York, NY 10003

Journal of Speech & Hearing Research
9030 Old Georgetown Road
Washington, DC 20014

Journal of Visual Impairment and Blindness
15 West 16th Street
New York, NY 10011

Paraplegia Life
333 North Michigan
Chicago, IL 60601

Paraplegia News
333 North Michigan
Chicago, IL 60601

Rehabilitation Counseling Bulletin
1607 New Hampshire Ave, NW
Washington, DC 20009

Rehabilitation Digest
One Yonge St., Suite 2110
Toronto, Ontario M5E 1E8
Canada

Rehabilitation Gazette
4502 Maryland Avenue
St. Louis, MO 63108

Rehabilitation Literature
Natl. Easter Seal Society for Crippled Children & Adults
2023 West Ogden Avenue
Chicago, IL 60612

Rehabilitation Network News
Rehab Center Planning Office
Allied Health
University of North Carolina
Chapel Hill, NC 27514

Rehabilitation Psychology
P. O. Box 26034
Tempe, AZ 85282

Rehabilitation Teacher
88 St. Stephen Street
Boston, MA 02115

The Rising Tide
Enabling Dept.
P. O. Box 246
Suisun City, CA 94585

Special Education: Forward Trends
Nat. Council for Special Ed.
12 Hollycroft Ave.
London NW3 7Q1
England

Teaching Exceptional Children
1920 Association Drive
Reston, VA 22091

Teacher of the Blind
Royal School for the Blind
Church Road North, Wavertree
Liverpool L15 6TQ
England

Teacher of the Deaf
50 Topsham Road
Exeter EX2 4NF, England

Voice and Choice
University of Maryland
Ctr. of Rehab. & Manpower Service
College Park, MD 20742

Volta Review
3417 Volta Place NW
Washington, DC 20002

APPENDIX G

A-V/Tactile Resources

Audio/Visual/Tactile Resources for Sex Education

Listed below are some of the audio/visual/tactile resources available which deal with sexuality and disability. Some are materials which have been designed for use in sex education courses for people within particular disability groups (e.g., mentally retarded individuals, visually-impaired people). Others have been developed specifically for use in training service providers (e.g., nurses, counselors). Most, however, are extremely versatile. They may be used to introduce potential service providers to sexuality and disability and to various sex education/counseling techniques; to instruct both disabled people and potential service providers in sexuality; to increase awareness of the needs of disabled individuals; and to develop more positive attitudes toward sexuality and disability, both among disabled people and among the able-bodied individuals with whom they come in contact.

This resource listing is the result of a careful search of catalogues and literature related to sexuality and/or disability. Members of the Sex & Disability staff have not previewed all of these materials. It is, therefore, very important that those of you who wish to utilize any of these resources examine them carefully prior to use to assure yourself that they are appropriate to your particular education/training needs.

The source for each of these materials is indicated at the end of each summary. A complete listing of these sources and their mailing addresses is included at the end of this appendix.

AASECT Tapes
Audio-cassettes

A series of tapes giving advanced sexuality-related information (e.g., homosexuality and sex roles). May be particularly useful for visually-impaired adults.

AASECT

The ABC of Sex Education for Trainable Persons
16 mm. film/20 mins./color/sound

The first film in the "Sex Education for the Mentally Handicapped" series, this film serves as an introduction to the field. It is designed primarily to be used for in-service training of teachers, but should also prove useful to counselors and to parents who wish to teach in a home setting.

Educational Division

About Conception and Contraception
8 or 16 mm. film or video-cassette/11 mins./color/no sound

Clear and basic animated presentation showing how conception occurs and how various birth control methods work. Since there is no narration, may be particularly helpful for teaching people with communication difficulties.

Perennial Education

About Puberty and Reproduction
16 mm. film/12 mins./color/no sound

Clear and basic animated presentation of the internal and external changes that occur during puberty. Pregnancy and childbirth are also outlined. Since there is no narration, film may be particularly useful in sex education for people with communication difficulties.

