

SEXUALITY AND DISABILITY: LOOKING BACKWARD AND FORWARD

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In the spring of 1978, I found myself walking the streets and avenues of New York City, resume in hand, trying to decide just what to call myself. Should I look for a job as a rehabilitation counselor who specialized in sexuality and disability, or should I say I was a sexuality and disability counselor-educator who had a masters degree in rehabilitation counseling? After I figured out how I would identify myself, where would I seek employment? A hospital? Rehabilitation center? The private sector? A state funded organization? Would anyone hire an individual with my specific skills? Finding a job seemed impossible. There were lots of pats on the back, statements about how interesting I must find my work "What work?" I thought to myself, "I'm hoping you'll give me work!!!" About this time, a meeting was held at United Cerebral Palsy of New York City. The meeting was attended by numerous professionals from the city who were working in rehab and who were interested in doing work in the field of sexuality and disability. Also in attendance were Susan Knight and David Bullard from the Sex and Disability Training Program at the University of California, San Francisco. In 1977, I had been a trainee at UCSF in the first training session they had conducted, which followed on the heels of my completion of graduate school. We sat together and talked about the emerging field of sexuality and disability. We were all in agreement that it had a rightful, important place in service programs for people with disabilities. Why, if this is true, I asked, can't I find a job?!!

I was fortunate to be in the right place at the right time. Giovanna Nigro of UCP/NYC advised me that UCP of Queens was looking for a person to work on sexuality education and counseling with its clients. "This is too good to be true," I thought, as I surveyed the blisters on the bottoms of my feet and the callouses on my knuckles. It was just about two weeks later that I found myself sitting behind a desk at UCP/Queens, organizing my books and thoughts. After a fantastic experience of working with clients who were developmentally disabled for one and a half years, I packed up my skills and moved on to work at UCP/NYC under the supervision of Giovanna Nigro. I worked at the New York City office for about an equal length of time and served a similar client population. Since 1981 I have

had the pleasure of coordinating the Reproductive Health Care and Disability Program at Planned Parenthood of New York City. Happily, I've come a long way since 1978—although I've still not decided exactly what to call myself!

There are now many people working in the field of rehab to ensure that people with disabilities have access to complete, factual information related to their sexuality. The field of sexuality and disability probably had its organized beginnings in the early 70's, when the first training programs in sexuality and disability were being perfected by Theodore and Sandra Cole at the University of Minnesota. After more than fifteen years of growth and development, now may be the time to examine just how this adolescent is doing.

I recently spoke with a number of professionals who could be considered "pioneers" in the field of sexuality and disability and asked them to share their feelings about the progress we have made. We also discussed what we must do to ensure that the field will continue to grow into adulthood and many years beyond, into the distant future. Those I spoke with include Giovanna Nigro, United Cerebral Palsy of N.Y.C.; Isabel Robinault, United Cerebral Palsy Associations, Inc.; Sandra Cole, University of Michigan; Mary Romano, National Rehabilitation Hospital; Simi Linton, private psychologist; Sol Gordon, Syracuse University; Anne Welbourne-Moglia, SIECUS; and Tuppy Owens, Outsiders Club in London, England.

Each of these individuals felt that we have made significant progress in increasing public and professional awareness of the general needs of people with disabilities, including their social sexual needs. People with disabilities, as well as their families, have become more vocal as a consumer group. This is progress. Perhaps it is slow, but an important message is reaching society: people with disabilities are more alike than different from the able-bodied.

The media has played an important role in exposing the general public to disability and the social/sexual needs of those who are disabled. Recently a major morning talk show in New York City invited three individuals to discuss sexuality and disability. The segment lasted some twenty minutes and was well received by the public. Now that's progress! In the mid

1970's the film *Coming Home* encouraged consideration of sexuality and the needs of people with disabilities in its presentation of a beautiful and sensual love scene between Jane Fonda and a spinal cord injured, Vietnam veteran played by Jon Voight. Similarly, television has gradually improved its depiction of people with disabilities. Actors who are disabled are being cast in the roles of the disabled, instead of casting able-bodied actors in these roles. Television is stepping back from the two extreme views of the disabled. The disabled person is no longer portrayed as either the super-hero or the angry person with an enormous chip on his shoulder. If you look closely at a recent television commercial for MacDonald's, you will spot a young man in a wheelchair. This too is progress.

The professionals I spoke with each felt that progress has been made in the area of staff training, but that the field may have reached its peak in the mid to late 1970s in terms of securing grants and other monies to finance training for those working in rehabilitation. There appears to be little money in agency budgets allocated for the hiring of consultants to provide the groundwork for training programs, or so we are told. Could it be that issues of socialization and sexuality continue to be on the bottom of the priority list in rehab centers, in community residences for the developmentally disabled, and other facilities serving people with disabilities? It seems that "line staff," those who work on a daily basis with the disabled population, often identify their need for training in sexuality but do not receive it. All too often, "trainers" show a film on sexuality and disability and call it "training." Isabel Robinault describes these meetings as "rah-rah" sessions, or as Mary Romano says, the gathering of staff which produces the "let's win this one for

the Gipper" feeling. We must not mistake this as training in its truest sense. Because of the lack of staff training time, other priorities, lack of funding, scheduling problems, etc., we as professionals may find ourselves being cheerleaders for the cause. Substantive training requires much more, including adequate time to return to the agency to offer support and guidance of staff.

Often mentioned in discussions about training was the lack of training of students at all levels and in all disciplines. Medical students, nurses, social workers, rehab counselors, special ed teachers, physical, occupational and speech therapists, and psychologists, etc., need to receive adequate exposure to issues of sexuality and disability within the context of their overall training programs. We should be producing a group of professionals who are well-rounded in their approach to the concept of total rehabilitation, who do not omit issues of sexuality and hope that someone else will deal with the topic. Interesting discussions were sparked by the question of why so few sexuality professionals—therapists, counselors and educators—have chosen to add to their set of skills by increasing their knowledge of sexuality and disability. Many found that training programs were far more often attended by professionals working in jobs directly related to rehab or special education than by individuals in sex education, counseling, or therapy. It was noted that workshops and round table discussions on sexuality and disability held at SSSS and AASECT national conferences have been very poorly attended. Throughout the country there are far too few knowledgeable resources for individuals with disabilities even though in most metropolitan areas there is no shortage of people working in the field of sexuality. People interested in expanding their expertise in sexuality to include the provision of services to disabled individuals should locate the nearest Sexual Attitude Reassessment Seminar Center (SAR). They are located at some of the major rehabilitation centers throughout the country. (Contact SIECUS for the SAR center closest to you.)

Two organizations concerned with issues of sexuality and disability have been developed. Their primary aims are to ensure the continued progress in this field as well as to create an atmosphere wherein sexuality and disability is legitimized as an important issue. The Coalition on Sexuality and Disability, Inc. is an organization committed to advancing the full social integration of people with disabilities. It works to increase the availability of accessible, client-responsive sexual health information and services. It is a network of people, both disabled and non-disabled, professionals and members of the community. The Coalition provides educational programs and advocates the right of people with disabilities to have a social and sexual life. Another organization, the Task Force on Sexuality and Disability of the American Congress of Rehabilitation Medicine, has played a major role in keeping issues of sexuality in the forefront among the providers of medical services to disabled individuals. The establishment of the network of SAR centers is only one of the many important contributions made by this task force. SIECUS can put you in contact with these organizations.

Another step forward has been the inclusion, in some agencies servicing the disabled, of human sexuality studies programs coordinated by skilled individuals. United Cerebral Palsy of Queens and UCP of New York City serve as two shining examples of agencies that employ full-time professionals to work with clients and staff in sexuality and disability.

Non-rehabilitation agencies, such as Planned Parenthood of NYC and Planned Parenthood of LA (as well as other affiliates

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of PPFA), have identified the need of people with disabilities to receive the same kinds of reproductive health care services as any other individual. The Margaret Sanger Center of Planned Parenthood of NYC sought and received federal monies in the early 1980s. This funding has enabled Planned Parenthood to make its clinic accessible to people with disabilities. They purchased educational materials, installed hydraulic exam tables, lowered the button panels in the elevators, and, in 1981, opened its architecturally accessible doors to people with disabilities. After five years, and despite many budget cuts, the Reproductive Health Care and Disability Program is alive and well, evidence of the agency's commitment to meeting the needs of disabled people for sexuality counseling, education, and direct medical services. Sadly, the funding needed to open and sustain this kind of program is for the most part unobtainable given the current fiscal and political climate. As Giovanna Nigro stated, the good intentions of any agency are only realized when funding is available.

One must question why so few positions exist in the field of sexuality and disability compared to those found at Planned Parenthood and the UCP affiliates. Mary Romano suggested we must ask if there are so few jobs available because there is a limited number of people seeking employment of this nature or if the number of people specializing in the field of sexuality and disability is painfully small because of the scarcity of agencies seeking to employ people with these skills.

Many suggestions relating to what professionals in the field of sexuality could do to ensure the future growth of this field were offered. Some of the suggestions are as follows:

1. We need more research in such areas as sexual abuse, pregnancy, child-birth, parenting, and sexual functioning of disabled people.

2. We must increase the accessibility of information related to sexuality and disability for all—students and professionals, disabled and non-disabled. According to Anne Welbourne-Moglia, the SIECUS Resource Center finds that sexuality and disability is the third most asked about topic following sex education and adolescent pregnancy. Essential publications such as *Who Cares?*, *Sexual Options for Paraplegics and Quadriplegics*, and *Sex, Society and the Disabled* are just a few examples of books no library should be without. Universities, hospitals, as well as public libraries should seriously consider increasing their holdings in this very important area.

3. We must find ways to decrease the isolation of people with disabilities. This isolation prevents social skills to be developed because of lack of practice. Friendships, which are the basis upon which deeper relationships are formed, may not be initiated. We must not forget that the socialization aspect of our sexuality is vital. Finding solutions to the issue of isolation isn't easy in a society filled by architectural and attitudinal barriers.

4. We must develop new treatment techniques to use in sex therapy and counseling for people who have organic impairments of their sexual functioning.

5. We must continue striving to ensure that professionals in all disciplines working with disabled people have appropriate training to increase their level of comfort about sexuality. They must become permission-givers who may not have all the answers but who know when to refer a patient/client to a professional with well-developed skills and knowledge in sexuality counseling, education, and/or therapy. If all helping professionals could do this, people with disabilities would benefit more than is imaginable.

6. We professionals who are skilled in sexuality and disability must nurture students and draw them into the field by providing internship opportunities. All of us realize that reading books can never provide the kind of education that actual one-on-one work with a client can offer. By offering these opportunities, we will increase the pool of professionals working in the field who have *skills*, not only good intentions.

7. We must continue networking. Cooperation between people with disabilities and service providers is essential. Organizations, such as CSD, SIECUS, AAECT, the Task Force on Sexuality and Disability and SSSS must forge a bond which will ensure that the needs for sexuality services for all individuals will be met.

8. We must continue to advocate issues of sexuality, individual needs, and basic human rights with public officials. This is especially needed in the area of mental retardation/developmental disability where the topic is all too often avoided due to fear, misunderstanding and "other priorities". We must act as an advocate for this population of consumers.

Finally, and perhaps most importantly, we must remember that almost everyone becomes disabled in some way, to some degree before they die. This fact may help us to avoid the "them" and "us" feeling that too often prevents full social and sexual integration of people within our society.

DO YOU KNOW THAT . . .

Resources to Write for . . .

Teaching People With Mental Retardation About Sexual Abuse Prevention (1982) by Cordelia Anderson of Minneapolis's renowned Illusion Theater Company is a 24-page guide for educators working with moderate-to-high functioning mentally retarded people. It emphasizes role playing, described in such sections as "Stranger on the Bus" and "When Touch Changes From Good to Bad," as well as the development of practical skills. This resource, priced at \$4.95, plus 15% p/h, may be ordered from: Network Publications, 1700 Mission Street, Suite 203, Santa Cruz, CA 95061-8506.

About Sexuality and People With Disabilities, a 1985 addition to the Scriptographic Booklet series, is a 15-page pamphlet encouraging family and friends to accept the sexuality of people with disabilities, help provide them with accurate information, and realize that there are many ways to express one's sexuality. Single copies cost 69¢, and bulk rates are available. Orders should be sent to: Channing L. Bete Co., 200 State Road, South Deerfield, MA 01373.

Love, Sex, and Birth Control for Mentally Handicapped People: A Guide for Parents, by Winifred Kempton, Medora S. Bass, and Sol Gordon, has been revised and issued in its seventh edition (1985). The 38-page guide offers supportive, practical suggestions for providing basic sex education in the home and also for dealing with the sexuality of mentally retarded daughters and sons. Topics covered include reproduction, puberty, masturbation, dating, sexual decision-making, contraception, sexual abuse prevention, marriage, and parenthood. It is available for \$2.95, plus 45¢ p/h, from: Planned Parenthood, 1220 Sansom Street, Philadelphia, PA 19107.

WHERE THE ACTION IS

Confronting the Myth of Asexuality: The Networking Project for Disabled Women and Girls

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There is a pervasive myth in our society that people with disabilities are asexual. This myth is reflected in our associations to disability: dependent, sick, childlike, helpless—not very sexy images; in our language: paras and quads, *the blind*, *the disabled*, rather than women and men who happen to have disability as one of their characteristics; and in our media images: telethons and poster children—appealing as fundraisers but lacking in sex appeal.

Women with disabilities are particularly likely to be perceived as asexual, for several reasons. So much of the traditional view of female sexuality is based on physical appearance, on meeting Madison Avenue standards of beauty and physical perfection. While disabled women are by no means unattractive, they often differ from these norms. In contrast, male sexuality, which is based less on physical appearance, includes other components, such as income level, status, and type of work; a disability in a man is thus less likely to detract from his sex appeal.

Differences in male and female socialization and gender role expectations also reinforce asexuality in disabled women. To the extent that passivity is still viewed by families and society as *appropriate female behavior*, disabled women and girls are not encouraged to challenge the myths about their lives that confront them. The woman's role in dating and courting continues to be a passive, waiting role. So that for disabled women, and indeed all women, feeling sexual is more dependent on being chosen, which in turn is more dependent on the attitudes of potential partners and society as a whole. In contrast, disabled men can take a more active role in validating their sexuality by choosing a partner. Also, sex is more readily seen as a physical need for men than for women, a need which must be met, disability and all. A further factor is that women are more readily seen as nurturers than men are, so that disabled men may more easily find and expect to find a woman to care for them; whereas it is less socially acceptable and hence more difficult to find a man to "tend to" a disabled woman.

In comparing disabled women with disabled men, it is important to note that disabled women may have fewer social opportunities with which to test out and disprove the myth of asexuality for themselves. Their families are more likely to be overprotective in the social and sexual arena. They do not have access to "old boys' networks," which often serve to introduce disabled men to the world of sexuality. And, the major social

stomping grounds—college campuses and the workplace—are often less available to disabled women.

