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SIECUS

REPORT

MEETING THE NEEDS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

APRIL/MAY 1995

// SIECUS

REPORT

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Debra W. Haffner, M.P.H.
Executive Director

Carolyn Patierno
Director, Program Services

Dore Hollander
Editor

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All article, review, advertising, and publication inquiries and submissions should be addressed to:

Dore Hollander, Editor
SIECUS Report
130 West 42nd Street, Suite 350
New York, NY 10036
phone 212-819-9770 fax 212-819-9776

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WHAT'S IN A NAME

Dore Hollander

This issue of the *SIECUS Report* has been months in the planning. Only now, though, as I emerge from the process of selecting and editing manuscripts for it, do I realize how laden with meaning is its title: "Meeting the Needs of People with Developmental Disabilities." This title itself conveys three important points.

First, because language both reflects and helps shape societal attitudes, the language that members of society use to refer to each other has important ramifications for individuals and groups. Labels are broad, and broadly misunderstood, and to identify a person by any one characteristic is to minimize the variety of an individual's experiences and the depth of his or her personality.

People with developmental disabilities have long been labeled in ways that have essentially denied their potential, limited their opportunities (for education, employment, and social relationships, among other things), and robbed them of their self-esteem. Such tags as "mentally retarded" and "handicapped" have carried global connotations, suggesting that the individual so labeled is incapable of doing many of the things that society expects of its members. Over the last several years, however, advocates for people with developmental disabilities have made a concerted effort to have society understand these individuals as "people first"—as children, men, and women who have a physical or cognitive disability, but are not defined by it. As this new way of thinking continues to gain currency, society will become ever more aware of the diverse talents and capabilities of people with disabilities, and individuals with disabilities will be ever more able to enhance their self-image and more motivated to explore their own potential.

Second, the title of this issue acknowledges that people with disabilities have sexuality-related needs. Sexuality is a natural part of living, and all people require education to help them understand their sexuality and express it in an appropriate and healthy manner. People with cognitive disabilities may have different styles of learning than others, may need more intensive instruction in what constitutes acceptable sexual behavior, and may benefit from greater attention aimed at protecting them from sexual exploitation or harmful sexual activity. People with physical disabilities, too, may need educational approaches that take into account their disabilities, as well as guidance in developing a satisfying sexual life that accommodates any limitations their disabilities may impose. But in all cases, people with developmental disabilities deserve nothing less than committed efforts—on the part of their families, their teachers, and other caregivers—to facilitate their healthy sexual development.

Which brings us to the third point: Now that families and professionals who work with people with developmental disabilities are, more than ever before, recognizing that these individuals have sexual needs, it is incumbent on them to help these people obtain the information and develop the skills they require to meet those needs. As the contributors to this issue point out, this may require adapting teaching strategies, obtaining innovative teaching aids, or repeating lessons. It may entail struggling with how to strike a balance between allowing a person the independence to express his or her sexuality freely and offering some measure of protection in the event that the individual is not prepared to make informed decisions. It certainly requires support and flexibility within the family, particularly a willingness to restructure routines and events in such a way as to allow the person with a disability to contribute to the family experience. A wealth of materials is available to help educators and families with this task, and although we can only scratch the surface in the space of one issue, the annotated bibliography on pages 26–36, in conjunction with the feature articles, provides a good foundation.

What's in a name? A name can encapsulate new information, raise a question, present a challenge; the title of this issue, we think, does a bit of each of these. The articles that follow offer some of the detail to expand on the title; more important, they offer tools that will enable the people who work with and care about people with disabilities to teach them about an important part of their life.

A NOTE ON OUR NEW DESIGN

With this issue, we introduce an entirely new look for the *SIECUS Report*. The new design was created by the talented staff of Stein, Killpatrick & Rogan (SK&R) Advertising, in New York, who donated their services. SIECUS is extremely grateful for SK&R's work on our behalf.

COMPREHENSIVE SEXUALITY EDUCATION FOR CHILDREN AND YOUTH WITH DISABILITIES

Lisa Küpper
Editor,
National Information Center for
Children and Youth with Disabilities

Today, owing to the work of advocates and people with disabilities over the past half century, American society is acknowledging that people with disabilities have the same rights as other citizens to contribute to and benefit from our society. This includes the right to education, employment, self-determination, and independence. Society is also coming to recognize—albeit more slowly—that persons with disabilities have the right to experience and fulfill an important aspect of their individuality, namely, their sexuality. As with all rights, this right brings with it responsibilities, not only for the person with disabilities, but also for that individual's parents and caregivers. Adequately preparing a child for adulthood, with its many choices and responsibilities, is certainly one of the greatest challenges that parents face.

For parents of children with disabilities—whether sensory, orthopedic, emotional, or cognitive—this challenge has many unique aspects. Children and youth with disabilities often have relatively few opportunities to acquire information from their peers; have relatively few chances to observe, develop, and practice appropriate social and sexual behavior; may have a reading level that limits their access to information; may require special materials that explain sexuality in ways they can understand; and may need more time and repetition in order to understand the concepts presented to them. Yet, with opportunities to learn about and discuss the many dimensions of sexuality, young people with disabilities can gain an understanding of the role that sexuality plays in all our lives, the social aspects of sexuality, and values and attitudes about sexuality and social and sexual behavior. They also can learn valuable interpersonal skills and develop an awareness of their own responsibility for their bodies and their actions. Ultimately, all that they learn prepares them to assume the responsibilities of adulthood, living, working, and socializing in personally meaningful ways within the community.

MISCONCEPTIONS ABOUT THE SEXUALITY OF INDIVIDUALS WITH DISABILITIES

Before considering sexuality education for children and youth with disabilities, it is important to understand that there are many misconceptions about the sexuality of people with disabilities. The most common one is that children and youth (and, yes, even adults) who have disabilities are asexual and consequently do not need education about sexuality. Nothing could be further from the truth. All people, including those with disabilities, are social and sexual beings from the day they are born. Children grow and become adolescents with physically maturing bodies and a host of emerging social and sexual feelings and needs. Parents need to be aware that a child's disability, even when severe, will not, in the vast majority of cases, prevent him or her from developing physically or from experiencing the same sexual feelings and needs that individuals without disabilities experience. Parents can help their child to cope in a healthy and responsible manner with physical and emotional development by anticipating it and talking openly about sexuality and the values and choices surrounding sexual expression.

Many people also think that individuals with disabilities will not marry or have children, and therefore have no need to learn about sexuality. This is not true either. As people with disabilities gain increased realization of their rights, more independence, and greater self-sufficiency, many choose to marry or become sexually involved. Children and youth with disabilities thus have a genuine need to learn about what sexuality is, its meaning in adolescent and adult life, and the responsibilities that go along with exploring and experiencing one's sexuality. They need information about values; morals; and the subtleties of friendship, dating, love, and intimacy. They also need to know how to protect themselves against unwanted pregnancies, sexually transmitted diseases, and sexual exploitation.

TAILORING SEXUALITY EDUCATION FOR CHILDREN AND YOUTH WITH DISABILITIES

Every child needs to learn accurate information about sexuality, and to accept sexuality as part of his or her identity. Since various disabilities affect learning and behavior in different ways, however, the type of disability that a child has may affect the way in which information should be presented and what type of information is presented.

For example, a person with mental retardation may need information presented in small amounts and in simple, concrete, and basic terms. A young person with a visual impairment, meanwhile, would be capable of understanding a wide range of concepts and facts about sexuality, but might need

materials that present this information in alternate formats—through touch, hearing, or Braille, or in large print. Similarly, a young person with an orthopedic disability would be capable of understanding material about sexuality, would not need the information to be presented in alternate formats, but might need specific information about how the disability affects expression of sexuality and participation in a sexual relationship.[1] Young people with learning disabilities generally do not require specialized materials or formats to learn about sexuality, but may need some modification in the pace and manner of presentation and increased emphasis on social skills.

THE IMPORTANCE OF DEVELOPING SOCIAL SKILLS

Many individuals with disabilities are socially isolated. The presence of a disability may make peers shy away, may make transportation to and from social events difficult, may require special health care, or may make an individual reluctant to venture out socially. A lack of appropriate social skills may also contribute to a person's social isolation. Most people with disabilities, however, are capable of learning the "rules" of appropriate social and sexual behavior, and they must do so to build gratifying relationships.

Acquiring socialization skills does not happen overnight; it takes years of observation, discussion, practice, and constructive feedback. Some of the most important aspects of socializing that individuals with disabilities may initially have difficulty grasping include taking turns during conversations, maintaining eye contact, being polite, maintaining attention, repairing misunderstandings, finding a topic of mutual interest, and distinguishing social cues (both verbal and nonverbal).