Perennial Education

About V.D.
16 mm. film/14 mins./color/no sound

Clear and basic animated drawings show how V.D. is transmitted, its symptoms, and its effects. As there is no narration, this film may be helpful in presenting this information to people with communication impairments.

Perennial Education

Anatomy and Physiology of the Sexual Response Cycle
1/2" or 3/4" video-cassette/30-40 mins./color/sound

Part of the "Sexuality and Physical Disability" series, this cassette presents a general discussion of female and male sexual organs and the process of arousal. Illustrations and photographs are used.

Multi Media Resource Center/Audiovisual Library Service

Artist's Fantasy
16 mm. film/15 mins./color/sound

A sexually explicit film in which a man with cerebral palsy discusses the importance of sexuality to his self-concept and feelings of competence.

Department of Physical Medicine/Multi Media Resource Center

Bertha
16 mm. film

A film for teachers and parents of mentally retarded children/adolescents which discusses the rights and responsibilities of parenting for all persons.

Joseph P. Kennedy Foundation

Birth Control Methods: A Simplified Presentation
Kit including: a captioned filmstrip, script, 25-panel flip chart, and monograph

A kit which may be used in presenting information on birth control methods and the need for sexual responsibility to mentally retarded individuals.

Perennial Education

Body Image, Disability, and Sexuality
1/2" or 3/4" video-cassettte/30-40 mins./color/sound

One of the "Sexuality and Physical Disability" tapes, this cassette presents a discussion among physically disabled men and women. They candidly discuss the effects of disability on their body images. The contrast between the psychological effects of early and later disability on body image is discussed.

Multi Media Resource Center/Audiovisual Library Service

Boy to Man
16 mm. film

A detailed description of the changes that occur in the male body during puberty. May be particularly useful in sex education for people with mental retardation.

Churchill Films

Bringing It Up
16 mm. film/17 mins./color/sound

A film for service providers which demonstrates interviewing skills and the integration of sexuality into a rehabilitation program. The person being interviewed is a hospitalized quadriplegic male.

Audiovisual Library Service/Multi Media Resource Center

Don't Tell the Cripples About Sex
2 parts/16 mm. film or 1/2" video-cassettes/total time: 35 mins./color/sound

A panel discussion among adults with cerebral palsy in which they discuss their experiences related to sexuality, self-image, and socialization. Part 1 deals specifically with how parents and doctors treated their sexuality. Part 2 focuses primarily on their adult experiences.

Multi Media Resource Center

Ease (Essential Adult Sex Education) Curriculum
Kit including: curriculum guide, teaching picture cards, pre- and post-tests, filmstrip, two audio-cassettes, set of menstrual and birth control materials, pupil profile sheet.

Instructional aids specifically designed to be used in presenting information to mentally retarded adults on physiology, sexual behavior, health, and interpersonal relationships.

Madison Opportunity Center

Fertility Regulation for Persons with Learning Disabilities
16 mm. film/18 mins./color/sound

One of the films in the "Sex Education for the Mentally Handicapped" series, this film is designed for teachers, counselors, and parents. It discusses the pros and cons of fertility regulations for mentally retarded people.

Educational Division

Girl to Woman
16 mm. film

A film designed to teach mentally retarded individuals about the changes that occur in the female body at puberty.

Churchill Films

Give It a Try
16 mm. film/33 mins./color/sound

A film for service providers which demonstrates sex counseling with a quadriplegic male and his able-bodied wife, who are experiencing sexual difficulties. It is non-explicit, but personal, and it is very informative and supportive. An advocate counseling couple also participates.

Audiovisual Library Service/Multi Media Resource Center

Group Home Parent Training Program
filmstrips/audio-cassettes/including prints

A series of eight programmed self-teaching units, including one on sexuality and one on recreation and leisure time activities. These films are designed primarily for house parents in group homes.