The myth of asexuality seriously limits the social and sexual options and opportunities of disabled women and girls in a variety of ways. It may limit their families' and friends' social expectations for them, which in turn may affect the expectations that disabled women and girls have for themselves. It may limit disabled women's access to sex information and sexual health care services, because parents, educators, and society may view such information and services as unnecessary. It contributes to the limited accessibility of social and singles' activities, often fraught with architectural and transportation barriers. It limits the number of potential partners who are able to recognize the social and sexual capacities of disabled women. Finally, the myth of asexuality may limit these women's own identity as desirable, attractive, sexual people and affect their self esteem. Disabled women pay a high price for this myth. Indeed, statistics suggest that disabled women are less likely to marry, are more likely to marry late, are more likely to be divorced post-disability, and are more likely to be alone and left alone in comparison to either disabled men or nondisabled women (Fine and Asch, 1981).

Yet disabled women are sexual and are entitled to and capable of an active, rich, social and sexual life. How can they confront the myth of asexuality in themselves, in their families, and in society?

For all women, disabled or not, access to strong, positive role models is one major strategy for confronting limiting myths and stereotypes and expanding their range of professional and personal options. Within the women's movement, strong emphasis has been placed on developing networks and programs that will provide women with access to other women from whom they can learn and emulate. Through role models and networks, women have been able to climb further up the corporate ladder, enter nontraditional fields, and explore new lifestyles.

Role models, which might help confront the myth of asexuality, are noticeably absent in the lives of most disabled women and girls. Disabled women do not usually have disabled mothers or other disabled family members with whom they can share their experiences; they are often the only disabled person in their community. Also, successful disabled women are quite invisible in our society. While there have

been many socially and professionally successful disabled women historically and currently—women like Harriet Tubman, Elizabeth Barrett Browning, Sara Bernhardt, Kitty O’Neal, Mary Tyler Moore, and Wilma Rudolph—the fact that these women have disabilities is rarely known. Because of the stigma of disability, when a disabled woman becomes successful, she is often no longer perceived as disabled. In people’s minds, “disability” and “success,” particularly social and sexual success, do not go together. Thus these well-known women do not serve as role models for other disabled women and girls.

One innovative program that seeks to confront the myth of asexuality and other stereotypes about disabled women by providing highly visible positive role models is the Networking Project for Disabled Women and Girls, sponsored by the YWCA of the City of New York. This project seeks to increase the social, sexual, educational, and vocational aspirations and options of adolescent girls who have physical and sensory disabilities by linking them with successful disabled women in the community who can serve as role models and mentors. These disabled women lead diverse life styles and work in a range of occupational areas, from carpentry to medicine, business to fine arts. These women’s very presence and visibility, as well as their willingness to share their experiences and advice, enables the girls and their parents to begin questioning the numerous myths and stereotypes about being a disabled female that subtly permeate their lives.

“How do you flirt when you can’t see?” “Where did you meet your partner?” “What is it like to have a baby when you have no sensation?” “Do your children feel self-conscious because you look different from other mothers?” “Is it scary to live on your own?” “How did you figure out how to ‘do it’?” These are some of the questions that adolescent girls have been able to ask their mentors at the conferences, small group discussions, home and worksite visits, and one-to-one encounters that the project provides.

The adult women try to answer these questions as openly and realistically as possible, acknowledging the myriad obstacles to “social success” that disabled women face, while at the same time opening new possibilities by offering strategies to address the barriers. For example, one of the women shares some of her experiences with prejudice: “Some partners may be put off by your disability. It is not fair, but this is the way it is in our prejudicial world. Sometimes you may want to confront the person, at other times it may be better to let it be. The important thing to remember, though, is that not everyone will be turned off. Some people will recognize that you are indeed desirable, attractive, and sexual. And, after all, you only need one.” Another mentor, who has visual impairment, offers her experience with flirting: “While it indeed may be easier to flirt if you can make eye contact, this is not essential; a telling smile or casual touch of the hand can be quite flirtatious, if you wish it to be.” Another woman offers some advice on learning about sex: “In order to figure out how to ‘do it’, disability and all, you should first learn as much about your body as possible. A lot of disabled women know relatively little about their own disabilities, and they also know too little about their anatomy as females. Nondisabled women share our problem—we all know too little about our bodies. To enjoy your sexuality as fully as possible, you need to know how your body works, what parts of your body work, and what parts don’t work as well. Get as much information as you can so you will know rather than have to guess about what you can and can’t do sexually; then you can make good choices.” Another woman, the mother of three children, explains having children when you are disabled:

“Having a baby when you are quadriplegic may involve some creative problem solving, but it is definitely possible and an experience that I would never have wanted to miss. My own parents thought I was crazy when I decided to have a child, and I got furious at them. As a woman, I am entitled to make my own choices about having children. Of course, that meant that my husband and I had to take responsibility for figuring out ways for me to feed, hold, and care for an infant without the use of my arms, and for him to be available for assistance when I needed it. But there are always ways, if you feel entitled.”

Utilizing role models to help young disabled women feel entitled to all aspects of themselves and their lives, including their sexuality, is what the Networking Project is all about. The project views sexuality as a broad concept, including all the ways people think, feel, and act as women or as men; our sexuality affects how we walk, talk, dress, work, play, feel about ourselves, and relate to others. It includes but is not limited to specific social activities, such as dating, or to acts of sex per se. Thus many of the activities and events sponsored by the project address issues of sexuality, although not necessarily as the main focus; in all cases, the emphasis is on choices and options. For example, many intergenerational discussion groups include discussion questions on identity and self-esteem as women, types of relationships, and parenthood, as well as educational and career choices. Also, worksite visits, where small groups of girls visit with a role model at her workplace, have included not only visits to courtrooms, computer terminals, and neurochemistry laboratories, but also to cosmetics firms and fashion houses, where the girls can experiment with makeovers, new hairstyles, and new looks on the road to self-definition.

An example of a project activity is attending a recent miniconference celebrating the artistic achievements of disabled women that included the performance of a play, “Love Letter,” by writer Bobbi Linn. This play describes the first love experiences of an adolescent girl with cerebral palsy. The performance led to a rich discussion by the more than 30 disabled high school girls attending, who were able to share their own anxieties and concerns about first dates and obtain support from the author and from one another. As one of the girls noted, “This play was the highlight of my day. Dating is a hot issue on my mind. I sometimes wonder if a teenager with a disability can make it out there. It is good to know others have survived.”

Dating and the social arena are also “hot topics” for parents of adolescent girls with disabilities, who are encouraged to participate in the project. Many of the parents involved with the project would like to help their daughters become more socially involved with their peers, yet have difficulty letting go. These parents may have great difficulty allowing their disabled teenagers to go out without their supervision, to explore transportation options, or to obtain much needed independent living skills, for fear that their daughters may be victimized when they are on their own. Suggestions, support, and gentle admonitions from adult disabled women enables parents to provide their daughters with more of the information and opportunities they need to become independent, successful women. One parent stated, “I never realized disabled women could do so many interesting things with their lives. Suddenly it seems like we have so many more options. We need more programs like this one.”

The intent is to create more programs like the Networking Project, since currently this is the only program of its type in the country. Over the next year, with funding from the U.S. Department of Education, The JM Foundation, and the New

York Community Trust, the project will be replicated in several sites nationwide, within YWCAs or other types of agency settings. Instructional materials, including a book highlighting the lives of 12 successful disabled women and a videotape illustrating the mentoring process, are being developed to facilitate replication and increase the number of disabled women, girls, and parents who are reached.

The Networking Project for Disabled Women and Girls is part of a larger effort to confront the myth of asexuality that unnecessarily and unjustly restricts the lives of women with disabilities. It is to the advantage of everyone, disabled or nondisabled, women or men, to join in this effort. Each of us has been restricted by an overly narrow definition of sexuality that says who is attractive, who is desirable, who is sexual. When we challenge this definition with regard to women with disabilities, we also challenge and expand it for all of us.

For further information about the Networking Project for Disabled Women and Girls, contact: Harilyn Rousso, Director, Networking Project for Disabled Women and Girls, YWCA of the City of New York, 610 Lexington Avenue—9th Floor, New York, NY 10022; (212) 735-9767.

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DO YOU KNOW THAT . . .

Resources to Write for . . .

A Hearing Impaired Woman's Incest Experience is a ½ or ¾ inch (150 mins.) color video tape in sign language with voice-over. The tape may be rented for \$50.00 or purchased for \$150 from: Mental Health Hearing Impaired Program, St. Paul-Ramsey Medical Center, 640 Jackson Street, St. Paul, MN 55101.

Spinal Cord Injuries: Psychological, Social and Vocational Adjustment (1980) by Roberta R. Trieschmann is a well-written, thorough, state of the art book that covers social and psychological treatment of patients with spinal cord injuries. Included in this book is a chapter on sexuality and spinal cord injury that states that sexuality cannot be overlooked, but instead, integrated from the onset of disability. The author advocates focusing on human needs and providing options for the patient. The cost of the book is \$25.00 and it can be ordered from: Pergamon Press, Maxwell House, Fairview Park, Elmsford, N.Y. 10523.

What is SEX ED Really? (1985) is a pamphlet written by Ann Thompson Cook and Mary Lee Tatum for parents, clergy, youth workers, and school board members and administrators. Questions about what sexuality is, how children learn about sexuality, what sex education does and does not do, and how sex education helps are answered. Other points made are that sex education should be age appropriate, tailored to the needs of the community and supported by parents. A five-point checklist for sex education programs is included. Priced at \$1.15

per copy; minimum order 25. Order from: Sex Education Coalition, 1309 L Street, N.W., Washington, DC 20005.

Tips for Parents (1984) is a four-page guide on talking to children about sexuality. Frequent concerns such as parental discomfort and fear of having to discuss their personal sex lives are addressed. Suggestions for bringing up the subject based on material from television and newspapers are given, along with ten communication tips. The point emphasized is that only parents can convey their family's values to their children. Available for \$1.00 each for single copies or \$.50 each for orders of 25 or more from: Sex Education Coalition, 1309 L Street, N.W., Washington, DC 20005.

Papers from a National Policy Conference on Legal Reforms in Child Sexual Abuse Cases (\$20.00) and **Evidentiary and Procedural Trends and other Emerging Legal Issues in Child Sexual Abuse Cases** (\$3.50) are two monographs published in 1985 by the American Bar Association. The first contains results from a national invitational conference held in Washington, D.C., in March 1985, where experts from around the country analyzed recent innovations in the legal system's handling of child sexual abuse cases. The second analyzes recent legislation, creating a special exception for out-of-court statements of child sexual abuse victims and allowing the use of video-taping and closed circuit television for children's testimony. Both are available from: National Legal Resource Center for Child Advocacy and Protection, 1800 M Street, N.W., Washington, DC 20036. Prices include p/h.

La Familia Es Importante is an 8-page Spanish language pamphlet in comic book format. This 1984 publication is designed to encourage couples to plan their families, visit clinics and doctor's offices where birth control services are available, and use contraceptives. Priced at \$.27 for a single copy, it is also available at \$25.00 for 100 from Planned Parenthood of Orange County, 1801 North Broadway, Santa Ana, CA 92706.

Changing Shapes of the Family (1984), by Robert Sayers and Carla Thornton, is directed toward the adults and children of single-parent, divorced, and blended families. This communication guide, giving practical suggestions to help ease the tension often found in new family structures, was developed by Heart-to-Heart, a project sponsored by Planned Parenthood of Marin and Sonoma and the Family Service Agency of Marin. The publication actually contains 2 booklets in one, each subtitled: "Guide to Dealing with New Family Forms and Changing Relationships," with the section for adults starting at the front and the section for young people at the back. Available for \$2.95 + 15% p/h from Planned Parenthood, 20 H Street, San Rafael, CA 94901.

Young, Gay and Proud!, much of which was originally published in Australia by the Gay Teachers and Students Group of Melbourne, has now been issued in a second U.S. edition. Both the 1980 and 1985 U.S. editions are edited by Sasha Alyson, who has added much new content, especially on AIDS. Addressed to gay high school students, the book also covers meeting other young gays, coming out in schools, telling parents, dealing with gay sexuality, and finding one's identity. Available for \$4.00 (incl. p/h) from Alyson Publications, 40 Plympton Street, Boston, MA 02118.

WHERE THE ACTION IS

Sexuality Education in a Psychiatric Day Treatment Setting

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As part of the rehabilitation curriculum of a long-term psychiatric day treatment program for the chronically ill a sexuality education program was initiated by the author. It consists of a weekly group session where facts are presented and discussions encouraged. Topics covered include basic reproductive anatomy and physiology, pregnancy and fetal development, abortion, contraception, sexually transmitted diseases, masturbation, and sexual preference. Audio-visual aids are used

frequently to facilitate concreteness. The outline is followed in a flexible manner, allowing the patient group the opportunity to progress at a comfortable pace. Methods are built in to provide the author with a mechanism for constant evaluation and revision to meet patient needs. Sexuality education is necessary and has a definite place along side the traditional daily living skills and psychology offered in a psychiatric rehabilitation setting.

My work in a partial hospitalization rehabilitation setting has led me to the conclusion that chronically mentally ill people need sexuality education as much as, if not more than, the general population. Reasons for this include the fact that sex is a readily available form of gratification, there is potential for abuse in this population, and there seems to be a general lack of basic knowledge. My conclusion was based on observations of other populations—school age children with their parents (as a family unit), teenagers, and college students—to whom I have taught the subject. Although there are related articles focusing on the sexual activity and education of institutionalized mentally ill people, I could not find a description of an actual sex education group in a psychiatric day treatment program. I decided to develop my own sexuality program in the Psychiatric Extended Rehabilitation Program, in the Capital Region Mental Health Center, a community facility of the University of Connecticut Health Center.

The patients I work with are adult men and women, most of whom have had several psychiatric hospital admissions. Many have literally been in and out of various institutions their entire lives. The intelligence level, educational background, and existing support systems are varied. The average stay in the program is about eighteen months. These people live in various community settings (supervised or unsupervised). The diagnoses vary, but most patients have a history of schizophrenia and/or an affective illness. The program's average daily census is twenty-three. A major goal of this program is rehabilitation with a return to or progression towards independent living. The days are structured with various groups (e.g. cooking, budgeting, social skills, psychotherapy). All patients are required to attend all groups.

For about three years I have been conducting a weekly sexuality education group. Each session lasts thirty-five minutes and is attended by all patients together. Group participation is encouraged in order to help me determine the level of under-

standing and identify individual needs. I try to answer all questions that are asked. If the question isn't directly related to the topic, I answer briefly and concretely, possibly referring to another group or an individual therapist for further discussion. Although I follow an outline, I avoid a strict time schedule for individual topics. The first few minutes of each session are devoted to a review of the previous session. Based on this review, I proceed to a new topic or continue with the same. It takes approximately four to five months to cover the range of topics. To facilitate concreteness, I use audio-visual aids, including diagrams, models, samples, and films. Also, common slang expressions are interchanged with technical terms (e.g., "the testicles, which are sometimes called 'balls', are where the sperm are made and stored").