Parents play a vital role in helping their child learn how to socialize; one way to do this is by giving the child a part to play in social situations. For example, when entertaining, rather than having their child safely tucked into bed before guests arrive, parents might involve the young person in greeting people at the door, taking their coats, or offering them food.[2] Many families find it helpful to take one aspect at a time (for example, shaking hands) and practice it with the child in advance. Even persons with severe disabilities can be creatively included.

These early interactions lay the foundation for interactions in the future, many of which will take place outside the home. Training at home should also emphasize the basics of good grooming, personal hygiene, and self-care. It is helpful to explore and discuss with the child what makes for good friendships, how friendships are formed and maintained, and some reasons why friendships may end. Children and youth with disabilities need to be aware that they may have to be the initiator in forming friendships. In the beginning, this may be difficult for a young person with disabilities. Parents may wish to model important social behaviors for their child and then have him or her role-play with other family members any number of typical friendly interactions, such as phone conversations, asking about another person's interests or describing one's own interests, inviting a friend to the house, or suggesting or sharing an activity with a friend. The family can also do the following:

- Help the young person develop hobbies or pursue special interests. Not only are hobbies gratifying in themselves, but shared hobbies or interests bring people together and provide opportunities for friendships to develop.

- Encourage the person with a disability to pursue recreational and leisure activities in the community. These might include youth groups; church groups; and activities through parks and recreation departments, local community centers, or the YM/YWCA. Such activities provide healthy outlets for youthful energy, build self-esteem by developing competence, and provide occasions for young people to interact with their peers.

- Encourage the young person to participate in extracurricular activities at school. Most schools have special-interest activities or clubs. Even after-school day care programs offer many opportunities for socialization.

- Be alert to opportunities for the child to become involved creatively at school. For example, a young person with disabilities that prevent him or her from participating in sports events may be able to contribute managerially to a school athletic team's activities. In this role, the youngster may have a chance to travel to games and get to know the players, cheerleaders, and their friends.

- Help teenagers with disabilities find employment or volunteer positions in the community. Working after school or on the weekends offers opportunities for social interaction and certainly enhances self-esteem.

- Try not to overprotect the young person. Although it is natural for parents and caregivers to want to shield children from the possibility of failure, hurt feelings, and rejection, a child must have the opportunity to grow socially. Family members need to be available to talk with the child about difficulties he or she is having socially and about his or her fears, questions, and feelings. When attempts to build a friendship do not work out, the child should be encouraged to try again.

Beyond developing basic interpersonal skills, there are two types of social mistakes that many individuals with disabili-

ties will need special help to avoid: stranger-friend errors and private-public errors. A stranger-friend error occurs when a person with a disability treats an acquaintance or a total stranger as if he or she were a dear and trusted friend. Individuals with mental retardation are particularly likely to make these kinds of mistakes—for example, hugging or kissing a stranger who comes to the family home. Private-public errors generally involve doing or saying something in public that society considers unacceptable in that context, such as touching one's genitals or undressing in plain view of others. Committing either type of error can put the person with a disability into a vulnerable position in terms of breaking the law or opening the door to sexual exploitation. One effective approach to teaching children with disabilities to avoid making stranger-friend errors is the CIRCLES method, developed by Leslie Walker-Hirsch and Marklyn Champagne (see Walker-Hirsch's article on page 9 of this issue). To teach children with disabilities to avoid public-private errors, modeling, explanation, and persistence are effective. Parents and caregivers can help children understand the difference between public ("being with others") and private ("being alone") by taking advantage of opportunities that occur naturally—for example, teaching grooming in private, or telling a child who touches his or her genitals in public that this is not appropriate behavior.

> *"What can help is encouraging children with disabilities to focus on and develop their strengths...."*

BODY IMAGE

Young people, particularly preteenagers and adolescents, can be quite preoccupied with what their peers think of them, and for many, body image may become an issue. Given the emphasis placed on physical beauty within our society, it is not difficult to imagine why many young people with disabilities, particularly those with disabilities affecting the body, may have low self-esteem in this area.

Parents and professionals can take a number of steps to help children and youth with disabilities improve self-esteem with regard to body image. They can, first of all, listen to the child and allow him or her the freedom to express feelings of sensitivity, inadequacy, or unhappiness. Listeners need to be careful not to wave aside a child's concerns, particularly as they relate to his or her disability. If the disability is one that can cause the young person to have legitimate difficulties with body image, then caregivers need to acknowledge that fact calmly and tactfully. The disability is there; parents know it, and the child knows it. Pretending otherwise will not help the young person develop a balanced and realistic sense of self.

What can help is encouraging children with disabilities to focus on and develop their strengths, not what they perceive as bad points about their physical appearance. This is called "refocusing." Many parents have also helped their child with a disability improve negative body image by encouraging improvements that can be made through good grooming, diet, and exercise. While it is important not to teach conformity for its own sake, fashionable clothes can often help any child feel more confident about body image.

As children enter puberty, their sensitivity about body image often increases. Without dismissing these feelings as "a phase you're going through," parents and other caregivers can try to help a young person understand that some of the feelings are a part of growing up. Parents may arrange for the youth to talk with the family doctor alone. If necessary, parents can talk to the doctor in advance to be sure he or she will be clear about the adolescent's concerns. If, however, the young person remains deeply troubled or angry about body image after supportive discussion within the family, it may be helpful to have him or her speak with a professional counselor. Counseling can be a good outlet for intense feelings, and often counselors can make recommendations that are useful to young people in their journey toward adulthood.

MASTURBATION

Masturbation is one topic that many parents find difficult to talk about with their children. With some children with disabilities, particularly those who have severe mental retardation or who are nonverbal, self-stimulation can be a persistent behavior that parents and caregivers may feel at a loss to curtail. Specific behavioral intervention strategies are necessary in these cases. For most young people with disabilities (and for those without), however, masturbation becomes a problem only when it is practiced in an inappropriate place or is accompanied by strong feelings of guilt or fear.[3]

When young children touch themselves in public, it is usually possible to distract them. During adolescence (and sometimes before), masturbation generally becomes more than an infrequent behavior, and distracting the youth will not work. Furthermore, it denies the real needs of the person, instead of helping him or her to meet those needs in acceptable ways.[4] Therefore, it is important for parents to teach their children that touching one's genitals in public is socially inappropriate and that such behavior is acceptable only when one is alone and in a private place such as one's bedroom.

REPRODUCTION AND CONTRACEPTION

While some disabilities make it difficult or impossible for an individual to become pregnant or to impregnate another, most individuals with disabilities can have children.

Therefore, they need to understand that sexual intercourse can lead to pregnancy, the responsibilities of parenthood, and how to protect oneself against unwanted pregnancy. They also need to know the importance of delaying sexual intercourse until they are emotionally prepared to deal with its many responsibilities and consequences.

Choosing a Contraceptive Method. In some families, contraception may be controversial, given personal, cultural, or religious beliefs. Yet, the decision to have children and when to have children is a personal one. Many individuals with disabilities will want to have children. Others may choose not to. Still others may be undecided or have specific concerns, such as the possibility that their disability may be passed on genetically to offspring. Information on contraception and family planning is, therefore, essential to help young people with disabilities to make responsible decisions about sexual health and behavior.

It is important to realize that some forms of contraception may be suitable for a person with a certain disability, while other forms may not. For example, young women who have difficulty with impulsivity, with memory, or with understanding basic concepts may have difficulty understanding and using natural family planning or birth control pills. An alternate method of contraception, such as Norplant, might be indicated. Similarly, for many youth with disabilities, learning to use a particular contraceptive method properly may involve more than just reading about the method or talking with their parents or doctor. For example, learning how to use a condom may require more than a simple instruction such as "you put it on." Some demonstration and practice with plastic models may be needed. It may be useful for parents to talk with the family physician about methods of contraception and how suitable each method is when the young person's disability is taken into consideration.

Sterilization. Families and caregivers might consider sterilization an effective and practical contraceptive option for some individuals with disabilities, particularly those who do not wish to have children and those who are incapable of understanding the consequences of sexual activity or of assuming the responsibilities of parenthood. All the people involved in making such a decision should be aware that there are strict laws regarding sterilization. These laws, which vary from state to state, are intended to protect individuals with disabilities against involuntary sterilization, a practice that was mandatory for persons with mental retardation in many states early in this century. Following the Supreme Court's 1942 finding that reproduction is a fundamental human right, many states passed laws prohibiting sterilization of persons with mental disabilities without their informed consent. For some individuals with severe disabilities, however, it may be impossible to determine whether or not the consent is truly "informed." If sterilization is being considered for a person with disabilities, all those involved in making the decision need to find out how their state defines informed consent and what laws exist regarding sterilization.