Stanfield House

Growing Up and Liking It
Booklet available in Braille or large print

A pamphlet specifically designed for visually-impaired adolescents which discusses menstruation, other body changes at puberty, and feminine hygiene.

Personal Products

The How and What of Sex Education for Educable Persons
16 mm. film/20 mins./color/sound

One of the films in the series "Sex Education for the Mentally Handicapped," this training guide is designed for teachers, counselors, and parents who are involved in sex education for mentally retarded individuals. Scenes of actual teaching situations are used. The film demonstrates what should be taught, teaching methods, and how to be at ease giving instruction in sex education.

Educational Division

Human Reproduction
16 mm. film

A film which gives information on the structure and function of the male and female reproductive systems, and traces the reproductive process. May be useful in sex education for mentally retarded individuals.

Precision Film Labs

Human Sexuality
Series of 30 one-hour audio-cassettes

A set of audio-cassettes which presents the physiological, psychological, and sociological aspects of sexuality. Included are varying life styles and modes of sexual expression. One half of each tape is a didactic presentation; the other half is a panel discussion or question and answer session. These tapes may be useful in advanced sex education for visually-impaired persons.

Jeffrey Norton Publishers

Human Sexuality and the Nursing Practice
Set of eight 35 mm. filmstrips and audio-cassettes

Instructional filmstrips to be used in training nurses to deal with the sexual concerns of their patients. Included in the set are several filmstrips dealing specifically with sexuality and disability, and one which focuses on developing sex counseling techniques.

Concept Media

The Human Sexuality Learning Package
Kit which includes 20 teaching cards, twenty 35 mm. slides, an audio-cassette of text, and a teacher's guide.

An instructional kit to be used in sex education for mentally retarded people. The topics covered include: body changes, sex differences, hygiene, intercourse, and varying life styles.

Educational Division

If Ever Two Were One
16 mm. film or 1/2" video-cassette/14 mins./color/sound (music only)

An explicit film showing sexual activity between a paraplegic man and an able-bodied woman. The "stuffing" technique is clearly demonstrated.

Multi Media Resource Center

Into Manhood
Filmstrip or slides/captioned filmstrip available

A presentation which describes ejaculation and other changes in the male body at puberty, and discusses the new feelings related to these changes. The filmstrip is specifically designed to help young men develop positive self-concepts during these transitional years. The captioned filmstrip makes this particularly useful in sex education for hearing-impaired adolescents.

Stanfield House

Into Womanhood
Filmstrip or slides/captioned filmstrip available

A presentation which describes menstruation and other changes in the female body at puberty, and discusses the new feelings related to these changes. The filmstrip is specifically designed to help young women develop positive self-concepts during these transitional years. The captioned filmstrip makes this particularly useful in sex education for hearing-impaired adolescents.

Stanfield House

Just What Can You Do
16 mm. film or 1/2" video-cassette/23 mins./color/sound

A presentation in which a panel of spinal cord injured individuals and their partners discuss the implications of their disabilities on their sexuality and interpersonal relationships.

Multi Media Resource Center

Like Everybody Else
16 mm. film/32 mins./color/sound

A film which examines the largest and one of the most comprehensive programs for mentally retarded adults. Included are: group and individual counseling, self-help training, sex education, work adjustment, and leisure and recreational activities.

Stanfield House

Like Other People
16 mm. film/37 mins./color/sound

A sensitive film showing a love relationship between two adults with cerebral palsy.

Perennial Education

Love Carefully
16 mm. film/17 mins./color/sound

A presentation designed to be used in sex education for mentally retarded individuals. Simple terminology and animation are used to demonstrate and explain various methods of birth control.

Perennial Education

Medical and Institutional Aspects
1/2" or 3/4" video-cassette/30-40 mins./color/sound

Part of the "Sexuality and Physical Disability" series, this tape is geared toward service providers. A physician presents illustrations and discusses the varied effects of disability and some of the devices to deal with altered sexual performance among disabled people.