Reproductive System

The module I developed begins with an explanation of basic male and female reproductive anatomy and physiology. Each patient is offered his or her own copy of simple diagrams of the male and female reproductive systems. They can label and keep them if they so desire. Full body diagrams with reproductive areas circled are displayed as a reference for perspective. The first week or two, I discuss the male system. This includes information about the scrotum, testicles, sperm, vas deferens, semen, various auxiliary glands, the urethra (including urination and ejaculatory functions), penis, and erection. The next one or two sessions are spent on the female system. This includes the ovum, ovaries, Fallopian tubes, uterus, cervix, vagina, clitoris, menstruation, fertilization, and menopause. I provide samples of tampons and sanitary napkins during the discussion on menstruation. Each time menstruation has been discussed, at least one group member has asked about Toxic Shock Syndrome. Thus, I decided to include this subject permanently.

Contraception

When I sense the group is fairly familiar with this information, the module continues. Several weeks are spent discussing masturbation, and the fact that it doesn't cause physical or mental illness; intercourse, including a consideration of physical maturity versus emotional maturity and responsibility; pregnancy, and fetal development; and abortion, both therapeutic and spontaneous. I use large photographs or diagrams of the successive stages of pregnancy, describing the weight, length, and developing systems at each stage. At this time I generally introduce contraception, unless questions indicate another topic is more appropriate. I review the various contraceptive methods over several weeks. I pass around samples of oral contraceptives, intra-uterine devices, diaphragms, jellies, cremes, foam and condoms for patients to look at. This often stimulates questions and sharing of personal experiences. I also discuss the surgical and rhythm methods of birth control. Following completion of contraception, I devote at least one session to group discussion of how an individual decides when and if contraception is appropriate.

Diseases

I then discuss sexually transmitted and related diseases for two or three sessions. I present the general signs, symptoms, and implications of the various diseases. I specifically mention gonorrhea, syphilis, herpes, trichomonas, monilia, scabies, venereal warts, and Acquired Immune Deficiency Syndrome (AIDS). I cover other diseases if it's appropriate to the discussion. A mild summertime outbreak of scabies offered an opportunity to emphasize the importance of hygiene and personal responsibility when coming in close contact (not necessarily in a sexual manner) with others. I stress the local availability of detection and treatment, the implications of not getting treatment, the responsibility to one's sexual partner(s) and the fact that there is no immunity from subsequent infections.

Patient Response

My program has shown some positive effects. A sexually active woman whom I was seeing concurrently in individual treatment frequently spoke about wanting to be a mother. After group sessions on reproduction, we discussed the responsibilities involved in caring for a child. In our individual work, she acknowledged her fears about responsibility for a child. We continued to explore this and she began using a reliable contraceptive method. Patients frequently discuss their decision to use contraception.

Sexual problems are also discussed. One man questioned his medication as the cause of his impotence. This question led to an evaluation and eventual medication change for him. It certainly may not eliminate his impotence, but it gave him some knowledge and input into his own treatment. Other indirectly related therapeutic benefits include peer support and communication skills practice.

I was initially surprised at the relatively small amount of discomfort or embarrassment that patients displayed. Although this is merely a subjective observation, it has been confirmed by visiting staff members and students. Keeping general group dynamics in mind, I try to direct potentially uncomfortable questions or situations to the group rather than to an individual. In response to the man who commented "... it's disgusting to talk about bodies, . . ." I said to the group, "How do you feel about this?" The majority of the members

reported positive feelings about the group although some admit to feeling "nervous, dumb, or embarrassed," even though they like the group. I encourage exploration of these comments whenever possible. I tell patients that sometimes people are embarrassed when they don't understand things or are not used to discussing certain things. Although attendance in the group is a program requirement, no one is forced to participate in the discussions.

Frequently questions or comments will reflect an individual's poor self-esteem or personal identity. The patient who asks, "What's the usual number of times a man will think about women (in a sexual manner), may really be asking "Am I normal?" In discussing topics that involve personal or religious values or feelings, I consciously try to avoid using words like normal or abnormal, right or wrong. If I'm giving my personal opinion, I will say so, for example, "I think that sexual activity is a personal decision; we all should be able to decide for ourselves just what is comfortable for us." Occasionally, being non-judgemental calls for self-control and values clarification on my part. When necessary, I discuss this during a supervision session.

Program Revision

I keep a journal documenting patients' reactions and frequently asked questions. This helps with program revisions. I continually note a group fascination with prenatal development, heredity, and genetics. Some patients have asked directly, "If I have children, will they get my mental disease?" Multiple births, unusual conditions, and defects are subjects that generate group interest. Often a theme is initiated by a comment or question. The topic of sexual preference is generally addressed by group members in terms of normal versus abnormal. As with other emotionally charged subjects, my goal is to factually explain and clarify, rather than make judgments. Group members are encouraged to discuss personal and religious viewpoints.

Current events frequently will influence the topic of the week. When there was much media coverage of AIDS, many patients shared concerns about possible symptoms. The group also initiated a discussion on the quality of life in response to local publicity about severely handicapped infants and their right to treatment.

In addition to patients' comments, I also rely on the feedback offered by visiting staff and students. Within the mental health center, there has been much staff encouragement. I presented a synopsis of this program at a general staff in-service education session. This resulted in requests for consultation from the Center's Outpatient and Acute Day Treatment departments. Subsequently I received a request for assistance in starting a program on an inpatient unit in a state hospital.

The fact that people have a mental illness does not make them different from other populations in terms of basic interest about their bodies. They have heard some of the same myths and harbor some of the same fears as others. The positive response to this program from patients and other mental health professionals has confirmed my assumption that sexuality education can be beneficial to chronically mentally ill people. It promotes responsibility rather than promiscuity, therefore it has a place in a rehabilitation program along with psychotherapy and daily living skills.

Note: The author would like to acknowledge Jane Hardy Davis of the Human Growth and Development Program.

SPEAKING OUT

Sexual Abuse and Disability

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Susan was born with cerebral palsy. She was the first of four children. She and her brothers and sister grew up in a poor rural neighborhood. Susan's mother worked nights in a factory. As a young child Susan could get around by walking and holding onto objects. When she reached the age of nine, crawling was her only means of movement. When Susan became ten, she got her first wheelchair.

It was at this time that Susan's mother remarried. On many occasions, Susan's stepfather babysat for her. Susan did not like her stepfather; he was always trying to hug and kiss her when she did not want him to. Susan's way of dealing with this was to stay away from him by going to her room. She frequently pretended to be asleep to keep her stepfather away.

One Saturday night when they were alone, Susan's stepfather came into her room and started touching her. She told

him to stop, but he just kept doing it. He then turned her so she was lying on her back. In this position, her disability made it impossible for her to move. Susan's stepfather then forced her to engage in oral and anal sex, followed by coitus.

Susan wished she would die. For the next two years her stepfather continued to force her to engage in sexual relations. In addition, he started to bring his male friends. When they paid him, they too had sexual relations. Not long after that, Susan's mother started to show Susan sex magazines. She also began to invite other male friends over to have sex with Susan.

Susan felt like a prisoner in her home. She felt there was no one she could tell about this terrible thing she was doing. After all, her mother had told her many times that their life was hard because of Susan's disability. Susan did not feel she had any right to complain.

Note: This is a true story. The names and identifying information have been altered.

We are beginning to realize that Susan's experience of sexual abuse is not that unusual. As there has been increasing public awareness about the frequency of sexual abuse in our society, there has also been more discussion and reports about the incidence of sexual abuse among the disabled. Unfortunately, the amount of data available documenting these cases is significantly lower for the disabled population than for the able bodied.

A 15-month study conducted in Minneapolis uncovered 60 cases of physical and sexual abuse (Center for Women's Studies, 1984). The Seattle Rape Relief Disabilities Project and Sexual Assault Center reported over 700 cases of sexual exploitation involving disabled children and adults in the period from 1977 to 1983. The Developmental Disabilities Project considers this figure to be low because of the many factors that cause the low reporting rate of sexual abuse cases among the disabled. They estimate that over 3,500 cases of sexual abuse have actually occurred during this period in the Seattle-King County area (Ryerson, 1984). Because of inaccurate reporting, it is

necessary at this time to rely on estimates from professionals who work with people who have disabilities.

In December, 1985, the Los Angeles Committee on Abuse of Disabled Persons sponsored the First Annual Conference on Abuse of Disabled Persons. At this meeting, it was estimated that 99% of disabled children experience at least one incident of abuse by the time they are 18. Abuse included incest, fondling, exposure, rape, physical injury, and financial harm. While this figure may seem high, it is corroborated by research conducted on a blind population (Welbourne, Lipschitz, Selvin, and Green, 1980) in which over 50% of the women who were blind from birth reported one or more forced sexual experiences. This frequency was significantly greater from their sighted counterparts, who were also interviewed.

Another estimate of the incidence of sexual abuse among the disabled is based upon applying the ratio of disabled to nondisabled to the incidence of all reported rape in this country. Using this method, the estimate would be 100,000 cases of sexual abuse a year (Center for Women Policy Studies, 1984).

Some experts, such as Barbara Rawn, a counselor at Deaf Community Counseling Services in Richmond, Virginia, and Howard Dickman, director of the Mental Health Hearing Impaired Program at St. Paul-Ramsey Medical Center, believe that the high rate of family violence among the deaf may be related to the additional frustrations encountered in their lives (Center for Women's Studies, 1984). One might postulate that if the rate of family violence is higher, then the rate of sexual abuse might also be higher.

Today a large portion of our society recognizes sexuality as an integral part of human life. When we deny or are denied that aspect of life, an important part of our identity suffers. This same society is constantly denying the disabled the right to their sexuality. The disabled are identified by society in terms of their disabilities. Their right to express their sexuality is bound to this social perception, and they suffer from the resulting myths (Worthington, 1985).

Growing up disabled is particularly difficult. Susan's history of the abused disabled person is typical, in fact it contains all the characteristics common to these cases. The circumstances, the abusers, the evolution of the victimization, and the feelings and frustrations of the victim are apparently classic according to the information available to us to date.

Parents of all children have difficulty coming to terms with their children's sexuality. Parents of disabled children rarely recognize their children's sexuality at all. When it is recognized, it is often ranked below other health concerns of the child. There is strong evidence that healthy sexuality is dependent on a healthy self image. But the disabled population is denied the opportunity to structure healthy self images because they have little or no contact with their peers, one of the greatest sources of information. Disabled children miss important cues to social and sexual feelings because they are isolated, either physically or emotionally, from their able-bodied peers. Although their normal biological sexual processes exist, lack of learning experiences and social experimentation can result in deficits in self esteem, body image, social skills and knowledge on which to base social and sexual skills as an adult (Glass, 1984; Knuth and Smith, 1984).

By the time disabled children reach adolescence, they have learned that passivity and cooperation are the keys to independence and survival (Center for Women's Studies, 1984). The same traits that are necessary for survival make the child vulnerable to exploitation and sexual abuse. Ellen Ryerson states that in the majority of abuse cases of the disabled in which the offender is a member of the family or care provider, the victim is either confused about the appropriateness of the behavior or unaware of his/her victimization (Ryerson, 1984). The offender has an additional advantage if the physically handicapped child has restricted mobility. These children are taught to comply with the instructions of family and care givers and may not be able to distinguish between handling done for care and handling for the sexual pleasure of the offender.

If the offender is a family member, it is easy for the abuser to create a reality that allows for the victimization to occur. The victim is taught that affection is connected to the sexual activity and that their relationship is "a special secret." These same behaviors are found in sexual abuse cases of normal children. The difference is that the disabled population is much more isolated from non-abused friends and non-abusive individuals. Therefore, the ability to learn or compare appropriate behavior is limited.

The lack of sexual health care facilities available to people

with disabilities adds to this lack of adequate information about sexual abuse. Many of the facilities designed for the able-bodied population are not accessible or adequately staffed for the disabled. On the other hand, those medical facilities specifically designed for the disabled often lack the resources to help with the sexuality concerns of their clients. Thus, the abused client who is also disabled is often faced with no place to turn. As a result the rate of unreported incidents of abuse increases.

The first and most important step that can be taken to prevent the sexual abuse of the disabled is to change attitudes through education. We must explore our own attitudes toward the disabled. Once we have accepted the sexual rights of the disabled, we can act as catalysts to help the disabled, their parents, and the institutions serving them to understand and take responsibility for their sexuality. A holistic approach dealing with the physical, social, and emotional aspects is necessary to assist people with disabilities to reclaim their sexual selves (Ryerson, 1984).

After coming to terms with our own feelings, the next step is to provide education in the institutions serving the disabled. Sexuality education should be a mandatory part of the curriculum of every disabled child. The disabled have as much right to healthy sexual development as the able bodied.

Our health care institutions must examine their facilities in relation to attending to the sexuality needs of the disabled. Those institutions giving direct services to abused individuals should eliminate the physical barriers that prevent the disabled from using their facilities. Even if the institution is physically accessible, there may be social barriers caused by inadequately trained staff that restrict their services to the disabled. The institutions that deal with the health concerns of the disabled must incorporate sexual health information as an integral part of the client's medical evaluation (Worthington, 1985).

In conclusion, most of us are disabled in one form or another, and, because many of us have experienced some form of sexual abuse or neglect, this challenge affects us all.

Postscript: Susan was able to make wonderful changes in her life through the guidance of a well-trained therapist who helped her learn about her sexual self. Unfortunately, during treatment, Susan's therapist was forced to find another office because the institution where the therapist was practicing was not "comfortable" with disabled clients.

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RESEARCH NOTES

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Ethical Guidelines for Ethics Committees

Elizabeth Rice Allgeier, PhD

Among people who do sex research, a sure-fire topic likely to elicit a spirited "I can top *that!*" response is "Ethics Committee Objections to My Sex Research Proposal." At my own institution, my students and I have never been prevented, ultimately, from doing any proposed research for which we have persevered. On the other hand, I have had many dialogues involving negotiations about various projects, and there have been a few instances in which I have simply given up on a particular project out of exhaustion. This problem has been compounded by the fact that some new faculty members rotate onto the committee every year, changing the constituency of the ethics committee. I've noticed that the first few proposals with new members involve considerably more discussion of projects than do subsequent proposals with those same members after they've been on the committee for awhile. In fact, after numerous visits to my office by one of the incoming members of our departmental ethics committee last year over proposals submitted by my students, I finally said jokingly to the EC member, "You don't have to keep using these proposals as an excuse to spend time with me; we could just go out to lunch together!" Much to my surprise, he took me up on it, we spent an hour and a half talking about sex research, and the amount of dialogue and hassle with him over my students' proposals has decreased. After that experience, I thought that maybe we sex researchers could use a bumper sticker that says "Make friends with an ethics committee member today!" However, in this instance, I happened to be dealing with a relatively rational and well-meaning person who was having his first experience with proposals involving research on human sexuality.

As may be suggested by the foregoing, I have tended to accept (if with some irritation) delays in the beginnings of data collection for our studies as part of what goes on with the process of doing research on sexuality. Further, my present situation is a great improvement over that in a former job, in which I was personally required to run all subjects, and at one point, one member of the ethics committee even recommended that I wear a white lab coat while administering anonymous, voluntary, confidential, questionnaires on contraceptive behavior (to reduce my sexual stimulus value)! My initial response was astonishment, followed by laughter. At the time, I perceived the difficulties I was having with the Ethics Committee as isolated incidents. However, my consciousness has begun to be raised by some informal comments/complaints about similar difficulties experienced by colleagues at other schools.