Protection against Sexually Transmitted Diseases. Youth with disabilities need to know that many contraceptive methods do not provide protection against disease. They need to know what methods do offer protection and know how to obtain and use those methods. And they need to know that abstinence from sexual intercourse is the surest way to avoid contracting a sexually transmitted disease (STD), including HIV.

It is important to communicate accurate, up-to-date information (rather than use scare tactics) about STDs. Providing this information may be difficult, depending on the nature of the person's disability. Individuals with mental retardation, for example, may have trouble understanding that a person can look healthy but still transmit a disease.[5] It may be important to present information about STDs in very concrete terms, including pictures of what the various symptoms (for example, lesions, blisters) look like, making sure that the presentation is matter-of-fact and not frightening. For individuals who have difficulty remembering information, it will be vital for parents and professionals to reteach and reemphasize the major points about disease prevention.

Parenthood. For individuals with disabilities who choose to have a child, conception may be difficult, depending on the nature of the disability. Furthermore, carrying and delivering a baby may present considerations unique to the disability. Many women with physical disabilities, for example, have difficulty finding an obstetrician who is willing to assume medical responsibility for a person who requires different treatment and consideration. Yet, many women have successfully borne and reared children in spite of such obstacles. For the young person looking into the future and the possibility of a family, it may be helpful to learn about the responsibilities involved in raising children and to meet, read about, or see on video individuals with disabilities who have successfully done so. These provide positive role models for young people who may feel that because of their disability, they will never have children of their own.

Genetic Counseling. Individuals with disabilities may be concerned that their disability might be inherited. Parents may wish to discuss genetic counseling with their child with a disability and with other children in the family, as well. Many materials are available to facilitate discussion about this issue with family members.

SEXUAL EXPLOITATION

One of the greatest fears parents and caregivers have is that a child with a disability will be sexually exploited. A number of factors can make individuals with disabilities more susceptible to sexual exploitation or abuse than their peers without disabilities. These factors include the following:

- physical limitations that make self-defense difficult;
- cognitive limitations that make it difficult for a person to determine if a situation is safe or dangerous;
- vulnerability to suggestion, because of a limited understanding of sexuality and human relations, including public and private behavior;
- lack of information about sexual exploitation and what to do if it is attempted;
- a tendency to act impulsively, low self-esteem, and poor decision-making skills; and
- lack of social opportunities, resulting in loneliness and vulnerability.[6]

The fact that many individuals with disabilities are vulnerable to sexual exploitation makes it all the more imperative for parents and caregivers to address this issue with their child. One message that is important to start mentioning when children are young is that their body belongs to them. They should know that while some adults have good reasons to look at or touch their body (such as a parent giving them a bath), they have the right to tell others not to touch them when they do not want to be touched. Likewise, children should know that they should not touch strangers. Children should also be taught that if a stranger tries to persuade them to go with him or her, they should leave at once and tell a parent, neighbor, or other trusted adult.[7]

Many child abuse prevention programs teach children to identify sexual abuse on the basis of the concept of "good touch" and "bad touch." This approach has raised concern among many professionals, for a number of reasons.[8] Perhaps the most critical concern is that young children are not necessarily capable of accurately distinguishing between a good and bad touch. Most children lack understanding of appropriate expressions of sexuality, yet this approach requires them to make distinctions about what expressions are inappropriate.

Because young children (preschoolers and early elementary school children) are not physically, cognitively, emotionally, or socially able to protect themselves against sexual exploitation or abuse, parents and professionals can take a number of steps to help protect them:

- Distinguish between teaching the child to be *polite* (for example, greeting other people appropriately) and to be *compliant* (for instance, requiring the child to kiss or be kissed by relatives, friends, or acquaintances when the child does not want to do so).
- Closely supervise the whereabouts and activities of young children.
- Carefully scrutinize the backgrounds and references of day care providers and other caregivers.
- Be informed about sexual abuse; particularly, know the physical and behavioral signs of abuse.

Closely supervising children does not mean that parents or professionals should strictly limit their activities (that is, deny opportunities to participate in play groups, social groups, or community activities). Shielding persons with disabilities from the outside world may limit their contact with strangers, but it will not protect them from exploitation by friends, family members, or caregivers. Parents need to be aware that in most cases, the abuser is someone the child knows.[9]

Another concern is that young children may be receiving their first messages about sexuality in the negative, frightening terms associated with discussing sexual abuse. What impact this may have upon the later development of healthy sexuality is unknown. The better approach is to ensure that before a child learns about sexual abuse, he or she learns about healthy, appropriate forms of sexual expression.[10]

Once a foundation of understanding has been laid in terms that are positive about sexuality, then information about identifying, avoiding, and reporting sexual abuse can be given to children with disabilities. Beyond that, "the strongest protection against... sexual exploitation is an ongoing training program emphasizing self-reliance."[11] Building self-reliance includes three tasks:

- Tell children that they have the right to say no to behaviors or touches that hurt or make them uncomfortable. (At the same time, children need to know that there are exceptions to this rule—getting a shot from the doctor, for example.)
- Teach children decision-making and self-advocacy skills, which provide a good foundation for saying no.
- Let children know that they should always tell someone when another person attempts to victimize them or when a situation makes them feel uncomfortable.

CONCLUSION

While sexuality is often difficult for parents and professionals to discuss with children and youth, it must be addressed in an open, frank, and matter-of-fact manner. Yet, sexuality education is not accomplished in a limited number of lessons parents deliver; it is a lifelong process of learning about oneself and growing as a social and sexual being. Children and youth with disabilities have a right and a need to be fully and accurately informed about what sexuality means; what responsibilities it involves; and what unique pleasures, joys, and pain this aspect to identity can bring. The special needs of individuals with disabilities must be taken into consideration when parents and professionals present information on attitudes, values, behaviors, and facts about social skills and sexuality.

REFERENCES

1. K. Kroll and E. Klein, *Enabling Romance: A Guide to Love, Sex, and Relationships for Disabled People (and the People Who Care for Them)* (New York: Crown, 1992).

2. J. P. Edwards and T. E. Elkins, *Just between Us: A Social Sexual Training Guide for Parents and Professionals Who Have Concerns for Persons with Retardation* (Portland, OR: Ednick, 1988).

3. Ibid.

4. Ibid.

5. R. K. Monat-Haller, *Understanding and Expressing Sexuality: Responsible Choices for Individuals with Developmental Disabilities* (Baltimore: Paul H. Brookes, 1992).

6. M. Rosen, *Sexual Exploitation: A Community Problem* (Walnut Creek, CA: Planned Parenthood Association of Shasta/Diablo, 1984).

7. National Guidelines Task Force, *Guidelines for Comprehensive Sexuality Education: Kindergarten–12th Grade* (New York: Sex Information and Education Council of the U.S., 1991).

8. J. J. Krivacska, "Child Sexual Abuse Prevention Programs: The Need for Childhood Sexuality Education," *SIECUS Report*, 19, no. 6 (1991): 1-7.

9. Ibid.

10. Child Protection Program, *Victim Services Resource Manual for Pastors and Lay Leaders* (Dallas, 1991); and U.S. Department of Health and Human Services, National Center on Child Abuse and Neglect, *Child Sexual Abuse Prevention: Tips for Parents* (Washington, DC, n.d.).

11. N. E. S. Gardner, "Sexuality," in J. A. Summers, ed., *The Right to Grow Up: An Introduction to Adults with Developmental Disabilities* (Baltimore: Paul H. Brookes, 1986): 45-66.

A vast array of materials dealing with sexuality education for young people with disabilities is available for families and other caregivers. Many of these are listed in the SIECUS annotated bibliography on pages 26–36 of this issue. For additional resources, contact the National Information Center for Children and Youth with Disabilities, PO Box 1492, Washington, DC 20013-1492; 800-695-0285 or 202-884-8200 (both numbers can be used for voice or TT).

REPRODUCTIVE HEALTH AWARENESS MATERIALS AVAILABLE FROM MARCH OF DIMES

The March of Dimes *Catalog of Public Health Education Materials* lists and describes low-cost, high-quality print and audiovisual materials promoting reproductive health awareness. Topics include sexually transmitted diseases, HIV/AIDS prevention, and teenage pregnancy. Products include booklets, videos, pamphlets, information sheets, and posters; many materials are available in Spanish. For more information or a free catalog, call the March of Dimes Fulfillment Center, 800-367-6630. For free samples of materials, call 914-997-4720.