Multi Media Resource Center/Audiovisual Library Service

Mental Retardation and Human Sexuality
Sound filmstrip/LP record/20 mins.

A film designed to introduce parents and teachers to the general problems related to mental retardation and sexuality.

Planned Parenthood Association of Southeastern Pennsylvania

Michael
16 mm. film/13 mins./black & white/sound

A film designed to increase sensitivity to and awareness of the needs of disabled people. It presents the barriers encountered by a physically disabled man who chooses to leave the hospital, rent an apartment, get a job, and establish a meaningful sexual relationship.

Multi Media Resource Center

Mimi
16 mm. film/12 mins.

A very emotional film about a paraplegic woman. It discusses the effects of the disability on her marriage, and touches on the attitudes of disabled and able-bodied people toward each other.

Billy Budd Films

Minnesota Soap Series
16 mm. film/21 mins./color/sound

Although not specifically related to disability, this film may prove useful in training service providers to deal with the sexual concerns of their clients. Twelve vignettes of counseling situations in which sexuality-related questions and concerns may come up are presented. Good and bad ways to initiate the discussion and deal with the topic are demonstrated.

Multi Media Resource Center

On Being Sexual
16 mm. film/22 mins./including a discussion guide, 4 audio-tapes, and a community resource guide

A training presentation in which parents and professionals discuss mental retardation and sexuality. The need for giving accurate sex information to mentally retarded individuals is emphasized.

Stanfield House

One Day, One Time
16 mm. film or 3/4" video-cassette/17 mins./color/sound

A sexually explicit film about a spinal cord injured woman and her family. It is an intimate presentation designed to introduce others to sexual concerns and abilities of disabled women.

Health Sciences Audiovisual Education

Orientation to the Sexuality of Physical Disability
1/2" or 3/4" video-cassette/30-40 mins./color/sound

One of the "Sexuality and Physical Disability" cassettes, this tape is designed to introduce people to the sexual needs and concerns of disabled people. It discusses the assumptions basic to sex education and counseling programs for this population.

Multi Media Resource Center/Audiovisual Library Service

PLISSIT Approach to Sex Therapy
audio-tape/60 mins.

One of the AASECT set, this tape presents the PLISSIT model of sexual counseling. It may prove useful in training programs for service providers.

AASECT

Possibilities
16 mm. film or 1/2" video-cassette/12 mins./color/sound

An explicit film presenting the sexual relationship between a quadriplegic man and a nondisabled woman. The man candidly discusses the impact of the injury on his sexuality and self-esteem.

Multi Media Resource Center

Sex and the Handicapped
16 mm. film/20 mins./color/sound

Designed for disabled individuals, their partners, and for service providers, this film discusses options and techniques available to disabled people, and the need for positive attitudes toward sexuality and disability.

Focus International

Sex and the Professional
8 or 16 mm. film or video-cassette/25 mins./color/sound

A film designed to raise the consciousness of service providers by showing ways in which they can get in touch with their own sexual feelings and attitudes. This should enable them to deal more effectively with the sexual concerns of others.

Texture Films

Sex Education and Counseling for the Physically and Mentally Handicapped
Two audio-tapes/60 mins. each

Part of the AASECT set, these tapes present an introduction to sex education/counseling techniques for disabled people.

AASECT

Sex Education for Deaf Persons
audio-tape/60 mins.

Part of the AASECT series, this tape deals specifically with the sex education needs of hearing-impaired individuals and suggests methods by which these needs can be met.

AASECT

Sex Education for the Mentally Handicapped
Set of three 16 mm. films/18-20 mins. each/color/sound

See descriptions of individual films:
The ABC of Sex Education for Trainable Persons
The How and What of Sex Education for Educable Persons
Fertility Regulation for Persons with Learning Disabilities

Educational Division

Sex Problems in Paraplegia
Audio-tape/regular 4-track/90 mins.