Most recently, I was reminded of the issue after receiving an eloquent 17-page document from Donald Mosher, a psychologist at the University of Connecticut. Mosher is one of

our most eminent researchers. His sex guilt scale, developed a dissertation project, and published in 1966, has been extensively used ever since then. Most recently, he and his students have been studying variables related to sexual assault and have developed a measure of the macho personality (Mosher and Sirkin, 1984). Mahoney, Shively, and Traw (1986) have just published fascinating data showing that macho males (using the Mosher and Sirkin scale) report more sexually coercive behaviors than do non-macho males, and sexually coerced females report being attracted to macho males more than do non-victimized females. Mosher and his students are currently conducting (or attempting to conduct) research involving guided imagery of rape and the role of the macho personality in marital rape. However, Mosher, too, has been suffering the "chilling effect" of extensive scrutiny of research by him and his students.

In November, 1985, Mosher was invited to a meeting of his Ethics Committee, ostensibly to answer two questions about their informed consent and debriefing procedures. This meeting, however, involved considerably more questioning than Mosher had been led to believe, including:

1. Does participation in a study involving guided imagery of rape increase the probability that subjects will commit aggressive or illegal acts?
2. Is it appropriate to ask subjects to fantasize committing illegal acts or to imagine actions contrary to their moral code?
3. Are researchers directly speaking to the unconscious and instructing subjects to commit rape by using indirect suggestion?
4. How are psychologists viewed by the public when we ask people to fantasize illegal acts?
5. Is their debriefing too judgmental and might it induce shame or guilt in subjects who responded with sexual arousal to realistic guided imagery of rape?
6. Will Mosher's sex research pose a threat to the continued existence of the subject pool?
7. Can Mosher defend the "appropriateness" of his research program in general?

Mosher described his response to each of these specific lines of questioning in the 17-page document that I mentioned above, and he will be discussing the whole issue of human subject review board procedures at the annual meeting of the Eastern Region of The Society for the Scientific Study of Sex in Philadelphia, April 11-13, 1986. Mosher (1985) has written a document that I think many of you who may be faced with similar problems from your ethics committee may find useful. I'm including it here with Mosher's permission.

Ten Ethical Principles for Human Subject Committees

Principle 1: Humility takes precedence over hubris in making ethical judgments. If absolute power corrupts absolutely, bureaucratic power breeds conservatism. Appointment to a Human Subjects Committee is, in itself, not a preparation for making ethical judgments. The appropriate model is collegial communication on ethical matters, not a hierarchical board of review. The HSC is not one-up; the investigator is not one-down.

Principle 2: The Belmont Principles and the Disciplines' Principles of Ethics are the same for every topical area of research. Socially sensitive and nonsensitive topics are to be judged by the identical principles. The Belmont Principles disavow concerns with public policy and public reactions as relevant to a decision about a specific research proposal.

Principle 3: Human Subject Committees are as accountable to the ethical principles as are investigators. To ensure fair application of principles, specific problems in a proposal should be related to specific principles or subprinciples in the ethical codes. This will prevent the use of excessively vague charges of "inappropriateness" and problems will be related to principles. This is directly parallel to the method used by the American Psychological Association in formulating its principles.

Principle 4: The Belmont Principle of respect for persons applies to both human subjects and investigators. The issue for an HSC is to find the proper balance in concern for human dignity and individual, societal, and scientific welfare. Both human subjects and scientists should be regarded as autonomous persons capable of making informed choices. Much of the effort of HSCs should focus on this issue by examining the procedure used to obtain an informed consent. The principle of respecting the autonomy of informed individual choice specifically prohibits legal moralism and legal paternalism. The HSC is not there to prevent, out of paternalistic moral concern, subjects from having the opportunity to make an informed choice to participate or not participate in a particular investigation.

Principle 5: The principle of beneficence is based upon an assessment of risk in which priority is given to scientific evidence. In attempting to maximize benefits and minimize risks, scientific methods remain the best source for obtaining and evaluating evidence. The concept of risk combines a concern with the probability and seriousness of harm or danger.

Principle 6: Whether dealing with socially sensitive or nonsocially sensitive proposals, caution should be directly proportional to known probabilities and seriousness of risk. Caution should neither be abandoned nor the likelihood of dangers and harms exaggerated. It is as reasonable to ask any scientist serving on an HSC about scientific evidence for probability and seriousness of potential risks as it is to ask the principal investigator. Both the principal investigator and concerned HSC members are accountable to evidence to support alleged risks and benefits.

Principle 7: Prior restraint of research, in the absence of strong evidence meeting specific criteria given below, is inconsistent with First and Fourteenth Amendment protections of the U.S. Constitution. In the landmark case of *Near v. Minnesota*, the principle of no prior restraint of the press to prevent libel was advanced by the U.S. Supreme Court. Damages can be recovered after injury has indeed occurred in the press; a free

press cannot be restrained because someone judges it as likely to damage without meeting stringent criteria. Awards of libel against the press and awards for damage to human subjects under civil tort law are sufficient means of redress. Principles of freedom of inquiry and freedom of expression share much in common as basic civil liberties. This principle is to be applied in conjunction with the one above related to scientific evidence and the one below suggesting appropriate criteria.

Principle 8: The following three criteria must be met before prior restraint (or censorship) of research is justified: (a) There must be strong evidence (with a priority given to scientific evidence) of a very likely and serious harm; (b) the harms must be closely and directly linked (i.e. a causal connection) with participation in the research study; and (c) it must be unlikely that further speech or expression (e.g., debriefing and counseling) can be used to effectively minimize the harm. These principles are adapted from the philosopher Fred Berger's suggested criteria for permissible censorship of expressions such as pornography. Because free inquiry is basic to a democratic society and to science itself, the burden of evidence for prior restraint should fall upon those institutions that seek to limit these freedoms. It is not enough merely to speculate on possible risks and harms and to deny approval for proposed research without creating a chilling effect on free inquiry.

Principle 9: The Belmont principle of justice not only applies to protecting human subjects in vulnerable states and certain classes of persons, it also implies that justice is served by research designed to promote the welfare of vulnerable classes. Many so-called socially sensitive research topics are concerned with reducing power inequities in the society. The U.S. Constitution with its Bill of Rights is designed to protect the rights of a minority from the majority in our democratic nation. These rights extend to gender, race, ethnic group, age, religion, physical and mental handicaps, prisoners, and, increasingly, to sexual minorities. The Fourteenth Amendment's clause on equal protection under the laws should serve as an ethical principle that favors research into discrimination and promotes the rights of such vulnerable classes. Socially sensitive research is exactly that research which expresses a sensitive appreciation of these issues that so profoundly affect human welfare. Human Subject Committees have an affirmative duty to promote, rather than to hinder, such research to ensure that justice is served.

Principle 10: Procedural justice in the conduct of a Human Subject Committee's mission is basic to equity in justice. As the seriousness of ethical concerns increases, there should be a proportionate increase in the use of due process procedures. The due process clause in the Fifth and Fourteenth Amendments ensures procedural justice in the American system of laws. When administrative social controls begin to serve the same functions of social control as the judicial system, institutions need to adopt corresponding protections of scientific investigators to ensure procedural justice. Although the vast majority of HSC actions will be collegial consultations to increase mutual awareness of ethical issues designed to protect human subjects, more draconian interventions by HSCs require formalities modeled after due process protections, including information in advance on specific principles believed to be violated or potentially violated in order to prepare a defense, right to legal counsel, formal records of the appearance, an appeal process, and so on.

Mosher offered these ten principles for consideration by the Ethics Committee of his own department, but I hope that ethics committees at other universities will discuss them. I would like to hear from any of you who have experienced difficulties in obtaining support from your ethics committee regarding the kind of research questions you are studying and the bases for their objections. Specifically, I am wondering about the extent to which sex researchers are experiencing unusual levels of scrutiny that go beyond the specific task of protecting the rights of subjects to informed consent and freedom from coercion.

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Editor's Note: *I accepted the editorship of "Research Notes" in 1981, and with the completion of the column for this issue, I have resigned. If I hear from a number of you regarding difficulties with your ethics committees over sex research proposals, however, I will write a description and submit it to the SIECUS Report.*

In the years that I have been involved with this column, I have had helpful advice, ideas, criticism, and support from a number of people, but there are three people in particular that I want to thank. Mary Calderone has been an inspiration and a model for me, and I think that we all owe her a huge debt of gratitude for founding SIECUS in the first place. I have had numerous conversations with Bobbie Whitney; she has been direct and forthright in her disagreements with me, warm in her support, and delightful in her sense of humor. Most of all, I will miss the monthly telephone and letter interactions with Anne Backman. She is the best editor I have ever experienced: talented, conscientious, and thorough. I want to acknowledge the large debt I owe her, and the larger amount of affection that I feel toward her.

DO YOU KNOW THAT...

Conscience Seeking Articles

Conscience, a newsjournal of pro-choice Catholics, is soliciting articles for publication in 1986 on a variety of topics related to reproductive rights. For writer's guidelines send a SASE to: *Conscience*, Catholics for a Free Choice, 2008 17th St. NW, Washington, DC 20009.

Call for Journal Articles

The Colombia Sexological Society is preparing the first *Latino-american Journal of Sexology (Revista Latinoamericana de Sexologia)* to be published twice a year initially. The journal will consist of research, sex therapy, sex education, and book reviews. Send article correspondence to: Octavio Giraldo-Neira, Editor, *Revista Latinoamericana de Sexologia*, Apartado Aereo 3441, Cali, Columbia, South America.

Guelph Human Sexuality Conference

The University of Guelph's 8th Annual Sexuality Conference will examine current issues in Human sexuality, teaching approaches in sex education, and counseling methods for sexual problems on June 9-11, 1986 at the University of Guelph, Guelph, Ontario. For further information write: Continuing Education Division, University of Guelph, Guelph Ontario, N1G2W1, or call: (519) 824-4120, ext. 3957.

Teacher Training Workshops on Disabled Adolescents

Joan Davies Associates offers teacher training workshops and parent group lectures concerning special education students, including topics such as Socio-Sexual Development of Special Students, Child Abuse Prevention for Special Students, and other concerns of disabled students. For further information write or phone: Joan Davies Associates, 98 Southview Terrace, Middletown, NJ 07748, (201) 671-5490.

Women's Health Conference

Planned Parenthood Centers of West Michigan will hold a Women's Health Conference on April 11, 1986. Workshops will include such topics as sexual wellness and chlamydia as well as other health and social issues. For further information call: (616) 774-7005.

Juvenile Sexual Abuse Conference

On April 27-30 the University of Minnesota Human Sexuality Program will sponsor a national training conference entitled "Treating the Juvenile Sexual Abuse Perpetrator." This conference will bring together researchers and clinicians in the field of sexual abuse to examine issues relevant to the assessment and treatment of juvenile sexual abuse perpetrators. For further information contact: Workshop Coordinator, Program in Human Sexuality, 2630 University Ave. SE, University of Minnesota, Minneapolis, MN 55414 or call: (612) 376-7520.

Forensic Mental Health Seminars

Forensic Mental Health Associates will present two-day seminars on the following topics:

"Child Sexual Abuse Assessment and Treatment: Victims and Offenders" on April 23-24 in Buffalo, N.Y., and on May 8-9 in Minneapolis, MN.

"Assessment and Treatment of Juvenile and Adult Sex Offenders: A Medico-Legal Approach" on March 27-28 in Seattle, WA, and on May 22-23 in Rapid City, SD.

"Child Sexual Assault: Rape, Incest, and Molestation: The Psychology of the Offender" on April 10-11 in Nashville, TN, and on June 26-27 in Atlantic City, NJ

For further information contact: Dorothy Molis, Forensic Mental Health Assoc., 29 Linwood St., Webster, MA 01570, (617) 943-3581.

SUMMER 1986 GRADUATE STUDIES IN HUMAN SEXUALITY AND SEX EDUCATION

Programs are listed alphabetically by state. Announcements arriving too late for this listing will be published in the May 1986 SIECUS Report.

California

National Sex Forum, San Francisco, CA.

- SAR XXVI (Sexual Attitude Restructuring), June 28–July 5, 60 hours.
- *Introductory Course in Human Sexuality #101*, June 7–June 8, 15 hours.
- *The Sexology of AIDS*, August 2–3, 15 hours.

Write to: Don Nesland, National Sex Forum, 1523 Franklin St., San Francisco, CA 94109.

Indiana

The Kinsey Institute for Research in Sex, Gender, and Reproduction, Bloomington, IL.

- *Summer Institute I—Human Sexuality: Emerging Perspectives*, July 26–31.
- *Summer Institute II—Values Attitude Reassessment (VAR)*, August 1–3.
- *Summer Institute III—The Human Male: Sex, Gender, and Reproduction*, August 3–8.

Write to: Dr. June Reinisch, Kinsey Institute for Research in Sex, Gender, and Reproduction, Morrison Hall, Third Floor, Bloomington, IL 47405.

New Jersey

Kean College of New Jersey, Union, NJ.

- *Advocacy for Family Life Education*, June 30–July 17, 3 units.
- *Parenting Education*, June 30–July 17, 3 units.
- *Contemporary Issues in Human Sexuality*, June 30–July 17, 3 units.
- *Family Life Through Media and Literature for Young Children*, June 30–July 17, 3 units.

These courses are part of the 6th Annual Family Life Institute.

Write to: Dr. Russ A. Mahan, Dept. Early Childhood/Family Studies, Kean College, Union, NJ 07083.

UMDNJ-Rutgers Medical School, Piscataway, NJ

- *Sexuality Today: A Summer Institute for Educators and Counselors*, June 23–27, 1 or 3 credits.

***Write to:** Marcia Kosofsky, MSW, Rutgers Medical School, Environmental and Community Medicine, P.O. Box 101, Piscataway, NJ 08854.

New York

Adelphi University, Garden City, NY.

- *Changing Views of Masculinity and Femininity*, June 30–July 11, 3 credits.

Write to: Dr. Richard Eberst, Adelphi University, Garden City, NY 11530.

Cornell University, Ithaca, NY

- *Sexual Abuse, Assault, and Prevention*, July 7–11, 2 credits.

Write to: Dr. Andrea Parrot, N134 MVR Hall, Cornell University, Ithaca, NY 14853.

Hofstra University, Hempstead, NY.

- *Sexuality Counseling*, May 26–June 5, 3 credits.

- *Values in Sexuality*, June 9–24, 3 credits.

- *Sexual Health*, July 7–22, 3 credits.

Write to: Dr. Efreem Rosen, c/o New College, Hofstra University, Hempstead, NY 11550.

New York University, New York, NY

- NYU—*International Graduate Program in Human Sexuality: South America*, July 7–Aug. 22, 12 credits.

- NYU—*SIECUS Professional Colloquium*, Aug. 2–17.

Write to: Dr. Ronald Moglia, New York University, Human Sexuality Program, 715 Broadway, 2nd Floor, New York, NY 10003.

Oregon

Oregon State University, Corvallis, OR.

- *Sexuality Education*, June 23–July 17, 3 credits.