SPECIAL EDUCATION MEETS SEXUALITY EDUCATION: A TEACHER'S PERSPECTIVE

Leslie Walker-Hirsch, M.Ed.
Private Practitioner and Consultant

"At first people refuse to believe that a strange new thing can be done, then they begin to hope it can be done, then they see it can be done—Then it is done and all the world wonders why it was not done centuries ago."—Frances Hodgson Burnett

In the bad old days, people thought that individuals with developmental disabilities could not learn to express their sexuality in ways that were both personally satisfying and socially responsible. They were protected from society, and society from them, as they lived locked in the back wards of institutions or in the deep recesses of family under the mistaken belief that it was for their own good. Little or no effort went to create the basis for their healthy social and sexual development in the world beyond the institution walls or family fortresses, since the expectation was that people with disabilities would never be allowed to leave those environments.

Nowadays, increasing numbers of people with developmental disabilities live, learn, work, enjoy recreational activities, and socialize outside those walled settings. They are exposed to an expanded universe and its attendant benefits, risks, and complexities. Successful participation in community settings, at home, at school, at work, and at leisure requires that people with developmental disabilities learn new skills for social acceptance, personal satisfaction, and self-protection. As individuals with developmental disabilities (and those who are concerned with their well-being) look to adult life in a community setting, it becomes clear that academic and vocational education will only partially prepare them for the expanded world in which they will be living. Social and sexuality education is a basic building block that is necessary for a safe, satisfying, and successful transition from protected childhood to more self-sufficient and autonomous adulthood.

Social and sexuality education beginning early and continuing throughout adulthood is of great importance for people with developmental disabilities: Of course, parents, and others who have primary child-rearing responsibility, are the first sexuality educators of their children. They establish the security of a loving relationship, which becomes the basis for trusting in future relationships. Parental figures provide physical and emotional gratification and are role models for responsible, loving adult relationships.

As more complex relationship issues and social opportunities arise in adulthood, the more pressing the need becomes for successful resolution of social and sexual dilemmas.

WHY SPECIAL EDUCATION IS SO SPECIAL

Public Law 94-142 extended a "free and appropriate education" to children with disabilities. This law became the impetus for educational change and created a field that focuses on teaching those with idiosyncratic learning styles and developmental or other disabilities. This is now the field of special education.

Before special education became a household term, teachers, by and large, learned to teach using only a limited number of instructional techniques. If a student did not learn through the traditional approach, there was little help available to him or her within the public schools. Although many students could learn from traditional teaching methods, some could not adapt their learning styles so as to benefit from these teaching strategies. Nevertheless, such students could still learn. Teachers had to develop new ways to teach that would accommodate the various ways that nontraditional and handicapped students were able to learn, and college and university departments of special education began training teachers in these new techniques.

As a result of these innovations, a new generation of students with disabilities is emerging: high school graduates who have grown up at home and can read, write, and perform vocational tasks. And a host of new experiences are available to them: a loving home life, school and community participation, employment potential, even social and sexual awareness. Great effort has been made and good success has been achieved in the first three areas, but some hesitation remains about social and sexuality training for these students.

SOCIAL COMPETENCE IN SPECIAL EDUCATION

Special education for social and sexual competence is beginning to become a reality. Special educators, health educators, psychologists, social workers, parents, nurses, and other professionals are applying the techniques of special education to the broad subject of social and sexual awareness. Those concerned with assisting individuals with developmental and other disabilities to access a full life have available to them the specialized learning techniques and

tools that work and lead toward greater social competence and sexual responsibility. People with developmental disabilities often do not have the ability to think in abstract or hypothetical terms at the usual chronological age. Consequently, they may not meet the social expectations that our society has for people of their chronological age. This is not to say that they cannot ever achieve that social mastery, but different degrees of physical maturity and the passing of more birthdays usually accompany mastery of developmental milestones. And, indeed, some people achieve more milestones than others do.

SIX KEY COMPONENTS

Sexuality education for students with developmental disabilities includes six key components, which are detailed below. In examining these components, and the special education vehicles that have consistently yielded success, the following points are necessary to keep in mind:

- Each component has an informational element; an attitudinal, or affective, element; a behavioral element; and a social element. Each element needs to be addressed, although not always in the order listed here.
- The chronological age, social maturity, cultural influences, and developmental ability of the individual will affect the emphasis on each element.
- The above factors will also affect the depth of understanding that is possible at a particular time in development.
- The personal style and ability of the teacher will determine both what activities are implemented and how effective they are.

Yet, despite these qualifiers, some generally applicable principles for successful teaching emerge.

Key Component 1: Adult Self-care. This category includes basic tasks such as toileting, bathing, grooming, dressing, and genital hygiene. Since instruction in these tasks usually occurs early in a person's chronological development, the emphasis is on encouraging particular behaviors; details that are not directly involved with the behaviors to be learned—how the excretory system or the shower plumbing works, for instance—are unimportant. Positive attitude is developed through social approval and maintained with primary, secondary, and social rewards. (Primary rewards are direct rewards, such as food, that satisfy a basic human need; secondary rewards are tokens that can be exchanged for primary rewards; social rewards are the praise and other feedback one gets when one pleases someone else.)

Behavioral psychology has made a substantial contribution to teaching and training people with developmental disabilities the tasks of adult self-care. Task analysis (breaking a task down into several components); forward and backward chaining (performing the components of a task in their usual sequence or in reverse, whichever is easier for the individual); motivation sequences (reward menus of positive and negative reinforcers with intermittent schedules, rather than harsh punishment)—these form a strong behavioral approach, especially for the very young or the very delayed learner. Hand-over-hand assistance, extra practice, overcorrection, and even the use of drawings and photos are concrete, successful teaching practices for these basic self-care tasks. Fine-tuning with shaping techniques (rewarding the individual for closely approximating a task, even if he or she does not perform it perfectly) and continued social rewards can continue long after basics are mastered. Most individuals with developmental disabilities can achieve total independence in this category. The less intimate the care needed, the less custodial the caregiving and instruction.

Key Component 2: Anatomy and Physiology. This category includes information about the genitals and their functions, not only from a reproductive perspective, but perhaps more importantly from self-protective, self-valuing, health, and sensual perspectives.

Since information about the genitals may involve sexually explicit material, it is important that visual material be made specifically for educational purposes, and not in a way that might be misconstrued as erotic or pornographic. Because people with developmental disabilities often need visual supports to augment language processing, drawings, photos, and videos are a great help for conveying information and developing the language skills needed to communicate about our physical selves. For a person who is a concrete thinker, the internal parts of a human body can become illusive, abstract concepts because they cannot be seen or visualized. Life-size models or drawings that can be superimposed over bodies assist in clear communication.

Inclusion of diverse body types—old, young, tall, short, standing, in wheelchairs, with a variety of racial characteristics—can affirm positive attitudes about all parts of the body.

It is not a good idea to model or role-play adult sexual activities; drawings, photos, and videotapes are much less intrusive and have a high likelihood of doing the job.

Identification of sexual body parts and how they work is certainly an important feature of this area of sexuality education. However, for those with disabilities, the management of privacy also has a strong behavioral and social component. A family's attention to consistent privacy routines at home (that is, ensuring that the person with disabilities has the same degree of privacy as all other family members) is a

critical piece in the social and sexual competence puzzle. Providing brief opportunities for practice daily or more frequently and using a natural home setting are two more ways to foster learning.

Key Component 3: Empowerment and Self-esteem. This area covers concepts of intrinsic self-worth, social and sexual decision making, internal locus of control, and assertiveness and self-direction. The important elements of this component are as abstract as one can get: a simple drawing or even a detailed photo will not be able to show empowerment, for example.

A person gains or loses self-esteem over a long period of time, a little each day. People with developmental disabilities generally suffer more than the usual number of insults to their self-esteem. Often, the assault is related to the person's disability. Feelings of powerlessness, depression, rage, and loss can become the norm.

Empowerment is taught by creating the opportunity for the person to experience self-esteem. The social element in the development of self-esteem is the overriding one in this category. In *Nourishing Self-esteem,* Earl White identifies several wellsprings of self-esteem.[1] Situations and activities that enhance self-worth include the following:

- *Belonging and including others.* Joining a club or religious community and inviting another to participate in a task or come to a party are ways of creating a feeling of affiliation and give-and-take. A person with a disability can sometimes be a spoke in the wheel, but can also be the hub. Both experiences serve well to teach empowerment and self-esteem.

- *Appreciating individuality and enjoying one's own idiosyncrasies.* A person's red hair may be unusual, but attractive, too. A person with a disability may also be artistic or generous, but unique talents need to be discovered and affirmed by others, lest stereotypes prevail.

- *Patience with effort in achievement.* Continuing to make the effort to teach a person, despite his or her slow progress, creates and sustains hope for future success. A teacher's optimism keeps people with disabilities from giving up too soon, perhaps precluding the chance for them to experience success.