This tape is designed for the training of rehabilitation professionals. Specialists in physical medicine, urology, neurology, psychology, and psychiatry discuss sexuality and spinal cord injury. All members of the discussion group are familiar with disability.

Joseph Goodgold, M.D.

Sexual Counseling of Physically Disabled Adults
1/2" or 3/4" video-cassette/30-40 mins./color/sound

One of the tapes in the "Sexuality and Physical Disability" series, this cassette presents a group discussion among four rehabilitation professionals. They exchange ideas on the initiation and actual discussion of the topic of sexuality with their physically disabled clients. In addition, the professionals examine how their own life styles affect their counseling of others.

Multi Media Resource Center/Audiovisual Library Service

Sexuality and Disability Adjustment
1/2" or 3/4" video-cassette/30-40 mins./color/sound

Another tape in the "Sexuality and Physical Disability" series, this one presents a discussion among a physician, a psychologist, and a disabled couple. The relationship of sexuality to other aspects of adjustment is examined.

Multi Media Resource Center/Audiovisual Library Service

Sexuality and Physical Disability
Set of seven 1/2" or 3/4" video-cassettes/30-40 mins. each/color/sound

See descriptions of individual tapes:

Orientation to the Sexuality of Physical Disability
Anatomy and Physiology of the Sexual Response Cycle
Medical and Institutional Aspects
Body Image, Disability, and Sexuality
Sexual Counseling of Physically Disabled Adults
Sexuality and Disability Adjustment
Sexual Variations

Multi Media Resource Center/Audiovisual Library Service

Sexuality and the Handicapped
Audio-cassette/60 mins.

Part of the AASECT series of tapes, this cassette presents a group discussion on sexuality and disability. Individuals with varied disabilities candidly discuss their own sexual attitudes and concerns. They examine the difficulties caused by society's definition of the "rights" and "wrongs" of sexual expression, and the emotional problems associated with being "different."

Jeffrey Norton Publishers

Sexuality and the Mentally Handicapped: Slides for the Teaching of the Mentally Handicapped
Series of several hundred slides

A seven-part slide presentation intended for use in sex education programs for mentally retarded individuals. Topics in the series are: parts of the body, male puberty, female puberty, social behavior, human reproduction, fertility and venereal disease, and marriage and parenting.

Stanfield House

Sexual Variations
1/2" or 3/4" video-cassette/30-40 mins./color/sound

One of the tapes in the "Sexuality and Physical Disability" series, this cassette presents several aspects of the wide range of behaviors and life styles. Its intention is to increase understanding among service providers.

Multi Media Resource Center/Audiovisual Library Service

Stigma: What It's Like To Be Disabled. The Physically Disabled and the World
Audio-cassette

A discussion of stigma and the reactions of disabled individuals to the attitudes of able-bodied people. Among other topics, members of the group extensively discuss problems related to sexuality and disability. Fear and embarrassment (for example, relating to leg bags and catheters) are examined. All participants in the discussion are disabled.

Center for Independent Living

Strictly Feminine
Booklet available in Braille or large print

A pamphlet specifically designed for visually-impaired adolescents which discusses menstruation, other body changes at puberty, and feminine hygiene.

Personal Products

To Plan Your Family
16 mm. film/15 mins./color/sound

A film in which mothers discuss family planning. Animation is used to present information on reproductive physiology and birth control. This film may prove useful in family planning counseling for mentally retarded persons.

Churchill Films

Touching
16 mm. film or ½" video-cassette/16 mins./color/sound

An explicit presentation of sexual activity between a spinal cord injured man and an able-bodied woman. The love-making evidences a great deal of intimacy and warmth.