Write to: Dr. Margaret Smith, Dept. of Health, Waldo 321, Oregon State University, Corvallis, OR 97331-6406.

Pennsylvania

Indiana University of Pennsylvania, Indiana, PA.

- *Psychology of Teaching Sex Education for Disabled People*, June 9–13, 3 credits.

- *Psychology of Teaching Sex Education*, July 28–August 1, 3 credits.

Write to: Leonard B. DeFabo, 246 Stouffer Hall, I.U.P., Indiana, PA 15705.

University of Pennsylvania, Philadelphia, PA.

- *Concepts in Human Sexuality*, May 12–16, 3 semester hours.

- *Concepts in Human Sexuality*, May 19–23, 3 semester hours.

- *Behavioral Foundations of Human Sexuality*, June 2–6, 3 semester hours.

- *Concepts in Human Sexuality*, August 11–15, 3 semester hours.

Write to: Dr. Kenneth George, University of Pennsylvania, Graduate School of Education, Human Sexuality Program, Philadelphia, PA 19104.

Vermont

University of Vermont, Burlington, VT.

- *Sexuality Counseling and Therapy*, July 7–18, 3 credits.

Write to: Kay Frances Schepp, UVM Counseling and Testing Center, Burlington, VT 05405.

- *Contemporary Issues in Human Sexuality: Focus on Social Policy and Practice*, June 16–July 4, 3 credits.

Write to: Dr. James R. Barbour, Dept. of Human Development Studies, University of Vermont, Burlington, VT 05405.

Wisconsin

University of Wisconsin-Madison, Madison, WI.

- *Child, Adolescent and Family Psychotherapy*, June 16–August 10, 3 credits.

- *Education and Sex Role Socialization*, July 14–August 10, 3 credits.

Write to: Susan Disch or Nancy Gebert, UW-Madison Division of Summer Sessions, 433 North Murray St., Madison, WI 53706.

SEXUALITY AND DISABILITY

A Bibliography of Resources Available for Purchase

This annotated listing of sexuality and disability materials was prepared by Leigh Hallingby, MSW, MS, Manager, SIECUS Information Service and Mary S. Calderone Library, and Marianne Glasel, RN, MS, intern, Mary S. Calderone Library. Almost all of these resources are available for use at the Mary S. Calderone Library, 715 Broadway, Room 213, New York University, New York, NY 10003; (212) 673-3850. All are available for purchase from the sources listed after each entry. Unless

otherwise indicated, the prices do not include postage and handling.

Single copies of this bibliography are available from SIECUS on receipt of **\$2.00 and a stamped, self-addressed, business-size envelope**. In bulk they are: \$1.50 each for 5-49 copies; \$1.00 each (plus \$2.00 p/h) for 50 copies or more.

Please note that, except for the items published by SIECUS itself, SIECUS does not sell or distribute any of these publications.

GENERAL WORKS

Books and Journals

HUMAN SEXUALITY IN HEALTH AND ILLNESS

Third Edition

Nancy Fugate Woods

Examines the biophysical nature of human sexuality, sexual health, and health care (including preventive and restorative intervention and sexual dysfunction), and clinical aspects of human sexuality in such concerns as chronic illness, paraplegia, and adaptation to changed body image.

C. V. Mosby (1984), 11830 Westline Industrial Drive, St. Louis, MO 63146; \$18.95

INCURABLY ROMANTIC

Bernard F. Stehle

This beautiful book of photographs is about love relationships where one or both members of the couple is severely physically disabled. Text represents their tape-recorded statements.

Temple University Press (1985), Broad and Oxford Streets, Philadelphia, PA 19122; \$29.95 + \$2.00 p/h

INTIMACY AND DISABILITY

Barbara F. Waxman, Judi Levin, and June Isaacson Kailes

The authors, who are themselves disabled, have written what they call a "working" guide for people with disabilities to assist them in overcoming barriers to develop intimate relationships. Topics include: self-image, body image, sexuality, dating, intimacy, contraception, and avoiding sexual abuse. Contains a list of resources for obtaining additional help. National Rehabilitation Information Center (1982), 4407 8th Street, NE, Washington, DC 20017; \$11.00 (for a photocopy)

OFF OUR BACKS—SPECIAL ISSUE: WOMEN WITH DISABILITIES Vol. 11, No. 5, May 1981

A number of the 20 articles are written from a feminist and/or lesbian perspective. Disabilities covered include stroke, visual and hearing impairment, and mastectomy.

Off Our Backs (1981), 1841 Columbia Road, NW, Washington, DC 20009; \$2.00 (incl. p/h)

SEX AND DISABILITY RESOURCE MANUAL

Denise Sherer Jacobson, ed.

Includes national and international listings of sex and disability educators, counselors, and consultants; methods for updating resource information; publications, organizations, and audio-visuals; and information on speakers bureaus.

United Cerebral Palsy of San Francisco (1983), Golden Gate Theater Building, 25 Taylor Street, Fifth Floor, San Francisco, CA 94102; \$9.00 (incl. p/h)

SEX EDUCATION AND COUNSELING OF SPECIAL GROUPS:

THE MENTALLY AND PHYSICALLY HANDICAPPED, ILL, AND ELDERLY

Second Edition

Warren R. Johnson and Winifred Kempton

Deals with problem areas in sex education and counseling of handicapped persons, and points out danger of losing the individual behind group labels. Offers suggestions for dealing with sex-related topics from masturbation to abortion.

Charles C Thomas (1981), 2600 South First Street, P.O. Box 4709 Springfield, IL 62708-4709; \$24.75

SEX, SOCIETY, AND THE DISABLED: A DEVELOPMENTAL INQUIRY INTO ROLES, REACTIONS, AND RESPONSIBILITIES

Isabel P. Robinault

An excellent resource, presenting a chronological discussion of the sexuality of people with physical disabilities.

Harper & Row (1978), Medical Department, 2350 Virginia Avenue, Hagerstown, MD 21740; \$22.75 + \$1.50 p/h

SEXUALITY AND LIFE-THREATENING ILLNESS

Margot Tallmer et al, eds.

This Foundation of Thanatology text is a collection of 20 articles, many by noted experts in the field, addressing issues of sexuality and long-term disability and/or death. Charles C Thomas (1984), 2600 South First Street, Springfield, IL 62717; \$24.75

SEXUALITY AND DISABILITY

Arnold Melman, ed.

A quarterly journal presenting clinical and research developments in the area of sexuality as they relate to a wide range of physical and mental illnesses and disabling conditions. Human Sciences Press, 72 Fifth Avenue, New York, NY 10011; annual subscription, \$30.00 individual, \$75.00 institutional

TEACHER WORKBOOK FOR FAMILY LIFE EDUCATION

Susan E. Knight and Carla E. Thornton

Helpful for teachers developing curricula for people with disabilities. Provides information on needs assessment, approaching parents and administrators, developing objectives, course content, and resources.

ERIC Document Reproduction Service (1983), 3900 Wheeler Avenue, Alexandria, VA 22304-5110; \$7.40 (to order, specify Document No. ED 229 685)

WHO CARES? A HANDBOOK ON SEX EDUCATION AND COUNSELING SERVICES FOR DISABLED PEOPLE

Second Edition

Sex and Disability Project

Unique, outstanding, and comprehensive resource containing excellent listings of available services and materials. Highly recommended.

PRO-ED (1982), 5341 Industrial Oaks Boulevard, Austin, TX 78735; \$17.00 (incl. p/h)

Booklets and Pamphlets

ABOUT SEXUALITY AND PEOPLE WITH DISABILITIES

George Marshall Worthington

A 15-page Scriptographic booklet covering what sexuality is, why disabled people need sex education, barriers to disabled people expressing their sexuality, special considerations for people who acquire a disability, the role of information in bolstering self-esteem and confidence and the role of family, friends and professionals.

George Marshall Worthington (1985), 345 West 21st Street, Suite 3D, New York, NY 10011; \$1.18 each for 25 (minimum order)—49 copies + \$3.00 p/h; bulk rates available

CHOICES: A SEXUAL GUIDE FOR THE PHYSICALLY DISABLED

Maureen Neistadt and Maureen Freda Baker

Makes suggestions for dealing with each of a number of physical problems (such as tremor and loss of mobility) that impede sexual functioning. Recommended positions for intercourse illustrated.

Spaulding Rehabilitation Hospital (1979), Occupational Therapy Department, 125 Nashua Street, Boston, MA 02114; \$3.00 (incl. p/h)

GETTING TOGETHER

Debra Cornelius, Elaine Makas, and Sophia Chipouras

Tenth in a series on attitudinal barriers facing disabled people, this booklet deals with myths about the sexuality of the disabled and steps that can be taken to overcome them. *RRRI (1981), George Washington University, Academic Center, Suite T-605, Washington, DC 20052, \$1.10 (incl. p/h)*

SEX EDUCATION FOR DISABLED PERSONS

Public Affairs Pamphlet #531

Irving Dickman

The pamphlet alerts professional people working with physically and mentally disabled persons to the importance of providing them with sex education and of helping their parents to do so.

Public Affairs Committee (1975), 381 Park Avenue South, New York, NY 10016; \$1.00 (incl. p/h)

TABLE MANNERS: A GUIDE TO THE PELVIC EXAMINATION FOR DISABLED WOMEN AND HEALTH CARE PROVIDERS

Susan Ferreyra and Katrine Hughes

Information for clinicians and clients about a cooperative approach to a comfortable and thorough pelvic examination.

Planned Parenthood Alameda/San Francisco (1982), 482 West MacArthur Boulevard, Oakland, CA 94609; \$4.00 + 2.25 p/h

TOWARD INTIMACY: FAMILY PLANNING AND SEXUALITY CONCERNS OF PHYSICALLY DISABLED WOMEN

Task Force on the Concerns of Physically Disabled Women

A discussion of various relationships within a disabled woman's life, aimed at promoting communication and understanding.

Planned Parenthood S.E. PA (1977), 1220 Sansom Street, Philadelphia, PA 19107; \$3.50 + 15% p/h

WITHIN REACH: PROVIDING FAMILY PLANNING SERVICES TO PHYSICALLY DISABLED WOMEN

Task Force on Concerns of Physically Disabled Women

Helpful for family planning providers serving disabled women.

Planned Parenthood S.E. PA (1977), 1220 Sansom Street, Philadelphia, PA 19107; \$3.50 + 15% p/h

Bibliographies

BIBLIOGRAPHIES OF HOLDINGS OF THE SIECUS INFORMATION SERVICE AND LIBRARY:

AGING, DISABILITY, OR ILLNESS AND SEXUALITY

Leigh Hallingby, comp.

Bibliographies on 35 separate illnesses or disabilities as they relate to sexuality. The 600 unannotated citations include periodical articles and chapters in edited books. Annual updating planned. Order blank available to those wishing to purchase individual bibliographies.

SIECUS (1985), 80 Fifth Avenue, Suite 801, New York, NY 10011; \$30.70 + 20% p/h

SEX EDUCATION FOR DISABLED PEOPLE: A RESOURCE GUIDE

An annotated bibliography of books, pamphlets, articles, and tactile materials concerning sexuality and disability. Contains information for both younger and older consumers, as well as for health care professionals. Easy to read and very usefully laid out.

Planned Parenthood Alameda/San Francisco (1981), 1660 Bush Street, San Francisco, CA 94109; \$12.50 + \$2.25 p/h; 1982 supplement, \$6.25 + \$2.25 p/h

SEXUALITY AND THE DISABLED: AN ANNOTATED BIBLIOGRAPHY

Includes 200 citations to books, periodical articles, curricula, conference papers, and dissertations.

Katharine Dexter McCormick Library, Department of Education, (1981), Planned Parenthood Federation of America, 810 Seventh Avenue, New York, NY 10019; \$4.00 (incl. p/h)

ALCOHOL ABUSE

ALCOHOL AND SEXUALITY: AN ANNOTATED BIBLIOGRAPHY ON ALCOHOL USE, ALCOHOLISM, AND HUMAN SEXUAL BEHAVIOR

Timothy J. O'Farrell, Carolyn A. Weyland, and Diane Logan

A bibliography of sources published from 1900 to 1982 covering effects of alcohol on sexual functioning, treatment of sexual problems of alcoholics, social and cultural issues, and a review of the literature.

Oryx Press (1983), 2214 North Central at Encanto, Phoenix, AZ 85004; \$55.00

ALCOHOLISM AND HOMOSEXUALITY

Thomas O. Ziebold and John E. Mongeon, eds.

An anthology on alcoholism in the homosexual community, including treatment, counseling techniques, and prevention. Originally published as Volume 7, Number 4 of the *Journal of Homosexuality*.

Haworth Press (1982), 28 East 22nd Street, New York, NY 10010; \$24.95 hc, \$17.95 pb + \$2.00 p/h

ALCOHOLISM AND SEXUAL DYSFUNCTION ISSUES IN CLINICAL MANAGEMENT

David J. Powell, ed.

Originally published in the fall of 1984 as Volume 1, Number 3 of *Alcoholism Treatment Quarterly*. Covers sexual function and dysfunction related to alcoholism, including recovery, assessment, sex therapy, and sexual dynamics of the therapeutic relationship. *Haworth Press (1984), 28 East 22nd Street, New York, NY 10010; \$17.95*

ALCOHOLISM IN THE LESBIAN/GAY COMMUNITY: COMING TO TERMS WITH AN EPIDEMIC

A pamphlet describing psychosocial reasons for alcoholism in the homosexual community. Offers suggestions for locating counseling and treatment.

D.I.N. Publications, P.O. Box 21126, Phoenix, AZ 85036; \$.25 pamphlet, \$1.00 booklet

A COUNSELOR'S GUIDE TO THE SPECIAL NEEDS OF SEXUAL MINORITY CLIENTS IN ALCOHOLISM AND DRUG TREATMENT

Chemical Dependency Program

Written to help counselors recognize the problems alcoholic homosexuals have in coming out to counselors, seeking treatment, and finding alternatives to gay bars. Emphasizes that a unique treatment is necessary.

Chemical Dependency Program (1980), 1207 Pine Street, Seattle, WA 98101; \$2.50 + \$.50 p/h

NALGAP BIBLIOGRAPHY: RESOURCES ON ALCOHOLISM AND LESBIANS/GAY MEN Revised Edition

A three-part bibliography including resources for alcoholic lesbians and gay men, information about the homosexual community, and resources on alcoholism.

National Association of Lesbian and Gay Alcoholism Professionals (1986), 204 W. 20th Street, New York, NY 10011; \$5.00 (incl. p/h)

SEX AFTER SOBRIETY: A WOMAN'S GUIDE

Gayle Rosellini

An 8-page pamphlet for women, with or without partners, covering meeting sexual needs, recovering self-esteem, rebuilding relationships, and sexual healing.

D.I.N. Publications (1983), P.O. Box 21126, Phoenix, AZ 85036; \$.25

CANCER

BODY IMAGE, SELF-ESTEEM, AND SEXUALITY IN CANCER PATIENTS

J. M. Vaeth, R. C. Blomberg, and L. Adler, eds.

The conference on which this outstanding book is based was a first in the specific area of cancer and its possible effects on sexuality and self-esteem in patients of all ages.