- *Caring for others and being cared for.* People with disabilities often are cared for by others, but do not always have the chance to care for others. Helping to improve the community, volunteering to do real and needed work, and even caring for a pet are opportunities to experience the give part of give-and-take.

- *Awareness of feelings and empathy.* Accurately recognizing and naming internal feelings is the first step to expressing them in ways that lead to empowerment and control, rather than rejection and punishment. Teachers can help a person with a disability understand his or her emotions, and can be a role model for expression of those emotions.

- *Influence over one's life and destiny.* Helping a person to decide what he or she wants and teaching him or her to ask for it is generating self-direction and internal locus of control. When a teacher gives a person what the teacher thinks he or she wants, or what the teacher wants the individual to want, that diminishes the person's power. It teaches helplessness and docility, rather than self-direction and assertiveness.

Teaching empowerment and self-esteem involves creating opportunities, and this can occur in a classroom or any other setting that allows a person to experience success. Being told one is successful is not the same as feeling successful. This aspect of social and sexuality education is much more complex. Its implications for making decisions and exercising self-control are far-reaching.

Key Component 4: Relationships. Most people value their relationships above all else. Good relationships are a source of satisfaction and joy. Some experts believe that social contact is a life-sustaining need.

This very important category of social and sexuality education involves starting, evaluating, and maintaining a continuum of relationships, and developing social judgment as the groundwork for intimacy and protection from sexual exploitation.

A full range of relationships with varying degrees of intimacy are becoming available to more and more individuals with developmental disabilities. Meeting social expectations and expecting others to do the same is a basis for mutuality in relationships and for recognizing relationships that overstep acceptable boundaries.

How do most people learn to have positive relationships? They are exposed to a wide array of social interactions, and they watch others in relationships at home, in public, on TV, and in the movies. These traditional osmosis techniques are not effective as quickly as is needed to teach people with developmental disabilities to cultivate, enjoy, and participate in social relationships. Trial and error in intimate relationships carries big risks: a broken heart, sexual abuse or victimization, and even infection with a sexually transmitted disease can be the result.

The CIRCLES Concept[2] has been successful in guiding people with disabilities through the discriminations required in social situations. An icon of six color-coded concentric

circles (purple at the center, blue, green, yellow, orange, red) becomes a non–language-based system of social distance and closeness. Each color becomes a symbol for a specific degree of intimacy. High-interest, low-complexity video minidramas visually support and model relationship values.

The CIRCLES Concept can be applied across Piaget's four stages of learning development:

- *Sensorimotor stage:* A repetition of tactile experiences and basic reinforcers fosters the development of acceptable social routines in a consistent paradigm.
- *Preoperational stage:* A social role (such as mother or friend) is linked with a specific color and distance, and an expectation about touch. For example, the blue close hug circle is appropriate for mother; the green faraway hug circle for friend.
- *Concrete operations stage:* The abstractions of talk and trust are added to touch, to flesh out a fuller sense of relationship. The resulting "What's the rule?" approach to relationships securely structures social interface.
- *Hypothethical thought stage:* An additional set of streamlined questions (how long, how often, how well, how much in common, how emotional, and how safe) isolate basic factors for evaluating relationships and setting reasonable boundaries.

The concepts of CIRCLES foster mutuality in relationships from an empowerment perspective.

Key Component 5: Social Skills. This area relates to making one's needs and wants known, using good manners, and negotiating social solutions to conflict, while remaining likable.

The ways in which a person asks for a date, responds to criticism, and manages and expresses feelings all lead to social responses from others. People with developmental disabilities are often unaware of how their actions, manners, or personal habits contribute to their social acceptance. Raising that awareness, without criticism, is an important step in replacing poor social skills or learning the more mature social skills required for new and sometimes more complex situations.

Teachable moments arise frequently on TV. They provide good opportunities to point out good and bad social skills, and for students to see the consequences of either. These fictional situations can be used to raise awareness, teach new rules, and solve relationship conflicts in ways that do not jeopardize an otherwise positive relationship.

And, of course, a chance to practice, practice, practice in a safe setting among supportive teachers and friends provides a measure of confidence to apply these techniques when there is no teacher present and without the shelter of a classroom.

James Stanfield's idea of designating a social reaction as hot, cold, or cool[3] is a shorthand way to recognize and categorize social styles of responding to difficulties with others:

- A hot reaction is an angry explosion involving yelling, name-calling, and even physical assault to communicate. Such a reaction may gain the desired end, but it is hard to continue a positive relationship with a person who is so volatile.
- A cold reaction is self-blaming. The person devalues himself or herself by considering one false step indicative of everything he or she could ever do. Depression and self-pity are not socially attractive qualities.
- A cool reaction is an assertive, adult way of handling social incidents by realistically assessing a social situation and expressing ways to solve a specific problem.

Even if a person cannot figure out the rules for being socially skilled or solving a problem, that individual can learn the rules and apply them. Positive attitudes toward social skill development can be best accomplished when a person has the optimism that he or she can influence the outcome of a situation, has the confidence to try learning a new skill, and knows that nonjudgmental help is easily available.

Key Component 6: Opportunities and Resources. Education about this area is somewhat different from the others: The content refers to awareness of and access to a broad pool of social contacts, mobility within a geographic area, and using community social and sexual resources. Every locality has different opportunities and programs that support socialization. Yet, each community has its own resources, or lack thereof, for people with developmental disabilities.

Using the social and sexuality education that was learned in the classroom to make real-life situations successful gives meaning to the struggle that has been hard won in class. Finding good opportunities for satisfying social interactions, or creating them if they do not exist, is also within the province of sexuality educators. A telephone directory can be a textbook for finding activities related to social opportunity. Even teaching a student to locate a bus stop can be part of this area of social and sexuality education.

Sometimes availability of sexuality resources in education, health-related services, psychological services specializing in sexual issues, and media and books for people with developmental disabilities is limited or nonexistent. This places an even greater burden on teachers.

NEXT STEPS

Professionals who have worked in programs for adults have been pioneers in developing the body of knowledge related to social and sexuality education. They have seen the impact that loneliness can have on the people they serve. They have seen the risks and results of sexual abuse and infection with sexually transmitted diseases, including HIV. They have realized that education is their best, and perhaps only, option to help program participants manage their lives.

But alas, sexuality does not begin when a person is an adult; it begins at conception, when gender is determined. By the time a person is an adult, a great deal of social and sexuality education has taken place, some of it good, but much of it limited to reproduction or couched in illicit erotica, neither of which is adequate to the needs of healthy adults with disabilities. Misunderstanding and confusion often result when people with developmental disabilities learn about sexuality only as a reproductive function or see sexuality only as it is portrayed in the popular media for entertainment, rather than for educational purposes.

Special education teachers are finely trained to teach academic skills, using creative and well-conceived techniques. But they have not been prepared to be sexuality educators and do not expect that sexuality will be the subject matter that they will teach.

Health educators are well versed in the body of information needed to teach that subject, but are not experienced in the kinds of specialized learning techniques that are often required for success with individuals with developmental disabilities.

Often, social and sexuality-related special education receives too little attention. Many public schools are not prepared to have students who receive special educational services learn the social and sexuality skills they need for success, satisfaction, and safety.

Colleges and universities are still not formally preparing teachers to bridge the gap between special educators and health educators. Perhaps this will be the next step: requiring a course in sexuality education for future special education teachers, and requiring a course in special education techniques for future health teachers.

At first, people refused to believe that this strange new thing, special education/sexuality education could be done, then they began to hope it could be done, because it was so desperately needed. Now it is clear that it can be done, and techniques are available to do it. What remains is for educators to ensure that people with developmental disabilities are included in sexuality education.

REFERENCES

1. E. White, *Nourishing Self-esteem* (n.p.: Whitenwife, 1981).

2. L. Walker-Hirsch and M. P. Champagne, *CIRCLES,* rev. ed. (Santa Barbara, CA: James Stanfield and Co., 1993).

3. J. Stanfield, *Be Cool* (Santa Barbara, CA: James Stanfield and Co., 1992).

SIECUS POSITION STATEMENT: SEXUALITY AND PERSONS WITH A DISABILITY

SIECUS advocates that persons with a physical and/or mental disability receive sexuality education, sexual health care, and opportunities for socializing and sexual expression.

SIECUS urges social agencies and health care delivery systems to develop policies and procedures that will insure that their services and benefits are provided on an equal basis to all persons without discrimination because of disability. SIECUS advocates educational and training programs for health care workers and family members to enable them to understand and support the normal sexual development and behavior of persons with disabilities. SIECUS advocates that both those who are disabled and those who care for them should receive information and education to deter sexual abuse or exploitation.

WHY DO PEOPLE WITH MENTAL RETARDATION NEED SEXUALITY EDUCATION?