Multi Media Resource Center

Your Changing Body
Two audio-cassetts/40 mins. each/including a parent-teacher guide and a teacher evaluation form

A program designed for visually-impaired children and adolescents. The individual is encouraged to explore his or her body in privacy while the tape describes the changes that occur in the female and male body at puberty.

Perennial Education

Sources for Audio/Visual/Tactile Materials Related to Sexuality and Disability

Below are the names and addresses of organizations which supply audio/visual/tactile resources on sexuality and/or disability, including the materials summarized in this appendix. Catalogues of resources are available from most of these organizations upon request.

AASECT (American Association of Sex Educators, Counselors and Therapists)
Suite 304
5010 Wisconsin Ave., NW
Washington, DC 20016
(audio-tapes)

Association Films, Inc.
866 Third Avenue
New York, NY 10022
(films)

Audiovisual Library Service
Continuing Education and Extension
University of Minnesota
3300 University Ave., SE
Minneapolis, MN 55414
(films, video-tapes)

Billy Budd Films, Inc.
235 East 57th St.
New York, NY 10022
(films)

Captioned Films and Telecommunications Branch
Bureau of Education for the Handicapped
U.S. Office of Education, DHEW
400 South 6th St., SE
Donahue Building
Washington, DC 20202
(films)

Carousel Films, Inc.
1501 Broadway
New York, NY 10036
(films)

Cathedral Films
2921 West Alameda Ave.
Burbank, CA 91505
(filmstrips)

Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(audio-tapes)

Churchill Films
622 North Robertson Blvd.
Los Angeles, CA 90069
(films)

Cleveland Health Museum
8911 Euclid Ave.
Cleveland, OH 44106
(anatomical models)

Concept Media
1500 Adams Ave.
Costa Mesa, CA 92626
(filmstrips)

Contemporary/McGraw Hill Films
1221 Avenue of the Americas
New York, NY 10020
(films)

Coronet Instructional Media
65 East South Water St.
Chicago, IL 60601
(films)

Jarvis Couillard Associates
142 Paseo de Gracia
Redondo Beach, CA 90277
(films)

Denoyer-Geppert
5235 Ravenswood Ave.
Chicago, IL 60640
(teaching aids, anatomical models)

The Department of Physical Medicine & Rehabilitation
Mr. Ed Monahan, Media Director
University of Minnesota Hospitals
Mayo Building
University of Minnesota
Minneapolis, MN 55414
(films)

Di Mat, Ltd.
Didactic Materials, Ltd.
Kaul Building
Box 367
McLean, VA 22101
(anatomical models)

Educational Division
Hallmark Films and Recordings
51-53 New Plant Court
Owings Mill, MD 21117
(films)

Family Films
5823 Santa Monica Blvd.
Hollywood, CA 90038
(filmstrips)

Films Incorporated
1144 Wilmette Ave.
Wilmette, IL 60091
(films)

Focus International Inc.
505 West End
New York, NY 10024
(films)

Gallaudet College Bookstore
Gallaudet College
Washington, DC 20002
(audio-tapes, large print and Braille books)

Glenn Educational Films, Inc.
P.O. Box 371
Monsey, NY 10952
(filmstrips)

Joseph Goodgold, M.D.
Director of Research and Training
New York University
Medical Rehabilitation Research and
Training Center
400 East 34th St.
New York, NY 10016
(audio-tapes)

Guidance Associates
757 Third Avenue
New York, NY 10017
(filmstrips)

Harris County Center for the Retarded
3550 West Dallas
P. O. Box 13403
Houston, TX 77019
(films)

Health Services Audiovisual Education, 1-157
Clinical Sciences Building
University of Alberta
Edmonton, Alberta T6 G 2G3
Canada
(films, video-tapes)

Hubbard Scientific Company
2855 Shermer Rd.
Northbrook, IL 60062
(anatomical models)

Joseph P. Kennedy Foundation
1701 E Street, NW
Washington, DC 20003
(films)