S. Karger (1980), 79 Fifth Avenue, 17th floor, New York, NY 10003; \$41.00 (incl. p/h)

SEXUAL ADJUSTMENT TO CANCER SURGERY IN THE VAGINAL AREA

M. Edward Clark and Javier Magrina

Describes vaginal cancer, the types of surgery involved, sex following surgery, sexual arousal, and partner involvement. Written for clients and medical practitioners.

Student Union Bookstore, University of Kansas Medical Center (1983), Rainbow Boulevard and 39th, Kansas City, KS 66103; \$9.75 + \$2.00 p/h

SEXUALITY AND CANCER

Jean M. Stoklosa et al.

Sensitively written discussion with useful sections on ostomy, laryngectomy, and mastectomy.

Bull Publishing (1979), Box 208, Palo Alto, CA 94302; \$2.95 + \$1.00 p/h

HEARING AND VISUALLY IMPAIRED

FEELING FREE: A SOCIAL/SEXUAL TRAINING GUIDE FOR THOSE WHO WORK WITH THE HEARING AND VISUALLY IMPAIRED

Jean Edwards et al.

A guide for teaching responsible decision making to all ages with the goal of increasing appropriate social and sexual behavior. Includes curriculum preparation, lesson plans, and appendices of resources.

Ednick Communications, Inc. (1982), P.O. Box 3612, Portland, OR 97208; \$30.00 + \$2.50 p/h

SEX EDUCATION FOR DEAF-BLIND STUDENTS

Ellen Cadigan and Roslye Roberts Geuss

Contains six units on: self-identity, anatomy of the reproductive system, human reproduction, growth from infancy through puberty, adolescence, and personal health care and hygiene. Within each unit is a series of skills to be learned and under each skill is a series of objectives.

Perkins School for the Blind (1981), Office of Public Relations and Publications, 175 North Beacon Street, Watertown, MA 02172; \$10.00 + \$1.00 p/h

HEARING IMPAIRED

GROWING UP SEXUALLY

Angela M. Bednarczyk

Includes a 138-page teacher's manual, a student text divided into seven chapters (each packaged as a separate booklet), and a booklet for parents. Student chapters are arranged according to comfort-level criteria, and each includes an introduction, discussion questions and activities, and review questions.

Kendall Demonstration Elementary School (1982), Gallaudet College, Kendall Green, Washington, DC 20002; teacher's manual, \$18.95; student manual, \$26.95 + \$3.50 p/h

SIECUS REPORT, March 1986

HUMAN SEXUALITY CURRICULUM: SELF-AWARENESS AND INTERPERSONAL RELATIONSHIPS

Pennsylvania School for the Deaf

This curriculum for hearing-impaired students in elementary, junior, and senior high schools provides course outlines for stages of development, emotional involvement, family and social relationships, sexual behaviors, reproduction and parenthood, and life styles. Divided for each grade into beginning, intermediate, and advanced levels.

Pennsylvania School for the Deaf (1977), 100 West School House Lane, Philadelphia, PA 19144, \$10.00 (incl. p/h)

SIGNS FOR SEXUALITY: A RESOURCE MANUAL

Susan D. Doughten, Marlyn B. Minkin, and Laurie E. Rosen

Contains over 600 photographs illustrating 300 signed words and phrases associated with human sexuality. Bound to lie flat, leaving hands free for communication.

Planned Parenthood of Seattle/King County (1978), 2211 East Madison, Seattle, WA 98122; \$11.95 + \$.50 p/h

SIGNS OF SEXUAL BEHAVIOR

James Woodward

Each sign, along with its etymology, is explained. Author also discusses deaf culture as it relates to the ever-changing signs.

T. J. Publishers (1979), 817 Silver Spring Avenue, Room 206, Silver Spring, MD 20910; \$7.95 + \$1.50 p/h

VIEWPOINTS: SEX EDUCATION AND DEAFNESS

Della Fitz-Gerald and Max Fitz-Gerald, eds.

A compilation of ten articles by the Fitz-Geralds and others. Deals with the need for and methods of sexuality education for hearing impaired children and adolescents.

Gallaudet College Bookstore (1985), Outreach Products, P.O. Box 10-D, Kendall Green, Washington, DC 12002; \$12.95 + \$2.50 p/h

KIDNEY DISEASE

SEX AND DIALYSIS

Barbara Ulery

A valuable resource in this special area of concern.

Barbara Ulery (1979), P.O. Box 2349, Durango, CO 81301; \$3.75 (incl. p/h)

SEX AND INTIMACY FOR DIALYSIS AND TRANSPLANT PATIENTS

Revised Edition

Norman B. Levy

This booklet for patients and health professionals covers: the nature and causes of sexual dysfunctions, sexual ability and interest, contraception, and treatment for sexual dysfunctions in the patient with kidney disease or transplant.

Virgil Smirnow Associates (1984), Health and Public Affairs, 8501 Burdette Road, P.O. Box 34425, Bethesda, MD 20817; \$1.50 (inc. p/h)

MENTALLY HANDICAPPED

For Parents and Professionals

AN EASY GUIDE FOR CARING PARENTS: SEXUALITY AND SOCIALIZATION—A BOOK FOR PARENTS OF PEOPLE WITH MENTAL HANDICAPS

Lyn McKee and Virginia Blackledge

An honest, upbeat book about the social and sexual needs of people with mental handicaps. Valuable aid to both parents and educators.

Planned Parenthood S.E. PA (1981), 1220 Sansom Street, Philadelphia, PA 19107; \$5.95 + 15% p/h

LOVE, SEX, AND BIRTH CONTROL FOR THE MENTALLY RETARDED: A GUIDE FOR PARENTS

Seventh Edition

Winifred Kempton, Medora Bass, and Sol Gordon

Thoughtful guide covering sex education and sexual responsibility. Spanish edition also available.

Planned Parenthood S.E. PA (1985), 1220 Sansom Street, Philadelphia, PA 19107; \$2.95 + \$.44 p/h

A SELECTED BIBLIOGRAPHY ON SEXUALITY, SEX EDUCATION AND FAMILY PLANNING FOR USE IN MENTAL RETARDATION PROGRAMS

Phyllis Cooksey and Pamela Brown

Bibliography includes materials for both professional and patient/client education. Topics covered are sexuality, sex education, reproduction, birth control, and sterilization.

Planned Parenthood of Minnesota (1981), 1965 Ford Parkway, St. Paul, MN 55116; \$3.50 + \$.35 p/h

SEX AND THE MENTALLY HANDICAPPED

Michael Craft and Ann Craft

Written for professionals and parents caring for the mentally handicapped, this British book looks at many of the questions, anxieties, and fears raised by the sexuality of this group. Offers guidelines to those wishing to plan sex education programs.

Routledge & Kegan Paul (1978), 9 Park Street, Boston, MA 02108; \$8.95 (incl. p/h)

SEX EDUCATION AND COUNSELING FOR MENTALLY HANDICAPPED PEOPLE

Ann Craft and Michael Craft, eds.

Written for professionals to enable them to educate and counsel parents, staff and the mentally handicapped on sexuality issues. Practical suggestions are given for developing seminars, workshops and programs. Contributors include American and British professionals.

University Park Press (1983), 300 North Charles Street, Baltimore, MD 21201; \$19.95

SEX EDUCATION AND THE INTELLECTUALLY HANDICAPPED

Wendy McCarthy and Lydia Fegan

This book, originally published in Australia, is designed to help parents and other caretakers understand the many aspects of the sexuality of mentally handicapped children.

John Wright (1984), *PSG Inc.*, Littleton, MA 01460; \$12.50

SEX EDUCATION FOR PERSONS WITH DISABILITIES THAT HINDER LEARNING: A TEACHER'S GUIDE

Winifred Kempton and Rose Foreman

This invaluable resource for instructors stresses the need to integrate sexuality with every facet of human experience.

Planned Parenthood S.E. PA (1975), 1220 Sansom Street, Philadelphia, PA 19107; \$7.95 + 15% p/h

SEXUALITY, LAW, AND THE DEVELOPMENTALLY DISABLED PERSON: LEGAL AND CLINICAL ASPECTS OF MARRIAGE, PARENTHOOD, AND STERILIZATION

Sarah F. Haavik and Karl A. Menninger

Presents research data, legal analysis, and programmatic recommendations concerning sexuality, marriage and reproduction for persons with developmental disabilities.

Paul H. Brookes Publishing Co. (1981), Box 10624, Baltimore, MD 21285; \$15.95 + \$1.69 p/h

For the Mentally Handicapped

AN EASY GUIDE TO LOVING CAREFULLY FOR MEN AND WOMEN

Lyn McKee, Winifred Kempton, and Lynne Stiggall

Basic information about sexual anatomy, reproduction, and contraception, presented in large print with many illustrations. Suitable for higher functioning mentally handicapped people to read on their own or with a parent or professional.

Planned Parenthood: Shasta-Diablo (1980), 1291 Oakland Boulevard, Walnut Creek, CA 94596; \$6.95 (incl. p/h)

GETTING IN TOUCH WITH YOURSELF

Sally S. Miller

Guide for mentally disabled to body exploration, including looking at their genitals with a mirror and masturbating.

Synergy Book Service (1984), 210 Main Street, Flemington, NJ 08822; \$6.00 + \$1.50 p/h

GROWING UP: A SOCIAL AND SEXUAL EDUCATION PICTURE BOOK FOR YOUNG PEOPLE WITH MENTAL RETARDATION

Victoria Shea and Betty Gordon

Designed to be read to moderately through severely mentally handicapped students aged 12 and up, although many parts may be suitable for younger students with mild learning problems. Basic information and illustrations are on right hand pages, and ideas for discussion and further learning activities on left.

Looseleaf format enables educators to remove and add pages.

Division for Disorders of Development and Learning (1984), BSRC 220H, University of North Carolina, Chapel Hill, NC 27514; \$18.50 + \$1.50 p/h

A SPECIAL BOOK: SEX EDUCATION FOR THE DEVELOPMENTALLY DISABLED

Nancy Genn

Meant to be read to or by the developmentally disabled teenager. Drawings and text address gender and sex differences, sexual anatomy and functioning, sexual development, reproduction, friendships, intimacy, and love. Birth control briefly covered.

Nancy Genn (1983), Association for Retarded Citizens of Greater New Haven, 1 State Street, New Haven, CT 06511; \$10.00 + \$.69 p/h

For Teachers: Curricula and Tests

BECOMING ME: A PERSONAL ADJUSTMENT GUIDE FOR SECONDARY STUDENTS

Teresa Throckmorton

Includes units on personal and social development, health and self-care, and human growth and development, all focused on nurturing the practical skills needed for everyday life. For each topic, a content outline, behavior objectives, learning activities, and suggested resources are presented.

Grand Rapids Public Schools (1980), 143 Bostwick, NE, Grand Rapids, MI 49503; \$12.00 (incl. p/h)

BEING ME . . .

Jean Edwards and Suzan Wapnick

Subtitle: A Social/Sexual Training Guide for Those Who Work With the Developmentally Disabled. Includes examples of curricula and lesson plans from a variety of sources approaching a broad student population from mildly to severely disabled, from age 6 up to young adults and older persons. Designed both to supplement existing training and to serve as a complete new program. Ednick Communications (1981), Box 3612, Portland, OR 97208; teacher's guide, \$30.00; assessment scale and photo cards, \$40.00; sex education slides, \$40.00, + \$2.50 p/h

CIRCLES

Marklen Champagne and Leslie Walker-Hirsch

Subtitle: A Multimedia Package to Aid in the Development of Appropriate Social/Sexual Behavior in the Developmentally Disabled Individual. The Circles Concept is used to teach appropriate social distancing, including individuals with whom various kinds of touch are and are not acceptable, as well as many other sex and family life education topics. Includes curriculum, two slide programs, a teaching drop cloth, and a set of 10 photographs.

Stanfield Film Associates (1983), P.O. Box 1983, Santa Monica, CA 90406; \$399 + \$25.00 p/h; curriculum guide only, \$25.00 + \$5.00 p/h

EDUCATION FOR ADULTHOOD

Madeline Greenbaum and Sandra Noll

Designed to help mentally retarded adolescents and adults reach an understanding of being sexual, aging, dealing with death and dying, being disabled, expressing feelings, developing relationships, and keeping fit. Includes training program for those who will teach this curriculum. Accompanying each unit are worksheets, discussion questions, and lists of additional activities and resources. Staten Island Mental Health Society (1982), Elizabeth W. Pouch Center for Special People, 657 Castleton Avenue, Staten Island, NY 10301, \$28.00 (incl. p/h)

ESSENTIAL ADULT SEX EDUCATION FOR THE MENTALLY RETARDED: E.A.S.E. SEQUENTIAL CURRICULUM GUIDE

David B. Zelman and Kathie M. Tyser

Sequenced set of objectives, procedures, and materials grouped into four instructional units: biological data, sexual behavior, health, and relationships. Pre/post tests and teaching picture cards are included in curriculum guide. Total E.A.S.E. package also includes two introductory cassettes, 100 Diagnostic Pupil Profile sheets, a color filmstrip, and a menstruation and birth control products kit.

Stanfield Film Associates (1979), P.O. Box 1983, Santa Monica, CA 90406; total curriculum package, \$199.00 + \$20.00 p/h; sequential curriculum guide only, \$50.00 + \$7.00 p/h

FEELING GOOD ABOUT YOURSELF: A GUIDE FOR PEOPLE WORKING WITH PEOPLE WHO HAVE DISABILITIES

Second Edition

Gloria Blum and Barry Blum

Covers socialization and decision-making skills and a wide variety of sexual topics. The continuing focus is on self-esteem as essential in preparation for adulthood. Ed-U Press (1981), P.O. Box 583, Fayetteville, NY 13066; \$9.95 + 15% p/h

FULLY HUMAN

Nancy Howes

In lesson plan format this comprehensive curriculum covers twelve sequential topics from sexual identity through parenting at four progressive levels of ability. Includes teacher training information, activity pages and drawings, and specific teaching techniques for each lesson.

Nancy Howes (in press for 1986), Box 2107, Hanover, MA 02339; price unavailable at press time

A GUIDE FOR TEACHING HUMAN SEXUALITY TO THE MENTALLY HANDICAPPED

Third Edition

Phyllis Cooksey and Pamela Brown

This curriculum guide contains nine categories, such as contraception and interpersonal relations. Under each category are listed topics to cover, points to make, and suggested activities and resources. A simple but very practical approach to teaching the mentally handicapped about sexuality.

Planned Parenthood of Minnesota (1981), 1965 Ford Parkway, St. Paul, MN 55116; \$3.50 + \$.35 p/h

GUIDELINES FOR TRAINING IN SEXUALITY AND THE MENTALLY HANDICAPPED
Winifred Kempton and Rose Foreman

Not a textbook, but a proposed training program for those working with staff, aides, or parents involved with the mentally handicapped.

Planned Parenthood S.E. PA (1976), 1220 Sansom Street, Philadelphia, PA 19107; \$9.14 (incl. p/h)

**HUMAN SEXUALITY:
A PORTFOLIO FOR THE
DEVELOPMENTALLY DISABLED**

Victoria Livingston and Mary E. Knapp

Consists of 10 separate drawings on stiffened paper, with discussion suggestions for the teacher printed on the back of each plate. Content areas include male and female genitalia, girl to woman, boy to man, masturbation, and sexual intercourse.