Louise Yohalem, M.A.
Associate Director of Education,
Planned Parenthood of Greater Northern New Jersey

Twenty years ago, Winifred Kempton, a pioneer in the field of sexuality education for people with mental retardation, wrote that such education was particularly important because some of these individuals "are deficient in reasoning ability. It is difficult for them to distinguish reality from unreality and cause from effect. Thus they are more likely to believe myths and are more often frightened and confused by them."[1] Kempton pointed out that persons with mental retardation are more likely than others to be sexually exploited or to demonstrate sexually inappropriate behaviors. She made it clear that like all children, those with mental retardation require sexuality education to enable them to learn values, how to interact with others in a healthy and nonexploitive way, and how to practice appropriate sexual behavior that is not physically harmful to themselves. Perhaps the most compelling reason for providing sexuality education is to establish a healthy model against which the individual can measure unhealthy—that is, abusive or violent—sexual experiences. However, despite the vulnerability of people with mental retardation, this kind of sexuality education is rare.

Numerous reasons account for why this is true, not the least of which is the widespread misconception that people with mental retardation are not sexual and do not need to be involved in sexual relationships. Many parents, as well as members of the general community, maintain that belief, partly because it is difficult to figure out the sexual needs of a person who is mentally and socially a child, but physically and emotionally an adult. Furthermore, accepting that an individual with mental retardation has sexual needs means permitting that individual to *be* sexual, and this may be personally and emotionally burdensome for parents. Parents of children with mental retardation frequently find themselves aware of all the details of their children's sexual relationships and behaviors, which may be unexpected and embarrassing. Parents do not expect to be confronted with postpubertal children masturbating openly, touching others inappropriately, or sharing every detail of their sexual encounters.

Understandably, these parents may feel confused. They may not have acknowledged their children's sexuality; as a result, they may not have expected to have to teach about it—and they may have no idea where to begin. Perhaps they would rather not think about their children's being involved in sexual relationships and the possible outcomes of sexual interactions. Ironically, however, children with mental retardation need education about sexuality more than other children do. They are less able to pick up on nonverbal clues, the incidental learning that is a major means of discovering societal mores. The youth with mental retardation who would like to kiss any person to whom she or he is sexually attracted does not understand that it is not acceptable to kiss someone without permission. Such youngsters need specific instruction in relationship skills, in how to know when it is appropriate to be sexually involved with someone, and on what makes sexual acts sexual. They particularly need to learn that in some cases, they may not have the opportunity to do some of the things that others do—engage in intercourse, marry, or have children, for example. This last point is the most painful and difficult educational message for the caring sexuality educator; often, it is not possible to enable students to engage in specific kinds of sexual behavior they have seen and may want to emulate. However, this does not mean that children with mental retardation should not have the same right as other children to try.

THE ROLE OF SEXUALITY EDUCATION

What can education do to enable a person with mental retardation to have the most fully realized sexual life of which she or he is capable? How does an educator teach a person who has limited capacity to communicate and understand? What is appropriate sexuality education for people with mental retardation?

The first consideration in working with students who have limited capacity to learn is to determine how much they can comprehend and what information is essential. For example, if a student who cannot determine cause and effect but can learn to follow instructions is engaging in intercourse, and prevention of sexually transmitted diseases (STDs) is the immediate concern, then the most important information to convey may be how to put on a condom.

In planning educational sessions, instructors may consider using the following strategies, which have proven successful in teaching students with mental retardation:

- Keep groups small—six or eight students at most.
- Keep sessions brief—no more than thirty to forty-five

minutes—because students with mental retardation typically have short attention spans. If students' attention begins to wander, discontinue the lesson.

- Use a variety of techniques in each lesson, including verbal, visual, and practical instruction.

- Break the information down into its simplest elements, with the fewest points covered in each session.

- Use simple, declarative language, and keep vocabulary consistent.

A good way to begin is to ask what words each student uses to describe his or her genitals, for example. While it is preferable to use correct terms, if a student is uncomfortable with them or adamant about using his or her own words, it may be more effective to use language with which the student is comfortable. Next, with appropriate teaching aids, educators can illustrate verbal instructions—for example, they can use a Jim Jackson model of the genitals to demonstrate how to use a condom—and then give students an opportunity to practice the skill. When it is clear that a student has learned a skill well, liberal praise will reinforce the experience.

Open-ended questions may be the most effective way to engage students with mental retardation in conversation about sexuality-related issues. Many people with mental retardation have learned to be compliant and will respond to a yes-or-no question with the answer they think is expected. "Can you show me what you did?" works better than "Did you do...?" Pictures or anatomically complete dolls in a variety of skin tones and illustrating different developmental stages can help the individual answer these questions. Having two dolls of each gender and pictures that include same-gender couples will facilitate discussion of gay and lesbian issues. Each time a question is asked, it should be repeated two or three times and illustrated with the dolls or pictures. Repeating questions yet again at the end of the lesson may ensure that the students have understood the material. It may be necessary to repeat an entire lesson several times before moving on to a new skill. Some students may benefit from one-on-one instruction, particularly if they are easily distracted, shy about responding in a group, or likely to mimic others.

In lessons on parts of the body, asking nonverbal students to point to particular body parts on a doll or picture is one way to make sure that they understand the vocabulary. It is important not to allow students to touch their own or anyone else's genitals, and to be sure they know that it is inappropriate to touch their genitals in the public setting of the educational session.

Students may learn from their instructors' behavior. Thus, for example, if a student touches an educator inappropriately, the educator may respond by saying "No! It's my body" and stepping away; eventually, the student will respond the same way to an unwanted touch. Parents' behavior likewise serves as a model for their children.

Appropriate sexuality education uses methods that are suitable for the student and takes into account his or her developmental and psychosocial age. For example, a person with mental retardation might at age thirty-five for the first time display an interest in having a sexual relationship. He or she needs to learn acceptable ways of expressing new feelings. Appropriate education also takes into account the individual's ability to understand consequences and his or her capacity for acting responsibly.

THE ROLE OF PARENTS

What can be done to change some parents' attitudes toward the sexual rights of their children with mental retardation? Sexuality education at home for such children has traditionally consisted of the admonition not to let anyone touch them, ever. If this approach worked, it would protect the child from sexual dangers resulting from intercourse—sexual victimization, STDs, and unplanned pregnancy—and would make it unnecessary to teach about contraception. However, this approach does not work. As Kempton stated, people with mental retardation are much more likely than others to be sexually exploited. This can be because they may behave inappropriately (exposing themselves in public, for example) or because they do not have the language with which to report exploitation; it can also be because parents and other caregivers assume they will not be perceived as sexually desirable and do not help them develop skills to protect themselves against exploitation. People with mental retardation become pregnant, have children, and get STDs, including HIV.

In addition to the more common outcomes of lack of education, for people with mental retardation, the result of lack of information is often inappropriate sexual behaviors. Providers of sexual and reproductive health services frequently receive requests for remedial education that teaches appropriate sexual behavior after instances in which individuals with mental retardation have exposed themselves in public, engaged in sexual acts in the workplace, and—most often—masturbated in public. The most usual explanation for these incidents is lack of opportunity for appropriate sexual interaction or expression; often, in the home environment, the individual with mental retardation is never left alone, is told he or she cannot have intercourse, or is not given the opportunity to form healthy relationships. The need for sexual expression is so basic and imperative that these individuals will frequently risk reprimand rather than comply with parental interdiction.

COMPREHENSIVE SEXUALITY EDUCATION FOR STUDENTS WITH MENTAL RETARDATION

Truly comprehensive sexuality education for children with mental retardation would involve parents as well as the children themselves. Parents would come to understand that sexuality education would teach self-protection. A comprehensive curriculum would enable parents to understand that their children are sexual, and would help them to recognize that enabling their children to express their sexuality in responsible and healthy ways includes an enormous range of possibilities that might or might not culminate in sexual activity with a partner, including intercourse. Parents and their children need to acknowledge that not everyone is able to marry, have children, and live independently—and that not everyone should. Furthermore, not everyone wants to do these things. Comprehensive sexuality education would teach parents how to talk to their children about these possibilities and help them set and accept limits.

Comprehensive sexuality education would include the following components to the extent of each individual's capacity to comprehend: reproductive anatomy; reproduction and pregnancy; child rearing; puberty, including physical and emotional changes, menstruation, and nocturnal emissions; proper health care, including breast and testicular self-examination; sexuality as part of being a whole person; social responsibility, values, and various moral standards; relationships with family members, friends, and dates; how to understand one's own and other people's feelings; gender identity; different forms of sexual expression, including masturbation and intercourse; sexual abuse prevention; STDs, including HIV; contraception; sexual orientation; self-control; the right to say no; and the basic value that sexual activity should be mutually agreeable and pleasurable.