Madison Opportunity Center
601 E. Main Street
Madison, WI 53703
(filmstrips, teaching aids)

Modern Talking Picture Service, Inc.
2323 New Hyde Park Rd.
New Hyde Park, NY 11040
(filmstrips)

Multi Media Resource Center
1525 Franklin St.
San Francisco, CA 94109
(films, video-tapes)

Jeffrey Norton Publishers, Inc.
Audio Department
145 East 49th Street
New York, NY 10017
(audio-cassettes)

Nystrom
3333 Elston Avenue
Chicago, IL 60618
(anatomical models)

Perennial Education, Inc.
477 Roger Williams
P. O. Box 855, Ravinia
Highland Park, IL 60035
(films, video-tapes, filmstrips, teaching aids, audio-tapes)

Personal Products
c/o Association Sterling, Inc.
P. O. Box 117
Ridgefield, NJ 07657
(large print and Braille books)

Planned Parenthood of Southeastern Pennsyulvania
1220 Sansom St.
Philadelphia, PA 19107
(filmstrips)

Planned Parenthood of Northern New York
161 Stone St. Annex
Watertown, NY 13601
(films)

Precision Film Labs, Inc.
21 W. 46th St.
New York, NY 10036
(films)

Professional Arts, Inc.
P. O. Box 8003
Stanford, CA 94305
(films)

Warren Schloat Productions, Inc.
150 White Plains Rd.
Tarrytown, NY 10591
(filmstrips)

Society for Visual Education
1345 Diversey Parkway
Chicago, IL 60614
(filmstrips)

Stanfield House
12381 Wilshire Blvd., Suite 203
Los Angeles, CA 90025
(filmstrips, slides, films)

Sterling Educational Films, Inc.
241 East 34th Street
New York, NY 10016
(films)

Texture Films
1600 Broadway
New York, NY 10019
(films, video-cassettes)

TRAFCO
The United Methodist Church
1525 McGavrock St.
Nashville, TN 37203
(films)

Visual Products Division
3M Center
St. Paul, MN 55101
(films)

John Wiley & Sons
605 Third Avenue
New York, NY 10016
(films)

Bibliographies of Audio/Visual/Tactile Resources

In addition to the catalogues listed above, at least four bibliographies of audio/visual/tactile resources on sexuality and/or disability may prove useful:

Craft, A., & Craft, M. *Health, hygiene, & sex education for mentally handicapped children, adolescents and adults: A review of audio-visual resources.* London: Health Education Council, 1976. (Available from: Health Education Council Resource Centre, 78 New Oxford St., London WC 1AH, England.)

Rehabilitation Services Administration. *Publications and audiovisual aids directory of the Rehabilitation Research and Training Centers.* Washington, DC: Department of Health, Education and Welfare, 1978. (Available from: Rehabilitation Services Administration, Office of Human Development Services, U.S. Department of Health, Education and Welfare, Washington, DC 20201.)

SIECUS. *Film resources for sex education* (D.L. Burleson & G. Barbash, Eds.). New York: Human Sciences Press, 1976. (Available from: Behavioral Publications, 72 Fifth Avenue, New York, NY 10011.)

SIECUS & American Foundation for the Blind. *Sex education and family life for visually handicapped children and youth: A resource guide* (I.R. Dickman, Ed.). New York: SIECUS, 1975. (Available from: SIECUS, 122 East 42nd Street, New York, NY 10017.)

APPENDIX H

Bibliographies

Bibliographies

Beasley, M.C., Burns, D., Weiss, J.M. *Human sexuality: The handicapped, the aging.* Available from: Office of Independent Study, P. O. Box 2967, University, AL 35486.

Colorado Department of Education. *Sexuality resource guide: A revised bibliography.* (1975) Available from: Gene Stortz, Colorado State Library, 1362 Lincoln St., Denver, CO 80203.

Council for Exceptional Children. *Sex education: A selective bibliography.* Available from: CEC, 1920 Association Dr., Reston, VA 22091.