Planned Parenthood of Seattle-King County (1974) 2211 East Madison, Seattle, WA 98112, \$23.00 (incl. p/h)

THE JOAN DAVIES FAMILY LIFE UPDATE

Joan Davies, ed.

This newsletter, published nine times per year—September through June—contains tips, materials, games, lesson plans, etc. for teaching family life education to special students.

Joan Davies Associates, 98 Southview Terrace North, Middletown, NJ 07748; annual subscription, \$19.95

**PERSONAL DEVELOPMENT AND
SEXUALITY:**

**A CURRICULUM GUIDE FOR
DEVELOPMENTALLY DISABLED**

Lenore Morrey et al.

Presents general statements, behavioral objectives, activities, and resources for a series of topics such as self-actualization, personal hygiene, and human sexual response. Also gives guidance about how to be a facilitator and how to plan and evaluate sex education programs.

Planned Parenthood of Pierce County (1978), 813 South K Street, #200, Tacoma, WA 98405, \$25.00 (incl. p/h)

**PRACTICAL APPROACHES TO SEXUALITY
EDUCATION PROGRAMS**

Ann Thompson Cook and
Pamela M. Wilson, eds.

A guidebook for sex education programs for preadolescents, adolescents, parents, and mentally retarded persons, giving course outlines and materials, questions students may ask, selected resources, and sample lessons for the four groups.

Sex Education Coalition (1982), 2001 O Street, N.W., Washington, D.C. 20036; \$5.50 (incl. p/h)

**SEXUALITY AND SOCIAL AWARENESS:
A CURRICULUM FOR MODERATELY
AUTISTIC AND/OR NEUROLOGICALLY
IMPAIRED INDIVIDUALS**

Dawn A. Lieberman and Mary Bonyai Melone

Valuable for sex educators working with lower functioning mentally handicapped individuals, aged 12 and older.

Benhaven Press (1979), Maple Street, East Haven, CT 06512; \$21.00 (incl. p/h)

**SOCIO-SEXUAL KNOWLEDGE AND
ATTITUDE TEST (SSKAT)**

Joel R. Wish, Katherine Fiechl McCombs,
and Barbara Edmonson

Can be used with mentally retarded persons and others whose language is limited. Responses to most questions consist of the subject's pointing to a choice of pictures and indicating "yes" or "no." There are 13 subtests, which can determine both sex knowledge and attitudes. Manual presents data from use of SSKAT with 200 retarded adults ranging in age from 18-42.

Stoelting Co. (1976), 1350 South Koster Avenue, Chicago, IL 60623; \$100.00 + \$4.00 p/h

MULTIPLE SCLEROSIS

**GUIDE TO PROGRAM PLANNING ON
SEXUALITY AND MULTIPLE SCLEROSIS**

Ann Barrett and Michael Barrett

Includes well-devised exercises for groups dealing with sexuality and multiple sclerosis. *Multiple Sclerosis Society of Canada (1978), 250 Bloor Street East, Suite 820, Toronto, Ontario M4W 3P9, Canada; \$3.00 (incl. p/h)*

SEXUALITY AND MULTIPLE SCLEROSIS

Revised Edition

Michael Barrett

Useful booklet for people with multiple sclerosis and the professionals working with them.

National Multiple Sclerosis Society (1982), 205 East 42nd Street, New York, NY 10017; single copies free of charge

OSTOMY

SEX AND THE FEMALE OSTOMATE (1982)

SEX AND THE MALE OSTOMATE (1982)

SEX, COURTSHIP AND THE SINGLE

OSTOMATE (1981)

Well-written booklets for ostomates and those working with them.

United Ostomy Association, 2001 West Beverly Boulevard, Los Angeles, CA 90057; \$1.00 each + \$.30 p/h each

SEXUAL COUNSELING FOR OSTOMATES

Ellen A. Shipes and Sally T. Lehr

A commonsense approach to sexual counseling of ostomates, covering easy-to-understand techniques.

Charles C Thomas (1980), 2600 South First Street, P.O. Box 4709, Springfield, IL 62708-4709; \$14.75

SEXUAL ABUSE PREVENTION

**ARE CHILDREN WITH DISABILITIES
VULNERABLE TO SEXUAL ABUSE?**

This five-page booklet acquaints parents of disabled children with the problem of sexual abuse and outlines steps to take to protect their children.

Minnesota State Documents Division (1983), 117 University Avenue, St. Paul, MN 55155; 50 for \$7.00 + \$1.50 p/h

**CHOICES: SEXUAL ASSAULT
PREVENTION WORKBOOKS**

Three different workbooks available. Those for the physically disabled and deaf-hearing impaired are in standard print. The one for the visually impaired is available in braille and large print and on cassette. They cover topics such as safety at home, on street, in workplace, and on public transportation, as well as assertiveness training.

Seattle Rape Relief Disabilities Project (in press for 1986), 1825 South Jackson, #102, Seattle, WA 98118; prices unavailable at press time.

**PREVENTING SEXUAL ABUSE OF PERSONS
WITH DISABILITIES:
A CURRICULUM FOR HEARING
IMPAIRED, PHYSICALLY DISABLED, BLIND
AND MENTALLY RETARDED STUDENTS**

Bonnie O'Day

This 175-page curriculum includes separate lesson plans for each of four populations named in title. Topics covered include positive and negative touch, vocabulary, myths and facts about sexual abuse, avoidance techniques, and assertive behavior.

Network Publications (1984), 1700 Mission Street, Suite 203, P.O. Box 1830, Santa Cruz, CA 95061-1830; \$19.95 + \$2.99 p/h

**PROVIDING COUNSELING AND
ADVOCACY FOR DISABLED PERSONS
WHO HAVE BEEN SEXUALLY ABUSED:
A TRAINING MANUAL FOR RAPE CRISIS
CENTER VOLUNTEERS**

This manual includes basic information about mental, physical, and sensory disabilities. Also provides directions and guidelines for organizing training sessions concerning sexual abuse counseling and advocacy with persons who have disabilities. All necessary handouts for trainees included.

Seattle Rape Relief Disabilities Project (1981), 1825 South Jackson, Suite #102, Seattle, WA 98118; \$22.00 (incl. p/h)

**SEXUALITY AND SEXUAL ASSAULT:
DISABLED PERSPECTIVES**

Revised Edition

Charles K. Stuart and Virginia Stuart

Curriculum guide for development of workshops for professionals on incest, rape, and sexual abuse of disabled people.

Learning Resources (1983), BA 246, Southwest State University, Marshall, MN 56258; \$7.94 (incl. p/h)

SPECIAL EDUCATION CURRICULUM ON SEXUAL EXPLOITATION

Seattle Rape Relief Disabilities Project

Designed for teaching mentally and physically handicapped students to be aware of sexual exploitation and to protect themselves. Two self-contained kits (elementary and secondary levels) provide a variety of educational materials such as teacher's guide, body maps, slide series, and pamphlets. Audio tape supplements are available.

Comprehensive Health Education Foundation (1981), 20832 Pacific Highway South, Seattle, WA 98188; Level 1, \$125; Level 2, \$495; Teacher's Guide with written narratives, \$35 per level.

TEACHER TRAINER MANUAL: TECHNIQUES FOR PLANNING AND IMPLEMENTING A SELF-PROTECTION PROGRAM

Provides a systematic approach to developing a special education program concerning sexual exploitation within a school system. Manual includes guidelines for training of special education personnel, counselors, nurses, other professionals, and parents concerning awareness about sexual exploitation of disabled individuals.

Seattle Rape Relief Disabilities Project (1983), 1825 South Jackson, Suite 102, Seattle, WA 98118; \$28.00 (incl. p/h)

TEACHING PEOPLE WITH MENTAL RETARDATION ABOUT SEXUAL ABUSE PREVENTION

Cordelia Anderson and Walter Brea

Particularly geared toward staff of residential facilities, but the concepts and role plays may also be used by parents and other educators in their homes and classrooms.

Network Publications (1982), 1700 Mission Street, Suite 203, P.O. Box 1830, Santa Cruz, CA 95061-1830; \$4.95 + \$0.74 p/h

WHAT PARENTS OF HANDICAPPED PERSONS SHOULD KNOW: PARENT BROCHURE

This brochure is designed to inform parents of developmentally disabled persons about sexual abuse.

Seattle Rape Relief Disabilities Project (1983), 1825 South Jackson, Suite 102, Seattle, WA 98118; \$1.25 (incl. p/h)

SPINAL CORD INJURED

THE SENSUOUS WHEELER: SEXUAL ADJUSTMENT FOR THE SPINAL CORD INJURED

Barry J. Rabin

Informal, positive treatment of the subject, stressing the sharing of sexual responsibilities and vulnerabilities.

Barry J. Rabin (1980), 5595 East 7th Street, Suite 353, Long Beach, CA 90804; \$11.45 (incl. p/h)

SEX AND THE SPINAL CORD INJURED: SOME QUESTIONS AND ANSWERS

M. G. Eisenberg and L. C. Rustad

Questions discussed include areas such as physical attractiveness, aging, drugs, catheters, divorce, adoption, and alternative methods of sexual expression.

Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402 (1975); \$2.00 (to order, use Stock No. 051-000-00081-1)

SEXUALITY AND THE SPINAL CORD INJURED WOMAN

Sue Bregman

Booklet providing guidelines concerning social and sexual adjustment for spinal cord injured women and health professionals who work with them.

Sister Kenny Institute (1975), Publications Department, 800 East 28th Street at Chicago Avenue, Minneapolis, MN 55407; \$6.00 + \$3.00 p/h

VISUALLY IMPAIRED

FOR BOYS: A BOOK ABOUT GIRLS

Braille booklet explaining menstruation. Includes braille diagrams of female reproductive system.

Personal Products Co. (1985), Milltown, NJ 08850; \$1.50; one complimentary copy per school system

GROWING UP AND LIKING IT

Booklet explaining menstruation to girls; available in braille.

Personal Products Co. (1985), Milltown, NJ 08850; \$2.00 (one complimentary copy per school system)

SEX EDUCATION FOR THE VISUALLY HANDICAPPED IN SCHOOLS AND AGENCIES: SELECTED PAPERS

Sound advice on the development and implementation of sex education programs for the visually impaired from professionals in a variety of settings.

American Foundation for the Blind (1975), 15 West 16th Street, New York, NY 10011; \$5.00 + \$2.50 p/h

OTHER DISABILITIES

GROWING UP WITH SPINA BIFIDA: A BOOK ABOUT PUBERTY, INDEPENDENCE, AND CARING

M. C. Treadwell and R. L. Patrias

A booklet with detailed diagrams, providing information on body parts, puberty, body image, hygiene, and sexuality. Includes resource list for more information, and a glossary.

Mason Barr, MD (1981), University Hospital, K2027 Holden, Box 07, Ann Arbor, MI 48109; \$1.00 (incl. p/h)

INTIMACY AND CHRONIC LUNG DISEASE

Carol J. Hossler and Sandra S. Cole

Presents effective ways to deal with lung disease, including relaxation and breathing exercises, diet, medication, and energy conservation. Intimacy, sexual anatomy and physiology, and positions for intercourse are also covered.

Department of Physical Medicine and Rehabilitation (1983), 1405 East Ann Street, Ann Arbor, MI 48109-0010; 5.00

THE SENSUOUS HEART: GUIDELINES FOR SEX AFTER A HEART ATTACK

Suzanne Cambre

A cartoon-style booklet covering concerns about depression, sexual activity, physical exercise, medications, sexual positions, eating, and drinking.

Pritchett and Hull Associates, Inc. (1978), 3440 Oakcliff Road, NE, Suite 110, Atlanta, GA 30340; \$2.60 + \$2.00 p/h

SEXUAL DYSFUNCTION IN NEUROLOGICAL DISORDERS: DIAGNOSIS, MANAGEMENT, AND REHABILITATION

Francois Boller and Ellen Frank

Reviews etiology, symptoms, and practical management of impairments of sexual function in patients with such disorders as diabetes, spinal cord lesions, strokes, and Parkinson's disease.

Raven Press (1982), 1140 Avenue of the Americas, New York, NY 10036; \$16.50 (incl. p/h)

SEXUAL HEALTH AND DIABETES

Linda K. Strodman and Ralph F. Knopf

This booklet is written for diabetics, but is useful for health professionals, as well. It addresses pregnancy, contraception, and sexual function and dysfunction.

Media Library, University of Michigan Medical Center (1983), R4440 Kresge I, Ann Arbor, MI 48109; \$18.50 for 10 copies (incl. p/h)

SEXUALITY AND NEUROMUSCULAR DISEASE

Frances Anderson, Joan Bardach, and Joseph Goodgold

This monograph's recommendations for helping disabled individuals with neuromuscular disease achieve sexual fulfillment are derived from interviews with patients, their families, and physical therapists, as well as from literature surveys.

New York University Medical Center (1979), Publications Office, 530 First Avenue, New York, NY 10016; \$2.00 (includes p/h)

SEXUALITY AND HANDICAP: PROBLEMS OF MOTOR HANDICAPPED PEOPLE

B. H. H. Duchesne, C. Pons, and A. M. C. M. Schellen, eds.

This book, originally published in Holland, has been translated into English by Robert Lyng. It is divided into three parts dealing with the medical, psycho-social, and ethical aspects of sexuality and motor disabilities. The medical section is strongest.

Charles C. Thomas (1986), 2600 South First Street, Springfield, IL 62717; \$34.75 pb

AUDIO-VISUAL REVIEWS

Members of the SIECUS Audio-Visual Review Panel for this issue were: Peggy Brick, MEd, Director of Education, Planned Parenthood of Bergen County, Hackensack, NJ; Patti Britton, Department of Education, Planned Parenthood Federation of America; Martha Calderwood, MA, University of Medicine and Dentistry of New Jersey; Rita Cotterly, Graduate Assistant, SIECUS Information Service and Mary S. Calderone Library, and doctoral candidate in Human Sexuality Program, New York University; Leigh Hallingby, MSW, MS, Manager, SIECUS Information Service and Mary S. Calderone Library; Jean Levitan, PhD, Assistant Professor, William Paterson College, Wayne, NJ; Valerie Pinhas, PhD, CSW, CAC, Associate Professor of Health Education, Nassau Community College, Garden City, NY; Alex Sareyan, President, Mental Health Materials Center; Linda Schwarz, Department of Education, Planned Parenthood Federation of America; Jan Sola, PhD, Program Consultant, National Board of YWCA of the USA; Jill Tabbutt, Information Specialist, SIECUS Information Service and Mary S. Calderone Library, and graduate student, Human Sexuality Program, New York University. The reviews were written by Leigh Hallingby.

The Attendant. 1984, video, 30 min. Purchase, \$300; rental, \$55. Filmmakers Library, 133 East 58th Street, New York, NY 10022; (212) 355-6545.