Why do people with mental retardation need sexuality education? To acknowledge their sexuality; to learn to express it appropriately; and to protect themselves from embarrassment, exploitation, and abuse. These reasons are no different than they are for other people. However, the need has been recognized much later for persons with mental retardation, and too few individuals have responded to it. Education for people with mental retardation should begin with training for sexuality educators to raise their awareness of the need, enable them to use a variety of methods, and familiarize them with the ever-increasing number of resources. For anyone interested in acquiring skills as a sexuality educator of persons with mental retardation, there are great rewards to be reaped: the satisfaction of fulfilling an unmet need and contributing to the more fully realized personal lives of one's students.

Why do people with mental retardation need sexuality education? Because they are people first and, like all people, have the right to know all they can comprehend that will enable them to become sexually healthy adults. To assure these rights, caring professionals are needed to commit themselves to acquiring the training that will enable them to effectively provide this knowledge.

REFERENCE

1. W. Kempton, *Sex Education for Persons with Disabilities That Hinder Learning* (Philadelphia: Planned Parenthood of Southeastern Pennsylvania, 1975).

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SEXUALITY AND SEXUAL EXPRESSION IN PERSONS WITH MENTAL RETARDATION

Paul J. Patti, M.A.
Behavioral Consultant,
New York State Institute for Basic Research
in Developmental Disabilities

In the past, many people believed that individuals with mental retardation and other developmental disabilities were "asexual," while others believed that they were "oversexed" or "aberrant" in their sexual interests, requiring controls and restrictions for their actions. Neither belief is true. In the past 10–15 years, with increased awareness of the needs of people with developmental disabilities—6.6 million Americans—and expanded advocacy aimed at meeting those needs, the issue of sexuality and sexuality education for individuals with developmental disabilities has emerged from neglect. Now, it not only is recognized as an important area in emotional and social development, it also is being addressed with better training and education programs by the many private and state agency service providers.

Part of being human is to experience sexual needs and desires. Every person has the right to express his or her sexuality in an appropriate and healthy way, to form loving relationships, and to be free from assault or exploitation.[1] Debatable and controversial positions, however, arise with regard to the sexuality-related rights of people with developmental disabilities. Some participants in the debate would attempt to reduce or limit appropriate sexual expression, but doing so does not eliminate these needs or desires. And denying sexual expression or interaction with others may create ongoing frustration, anxiety, and inappropriate behavior.

Individuals with mental retardation and other developmental disabilities have the same personal rights, opportunities, responsibilities, and concerns as the rest of the population at large. These include the right to personal privacy, to sexual expression with a person of one's choice, to decide whether to marry and whether to have children, and to have access to needed services (such as sexuality education, family planning, contraception, and abortion).

SEXUAL RIGHTS, CONSENT, AND LEGAL ISSUES

The question of whether a person is competent to make his or her own decisions has been the major issue when sexuality and the law is involved, especially in persons with mental retardation and other developmental disabilities. Sexual activity is a person's right under some circumstances, and is criminal under others, with the distinction often hinging on an individual's ability to consent.[2] Central to the issue of the right of a person with cognitive disabilities to engage in activities or decision making related to sexual matters—for example, having intercourse, undergoing sterilization, or using contraception—is the person's comprehension of such matters and the concomitant ability to make an informed choice to accept the inherent risks.[3]

From a legal standpoint, having a cognitive disability is not by itself grounds for depriving a person of his or her civil rights in any area. Furthermore, a finding that an individual is incompetent to make certain decisions does not necessarily mean that the person is incompetent to make decisions in every aspect of his or her life.[4] It has also been mandated that if persons with cognitive disabilities can "responsibly" enjoy fundamental rights with some assistance from care providers, then such assistance should be given. However, in certain circumstances (for instance, when a behavior is beyond a person's competence or when the potential for harm exists), third-party consent might be necessary, or limitations to restrict these rights and establish "protection from sexual or other harm," which is itself a constitutional right, may be appropriate.[5]

Several factors bear on an individual's capability to give consent: The individual must be "knowing," or able to understand the facts relevant to the decision to be made. He or she must also be "intelligent," or able to weigh the risks and benefits of the decision. And the decision must be "voluntary," meaning the individual arrived at it without coercion or other forms of undue influence.[6] In addition, each state has an established minimum age of consent (usually seventeen or eighteen years old).

Despite evidence to the contrary,[7] courts have often concluded that relatively high-functioning individuals with mental retardation are not competent to consent to sexual relations and, in cases where two such individuals have freely engaged in sexual activity, have affirmed convictions for sexual assault.[8] Criminal cases involving alleged consensual sexual relations between adults with mental retardation are unlikely to be prosecuted because although the individuals may have been competent to consent, their competence to stand trial and their responsibility for criminal conduct may be denied by reason of "mental disease or defect." This has ramifications for service providers, who have a

mandate to safeguard the welfare of people placed in their care and to protect them from harm, and who may be exposed to legal liability if the individuals involved in alleged criminal behavior are not held liable.[9]

SEXUAL ABUSE VERSUS INAPPROPRIATE EXPRESSION

Most reported cases of sexual abuse of people with mental retardation in residential facilities and community-based settings involve sexual assault, fondling, intercourse, supervisory neglect leading to "resident-to-resident" sexual interactions, or other questionable activities of a sexual nature. When the ability to consent to sexual activity is in doubt for one or both people involved, sexual interactions must be reported and, when service provider managers and clinicians deem them "abuse," investigated by the state agencies that ensure client protection.

Studies of sexual abuse of adults with mental retardation have provided data on which groups are likely to be abused, who the perpetrators are likely to be, and where sexual abuse is most likely to occur. One important finding is that sexual abuse of adults with mental retardation and other developmental disabilities is typically not a random act perpetrated by a stranger.[10] Recent studies in Connecticut[11] and Great Britain[12] reported very similar findings about sexual abuse among people with developmental disabilities. Among the findings both studies reported are these:

- The average age of individuals with mental retardation who are victims of sexual abuse is thirty years old.
- More than 70 percent of persons with mental retardation who are victimized are women.
- Most instances of sexual abuse (roughly 75 percent) take place in the victim's or perpetrator's residence, whether this is in an institution or in a community setting.
- In about 90 percent of cases, the perpetrator is a man who is known or familiar to the victim; in fewer than 5 percent of cases is the perpetrator a total stranger.
- Almost half of persons with mental retardation who are victims of sexual abuse function in the mild range of mental retardation; fewer than one-quarter, in the profound to severe range.
- In over 40 percent of reported cases, the abusers are other adults with developmental disabilities.

The Connecticut study also showed that in the majority of cases (92 percent), the victim of sexual abuse knows his or her abuser, and in most of these cases (77 percent), the abuser lives in the same residential setting.[13] And the British study revealed that more cases of alleged abuse are reported by the victim than by direct care staff (66 percent, as compared with 25 percent).[14]

The finding that many reported abusers are other adults with mental retardation may suggest that these individuals often lack the necessary social skills and education to be able to develop appropriate friendships or intimate relationships with the people they live with. Historically, service providers have provided little, if any, sexuality education either to staff who deliver the care and services or to the individuals they serve. Often, individuals receive mixed messages from direct care staff: some staff members may approve, while others may disapprove of any sexual activity between two adults with mental retardation, even when they have been deemed to be consenting individuals. This can result in the lack of accurate reporting of cases of possible sexual abuse when staff are "too permissive" and unclear as to how to address any type of sexual behavior between the individuals they serve. It can also result in staff's restricting all forms of privacy and sexual expression for fear of being held accountable or liable.

Punitive attempts to inhibit the development or expression of sexual behavior in persons with developmental disabilities may result in a different form of sexual abuse—"erotophobia," which is characterized by a "persistent and negative response to any form of sexual stimuli."[15] Individuals with mental retardation may be programmed to believe that all sexual behavior is wrong, but may engage in inappropriate sexual behavior to rid themselves of arousal. They may have difficulty judging when, where, and with whom it is appropriate to engage in sexual behavior: "since all sex is bad, it doesn't matter which behavior is exhibited."[16]

FUNCTIONING LEVEL AND SEXUAL EXPRESSION

The severity of disability may prevent some people from ever being able to make competent decisions or choices; services for such individuals should be planned on that basis. For others, education and training may improve their decision-making status. In sexuality-related matters, some situations may be inherently more complex and sensitive than others, and professionals assessing capacity to consent may decide accordingly: professionals "may lean toward the principle of self-determination" when an individual's prospective sexual partner is affectionate, free of sexually transmitted diseases (STDs), and so forth, or "toward the principle of protection from harm" when that partner may have an STD or a criminal record.[17]

Generally, with the proper information, training, and education, men and women with mild mental retardation

are capable of making informed decisions and are able to give consent to sexual contact. Under existing criteria, however, individuals with moderate or severe mental retardation are not likely to be deemed capable of providing informed consent. While these individuals have a right to self-exploration and to warm and caring relationships with others, service providers are obligated to place the principle of protection from harm over that of self-determination.