Diamond, M. *Sexuality: The handicapped and aged. A coded bibliography.* (1975) Available from: Dr. Milton Diamond, University of Hawaii, School of Medicine, Biomed 22, Honolulu, HA.

Griffith, E.R., Timms, R.L., Tomko, M.A., (Eds.). *Sexual problems of patients with spinal injuries: An annotated bibliography.* (1973) Available from: Dept. of Physical Medicine & Rehabilitation, University of Cincinnati, College of Medicine, Cincinnati, OH.

Institute for Sex Research. *Diseases and sex behavior. Physically handicapped and sex behavior. Special groups and sex education.* (1974) Available from: Institute for Sex Research, 416 Morrison Hall, Indiana University, Bloomington, IN 47401.

IRUC/AAHPER. *Sex education for handicapped children and adults,* (Topical information sheet No. 1). Available from: IRUC/AAHPER, 1201 16th Street, N.W., Washington, DC 20036.

Lassen, P.L. *Sex and the spinal cord injured: A selected bibliography.* (1973) Available from: Paralyzed Veterans of America, 4330 East West Highway, Suite 300, Bethesda, MD 20014

Minnesota Medical Rehabilitation Research and Training Center No. 2. *Psychological, sexual, social and vocational aspects of spinal cord injury: A selected bibliography.* (1977) Available from: Mrs. Sharon Scarlett, Librarian, Dept. of Physical Medicine and Rehabilitation, Box 297, University of Minnesota, Minneapolis, MN 55455.

Panieczko, S., Cornelius, D., & Frank, W. *Sex & disability: A selected annotated bibliography on sexuality and disability 1975-1977.* Available from: RRRI-ALLB, 1828 L St., N.W., Suite 704, Washington, DC 20036.

Rabin, B.J. *Options' resource guide to sexual adjustment in disability.* (1977) Available from: Association for Sexual Adjustment in Disability, P. O. Box 3579, Downey, CA 90242.

Rehabilitation Services Administration. *Publications and audiovisual aids directory of the rehabilitation research and training centers.* (1978) Available from: Rehabilitation Services Administration, Office of Human Development Services, U.S. Dept. of Health, Education and Welfare, Washington, DC 20201.

SIECUS. *A bibliography of resources in sex education for the mentally retarded.* (1973) Available from: Behavioral Publications, Inc., 72 Fifth Ave., New York, NY 10011.

SIECUS and American Foundation for the Blind, Inc. Irving R. Dickman, (Ed.). *Sex education and family life for visually handicapped children and youth: A resource guide.* (1975) Available from: SIECUS, 122 East 42nd St., New York, NY 10017.

Task Force on Concerns of Physically Disabled Women. *Female sexuality and physical disability.* Available from: Planned Parenthood of Snohomish County, 2730 Hoyt, Everett, WA 98201.

United Cerebral Palsy Associations, Inc. *Human sexuality.* (1976) Available from: United Cerebral Palsy Associations, Inc., 66 East 34th St., New York, NY 10016.

Veterans Administration Hospital. *Sex and the handicapped: A selected bibliography (1927-1973).* (1974) Available from: Veterans Administration Hospital, Spinal Cord Injury Service, 10701 East Blvd., Cleveland, OH 44106.

Virginia Spinal Cord Injury System. *The psychological, social, and sexual aspects related to spinal cord injury: A book of article summaries.* Volume I. (1977) Available from: Spinal Cord Injury Project, Woodrow Wilson Rehabilitation Center, Dept. of Vocational Rehabilitation, Fishersville, VA 22939.

Woodrow Wilson Rehabilitation Center. *Spinal cord injury project library bibliography.* (1977) Available from: Spinal Cord Injury Project, Woodrow Wilson Rehabilitation Center, Dept. of Vocational Rehabilitation, Fishersville, VA 22939.