The first two thirds of this video explores the relationship between Rik Berkenpass, a severely disabled young man, and his attendant David Harlan, who goes through two hours of strenuous work every morning to get Rik out of bed, toileted, washed, dressed, into his wheelchair, and ready for work. It is a symbiotic relationship, which enables Rik to function as a whole, dignified human being, and gives David the satisfaction of doing a job that is almost a matter of life and death. Beyond this, however, lies an even deeper dimension, which is the physical (but not sexual) and emotional intimacy that these men have developed and are able to

articulate. It is obvious that they love each other in a unique way, and David speaks of how he wishes he could have such close relationships with other men, especially those with whom he served in Vietnam. The last part of the video reveals another side of Rik's life: his love for Jean Schuster, a young woman with cerebral palsy. They explain how their relationship developed and how their dreams and desires are similar to those of other young couples.

One panel member summed up many of our feelings about *The Attendant* (the title of which unfortunately reflects only part of the content) when she described it as "a dichotomous film that works beautifully in the end. It demonstrates two remarkable relationships. . . . Each of the halves is quite special." Other panel members used adjectives such as "powerful," "beautiful," "moving," and

"profound" to describe this video, which is highly recommended for audiences from late teens up. It presents a beautiful model of male-to-male intimacy and also brings up issues of love, touch, physical dependence, disability, friendship, commitment, trust, and sexuality. **LT, A, P, PR**

Men Who Molest/Children Who Survive. 1985, 16mm or video, 52 min. Purchase, \$750 (16mm), \$450 (video); rental, \$80. Filmmakers Library, 133 East 58th Street, New York, NY 10022; (212) 355-6545.

This potent documentary opens with Alan, who began sexually abusing his daughter Amy when she was eighteen months old and did not stop until he was caught five years later. Alan and his wife are still together trying to salvage their marriage and family. Next, we meet Dawn, a young adolescent who took the unusual step of reporting her father Wayne to the Harborview Sexual Assault Center in Seattle, Washington, after he had been molesting her for two years. Lia, at age seven, is introduced during a therapy session in which she uses rag dolls to reenact her uncle David's molestation of her at age 4. Subsequently, in a powerful scene, she shows how a victim can become a survivor when she confronts her uncle in prison. Finally, we see Jim, who unlike the other three men, is not related to any of the more than 30 boys and girls whom he has molested.

Other scenes in this film include group therapy sessions with male sex offenders and separate sessions with women who are wives of molesters and/or mothers of abused children. This video also includes interviews with therapists and a judge who discusses the approach of the criminal justice system to child sexual abusers.

Some of the messages of *Men Who Molest/Children Who Survive* are that men engage in this offensive behavior because they derive sexual pleasure from it; that they are addicted to it, much the way an alcoholic is addicted to drinking; that relatively little is known about the phenomenon of child sexual

Choices: In Sexuality with Physical Disability

(16 mm & Video/Color/60 Mins.)

Produced for:
Institute of Rehabilitation Medicine
New York University Medical Center
Joan L. Bardach Ph.D., Project Director
Frank Padrone Ph.D., Co-Director

. . . Choices is a film which can be used time and time again in rehabilitation facilities human sexuality programs and in any group where issues of sexual interaction and adjustment to a disability are being discussed. If both parts cannot be purchased, Part 1 is a tremendously good discussion starter and should not be missed. . . .

Pam Boyle, Coordinator: Reproductive Health and Disabilities Program of the Margaret Sanger Center of Planned Parenthood. NYC.



Mercury Productions
17 West 45 Street, NYC 10036
(212) 869-4073

Audience Level Indicators: **C**—Children (elementary grades), **ET**—Early teens (junior high), **LT**—Late teens (senior high), **A**—College, general adult public, **P**—Parents, **PR**—Professionals.

abuse; and that there are no easy answers and perhaps no answers at all for some offenders as far as treatment and cure are concerned. The panel found this to be an interesting, intense, and rather pessimistic film, which would be most useful for therapists, child sexual abusers and their family members, and college and adult audiences interested in this complex problem. **A, P, PR**

Sudden Changes: Post Hysterectomy Syndrome. 1984, video, 29 min. Purchase, \$295; rental, \$50. Cinema Guild, 1697 Broadway, New York, NY 10019; (212) 246-5522.

If present trends continue, by the year 2000 at least half of all American women will have their uteruses removed at some time in their lives. *Sudden Changes* tells the stories of an important and generally previously unheard-from minority of women who experience significant negative after-effects from their surgery. The filmmakers admit that their intention is not to be objective, but to present an alternative view to the common one that hysterectomies generally do not cause unpleasant after-effects. As part of this process, they raise questions such as: When is such surgery necessary? Why is the rate so high? What alternatives are viable? The video includes interviews with women who have experienced such post-hysterectomy complications as lack of sexual drive, joint pains, hot flashes, and vaginal dryness. It also includes a visit to a self-help group for women who have undergone the operation, an interview with a couple who discuss the impact of the surgery on their marriage, and the stories of two women who have chosen alternatives to hysterectomy, such as having fibroid tumors removed from the womb. Many of the women who appear in the video are of premenopausal age. Graphics are used to explain some of the anatomy and physiology involved.

Generally, the panel reacted well to *Sudden Changes*, feeling that it is an audio-visual with a unique and important viewpoint that needs to be aired. A couple of members raised the question of whether it crossed over the line from educational to alarmist, and there was agreement that statistics comparing the situation of hysterectomies and women's gynecological health in the U.S. to other countries would have been an excellent addition. But the consensus was that it is important for women and physicians to see *Sudden Changes* and that it would be an excellent discussion starter. Its

messages—get to know yourself, question physicians, and consider alternatives—raise consciousness and cannot be heard too often by consumers or professionals. **A, PR**

BARN, the Body Awareness Resource Network. 1985. A 5-part computer program for adolescent health education. Purchase, \$1,195; human sexuality module only, \$499. Encyclopedia Britannica Educational Corporation, 425 North Michigan Avenue, Chicago, IL 60611; (800) 621-3900.

BARN is a friendly, spunky computer program that provides teens with information, resources, and decision-making aids about alcohol and drugs, human sexuality, smoking, stress management, and body management. It was developed by the Center for Health Systems Research and Analysis at the University of Wisconsin in Madison. A subcommittee of the Audio-visual Review Panel (Patti Britton, Leigh Hallingby, and Linda Schwarz) reviewed the human sexuality portion.

The human sexuality program uses a non-threatening and often humorous format. For instance, the "Skunk Barney"

game is a knowledge test pitting the adolescent against the computer. When the user correctly answers one of the questions about reproduction, sexually transmitted diseases, contraception, or human anatomy, she/he gains two points. An incorrect answer gives BARN two points. "Dear Barney" letters, generated from questions submitted by adolescents, provide more in-depth information about topics introduced in the "Skunk Barney" game. Decisions teens must make about first dates, peer pressure, and pregnancy are explored in "Soap Operas." "Am I Pregnant?" provides information about pregnancy symptoms, testing, and counseling. The same kinds of information regarding sexually transmitted diseases are provided in "Do I Have VD?"

The panel subcommittee was impressed with BARN for many reasons. Besides being user-friendly and providing a wealth of information, it gives teens permission to be sexual persons. Masturbation, for instance, is viewed not just as an activity that will not hurt teens, but as a potentially positive activity. Homosexuality is another controversial topic that is dealt with forthrightly. The program does not talk down to adolescents, nor is it sexist. It helps to build self-esteem and motivate teens not to get pregnant. In field tests, students said they like BARN because it is confidential, fun, and nonjudgmental. Furthermore, they pointed out that it is not embarrassing to ask questions of BARN and that they get more accurate answers than they do from their peers.

We did find some disappointments. For instance, the developers of BARN seem to have gone along with the societal tabu against showing an erect penis, and there were a few situations—such as discussions of ejaculation, condoms, and fertilization—where this was obviously missing. The option of abortion was not mentioned in the pregnancy section. There were places like the sections on testicular self-examination, breast self-examination, and birth control methods where more graphics were needed. Finally, the "Skunk Barney" questions about males and females were all aimed at girls avoiding pregnancy.

Despite these drawbacks, BARN is an exciting new approach to sex education and deserves wide distribution wherever computer terminals are available to teens. Currently, BARN is designed for use with the Apple II computer, but compatibility with other popular formats is in the works. **ET, LT, P, PR**

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BOOK REVIEWS

Sexuality and Handicap: Problems of Motor Handicapped People. B.H.H. Dechesne, C. Pons and A.M.C.M. Schellen, eds. Springfield, Illinois: Charles C Thomas (234 pp.; \$34.75).

Reviewed by Ann Welbourne-Moglia, Ph.D., Executive Director, Sex Information and Education Council of the U.S.

One of the first books written to address the topic of sexuality and disability was a book entitled *Not Made of Stone*. It contributed significantly by increasing awareness and information about the sexual needs of motor disabled people. Over ten years have passed since that time. The authors of *Sexuality and Handicap* begin their text by saying that what is needed now is a book with a more scientific character for a professional audience. They base this approach on the premise that there is no longer a need for a book providing basic sex education for disabled consumers. While this reviewer has some disagreement with this belief, *Sexuality and Handicap* does deliver what the authors promise.

The book is divided into three parts. Part One covers medical aspects, such as fertility, reproduction, sexual problems and neurological injuries, heredity and contraception. Part Two focuses on psycho-social aspects; rehabilitation and relationship issues are the principle topics covered. The final section of the book is concerned with the ethical issues of what is normal thought and behavior when one is disabled.

The strength of this book is in the first section. Comprehensive and very useful information and resources are presented when discussing the medical aspects of motor disability. In addition to discussion of assessment steps and procedures, illustrations of treatments, medical procedures, and sexual devices are very helpful. If one is looking for a basic overview of the physical/medical issues of motor disability, this book provides it.

On the other hand, if your interests are focused more on the social and emotional aspects of sexuality and disability, the book is less developed and insufficient. The authors tend to discuss the "problems" of disability, while offering minimal suggestions or reasons for hope in this area. Also, the research cited is not as current as it could be.

In sum, *Sexuality and Handicap* provides a basic overview of some of the key issues affecting the sexual satisfaction of individuals with motor disabilities. The book would be a good introductory text for someone not very familiar with this topic area, particularly the physical and reproductive aspects. The editors and authors are to be commended for their attempt to "escape the Chatterley syndrome" of impotent and infertile paraplegic and quadriplegic women and men. **PR**

Behavioral Intervention in the Sexual Problems of Mentally Handicapped Individuals in Residential and Home Settings. Lynda K. Mitchell. Springfield, Ill.: Charles C. Thomas, 1985 (106 pp.; \$19.75).

Reviewed by Winifred K. Kempton, Consultant, *Sexuality and the Developmentally Disabled*; author, *Sex Education for Persons With Disabilities That Hinder Learning: A Teacher's Guide*.

When people indulge in sexual activities in public, reactions to this behavior depend largely on the situation involved. For example, if they are on the street and a policeman is nearby, they may land in jail. If, however, they are mentally handicapped and with people they know, what happens usually depends on their caretakers' attitudes about sexuality: One individual may overreact and randomly punish; another may ignore out of discomfort; a third may ridicule the activity. This book is for the caretaker who recognizes the need to approach the

problem objectively and who is conscientious about finding the most appropriate solution. It provides guidelines for initiating behavioral changes. What is quite special about this book is that it treats sexual behavior in the same professional manner as other behaviors of mentally handicapped persons by systematically observing, reporting, and recording, and analyzing when problems arise. This is progress.

Interest in the beginning chapters will probably vary according to the background of the readers. For example, the material on sexuality, such as sexual rights, myths, social skills, and sex education for the handicapped will already be familiar to those who are involved in the field. The explanations on how behavior is learned and changed will seem elementary to behavioral scientists. However, it is important that readers who plan to utilize the following chapters clearly understand all of this basic background information. In describing the process of learning, the author states, "Behaviors are motivated and maintained by our expectation that we will receive some form of reinforcement for engaging in them, either positive or negative. In order to decide whether or not we are likely to be reinforced, we look for cues in the environment to guide our behavior. We also learn from observing others."

Mitchell's procedures for changing behavior, succinctly outlined in the third chapter, emphasize the need to analyze individual patterns before setting up such procedures. Sample baseline charts are presented for this purpose—to record what the behavior is, what triggers it, and what reinforcements, if any, are being used. From this data, intervention procedures for changing the patterns can be set up for staff to follow. The case cited in this chapter concerns helping a client overcome a masturbatory problem.

Most of the remaining chapters are devoted to applying these theories to

Audience Level Indicators: **C**—Children (elementary grades), **ET**—Early teens (junior high), **LT**—Late teens (senior high), **A**—College, general adult public, **P**—Parents, **PR**—Professionals.

the main problematic sexual activities characteristic of mentally handicapped persons. The chapter on self-stimulation is especially important for those involved with the very severely disabled. However, Mitchell does not discuss here how she defines masturbation. Does it include such behaviors as rocking, head banging, rubbing other than the sexual parts of the body, and various bizarre habits? Nor does she address a question caretakers often ask: When can self-stimulation be considered satisfying and what should be done if it isn't? The author does wisely recommend checking such items as physical causes, extreme boredom, and ignorance of the unacceptability of public self-stimulation before applying theories for changing behavior, and she points out the problem involved in deciding what can be considered private behavior in some group-living situations. Included in this chapter are two case histories illustrating the use of behavioral techniques in affecting masturbatory habits. Problems of public disrobing are also addressed.

In her discussions of sexual orientation, the author wisely cautions against assuming that a mentally handicapped

person prefers a homosexual lifestyle because he (or she, I assume, although lesbianism is not mentioned) is exhibiting one, and she cites considerations to be explored before drawing conclusions. Mitchell believes that, whatever the sexual orientations, the behavior must be changed if it is *publically* unacceptable, since otherwise clients cannot become free-moving members of society. Some readers, however, may join me in taking issue with Mitchell's view that intervention in *private* homosexual activities is an infringement of a client's privacy. There are many documented cases of physical harm and sexual exploitation occurring unchecked because the victims were ignorant of their rights or because their disabilities made it impossible for them to report or complain—too many such cases for us to support her opinion. The same argument extends to private heterosexual activity.

The two case presentations using intervention for overly aggressive and seductive behavior both have happy endings, which are encouraging to read. One wishes there had also been examples of intervention in some not-so-easily solved situations, such as in those involving men arrested because of their

seemingly incorrigible sexual acts, or women raped, impregnated, and used as prostitutes after repeated failure to correct their blatant seductive behavior. In fact, more case presentations throughout would have strengthened the book, perhaps taking the space allocated to the last chapter's outline of a training course. This is not to minimize the crucial role a trained staff plays in successfully implementing the book's guidelines, but it is true that the information given is available in other resources. Mitchell no doubt included this chapter because she is realistically aware that the effectiveness of the implementation depends upon full cooperation among the staff members and their consistency in following the procedures. Unfortunately, doubt and dissension about sexual matters still exists among professionals as well as parents.

The serious omissions in the book are footnoted references to specific sources. Though the annotated bibliography is fairly comprehensive, textual references are too casually made for sound documentation of the experts cited. Overall, however, the author has provided many useful suggestions for dealing with the sexual problems of mentally handicapped individuals. **PR**

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