Once a person has been deemed unable to provide consent, the determination limits his or her opportunities for sexual expression. For persons with more limited intellectual abilities, a "situational capability" (special circumstances in which sexual activity may occur with a particular person at a particular place and time) is one way of addressing this and establishing a potential balance between allowing individual self-expression and allowing service providers to ensure that individuals served are not being exposed to undue risk.[18] One attempt to redefine consent for individuals with severe mental retardation who engage in mutual sexual contact suggests that the individual's treatment team could be afforded the decision-making capabilities for such behavior to occur as they deem appropriate.[19] Evaluating individuals on the basis of their interactions—Do they appear happy or content? Do they seem to want to remain involved in the activity? Do they appear duressed? Do they make repeated attempts to engage in the activity on their own?—and taking into account any necessary health and safety issues for either individual should make it possible to create a management plan that can provide for appropriate sexual expression. However, from a legal standpoint, such an accommodation would not necessarily be viewed as favorable under the principle of protection from harm. In a majority of cases with individuals who fail to meet the established criteria for consent, service providers would see this approach as too risky, leaving them open to potential controversy and legal liability, and would not likely adopt it.

The following case illustrates an example of apparent "consensual" sexual activity between two individuals with severe mental retardation who have been deemed incapable of providing informed consent.

> Mr. H. is a nonverbal twenty-one-year-old who lives in a group home. He is alert and able to recognize familiar people and events around him. He occasionally is aggressive (hitting staff), but is not considered a behavior problem. Mr. H. engages in sexual activity with a particular male peer (Mr. B.) in the residence when the opportunity occurs. He either seeks out Mr. B. for such an encounter or responds to Mr. B.'s advances with some degree of privacy and cooperation. If staff redirect him from this activity, Mr. H. willingly responds. The treatment team has requested a behavioral evaluation to assess both individuals' sexual awareness, since both have been deemed not capable of providing consent for their sexual behavior.

At issue in the above case is whether any sexual activity that occurs between these two individuals is consensual or nonconsensual, given the men's limited cognitive and communicative abilities. Second, should staff allow these encounters to occur, or should they stop them? Declaring Mr. H. too limited in his capacity to be able to understand the risks and consequences of his behavior would support the restrictive and "protective" principle, and would require that this sexual activity be stopped. Other circumstances, however, can be taken into account that may alter the perception of his limited capacity.

An individual's inability to say (or gesture) no to a sexual advance or to leave an area without fear or intimidation may make him or her vulnerable to sexual exploitation that may lead to sexual abuse. This does not appear to be the case for Mr. H., since he sometimes seeks out his partner for some type of encounter. By confining his interactions to the same individual, Mr. H. indicates a relationship between them, as well as an ability to choose where and when sexual activity will occur. Although limited in cognitive and expressive abilities on standardized tests, Mr. H. *does* appear to be able to make some choices for sexual activity. Does this indicate a limited consensual ability?

Mr. H. does not appear to present a potential risk to others sexually. Staff have reported no instances of exploitation, fear, or injuries. And since these two men express a mutual interest in sexual contact, this behavior would best be addressed in a positive manner, acknowledging their right to have a relationship while maintaining the principle of protection from harm. Separating or redirecting these two individuals may eliminate sexual activity when staff observe it, but will not prevent the behavior from taking place in private, unless the staff restrict the men's right to privacy.

CONCLUSION

Sexual expression takes many forms; for some individuals, certain forms of sexual expression may be appropriate, while others may not be. An individual should be capable of giving consent—either verbally or by gesturing—to sexual behavior involving another person. To be judged capable of giving consent to sexual contact, an individual must meet the state's minimum age requirement; be able to indicate yes or no, behaviorally or verbally, to a sexual overture by another person; be free of coercion or intimidation; and demonstrate an understanding of the potential risks and consequences of sexual behavior. Individuals with severe and moderate mental retardation, however, typically fail to meet the last criterion and therefore are judged not capable

to give consent to sexual contact. Until the consent issue can be modified in some manner to address the limitations of individuals with severe and moderate mental retardation (for instance, third-party consent or situational determination by an individual's treatment team or service agency), ensuring these individuals' right to sexual expression will invariably give way to the principle of protection. This will only restrict sexual expression without allowing any "approved" sexual contact. The primary goal of any management plan that addresses mutual sexual behaviors should be to ensure, to the degree possible, the health and safety of the individual while still allowing for the occurrence of the behavior, even if this presents an element of risk.[20]

Evaluating and determining the capability of persons with mild mental retardation to consent to sexual activity does not pose a significant problem for most service providers. Although some agencies may formally or informally oppose and limit sexual activity among the people they serve on the basis of religious convictions, parental pressures or staff philosophies, this opposition is gradually receding with the increasing emphasis on "consumer empowerment" and self-advocacy. Difficulty almost certainly arises when individuals not capable of giving consent engage in sexual activity with each other.

Service providers continue to have the fundamental obligation to safeguard the welfare of the people placed in their trust, to promote their health and well-being, and to protect them from harm to the degree necessary and reasonable while still maintaining their right to self-expression.[21] The professionals given the task to evaluate individuals with developmental disabilities for the purposes of determining consent should include in their assessments each person's nonverbal behavior and interpersonal interactions, as well as communicative abilities. This is especially true for individuals with diminished intellectual capacities who are sexually active. As it exists now, the consent determining issue will continue to represent a major challenge for service providers and the individuals they serve.

AUTHOR'S NOTE

The opinions expressed in this article are those of the author and not necessarily those of New York State's Office of Mental Retardation and Developmental Disabilities.

REFERENCES

1. Bureau of Training and Development, Office of Work Force Planning and Development, New York State Office of Mental Retardation and Developmental Disabilities, *An Introduction to Human Sexuality (For Direct Care Providers)* (Albany, NY, 1990).

2. P. Stavis and L. Tarantino, "Sexual Activity in the Mentally Disabled Population: Some Standards of the Criminal and Civil Law," *Quality of Care* (October-November 1986): 2-3.

3. Ibid.

4. Ibid.

5. Ibid.

6. T. Grisso, *Evaluating Competencies: Forensic Assessments and Instruments* (New York: Plenum Press, 1986); and P. Stavis, "More on the Law, Sex, and Mental Disabilities," *Quality of Care* (September-October 1987): 2-3.

7. C. D. Morris, J. Niederbuhl, and J. Mahr, "Determining the Capability of Mentally Retarded Individuals to Give Informed Consent," *American Journal of Mental Retardation,* 98 (1993): 263-72; and J. Niederbuhl and C. D. Morris, "Sexual Knowledge and the Capability of Persons with Dual Diagnosis to Consent to Sexual Contact," *Sexuality and Disability,* 11 (1993): 295-307.

8. C. Sundram and P. Stavis, "Sexuality and Mental Retardation: Unmet Challenges," *Mental Retardation,* 32 (1994): 255-64.

9. Ibid.

10. D. Sobey and T. Doe, "Patterns of Sexual Abuse and Assault," *Sexuality and Disability,* 9 (1991): 243-59.

11. E. Furey, "Sexual Abuse of Adults with Mental Retardation: Who and Where," *Mental Retardation,* 32 (1994): 173-80.

12. V. Turk and H. Brown, "The Sexual Abuse of Adults with Learning Disabilities: Results of a Two-year Incidence Survey," *Mental Handicap,* 6 (1993): 193-216; and H. Brown and V. Turk, "Sexuality: Towards a More Balanced View," in N. Bouras, ed., *Mental Health in Mental Retardation: Recent Advances and Practices* (Cambridge, UK: Cambridge University Press, 1994).

13. Furey, "Sexual Abuse of Adults with Mental Retardation."

14. Brown and Turk, "Sexuality: Towards a More Balanced View."

15. D. Hingsburger, "Erotophobic Behavior in People with Developmental Disabilities," *Habilitative Mental Healthcare Newsletter,* 11, no. 5 (1992): 31-34.

16. D. Hingsburger and S. Tough, "Treating Erotophobic Behavior in People with Developmental Disabilities: A Case History and Therapeutic Model," *Habilitative Mental Healthcare Newsletter,* 12, no. 3 (1993): 33-36.

17. Morris et al., "Determining the Capability of Mentally Retarded Individuals to Give Informed Consent."

18. Niederbuhl and Morris, "Sexual Knowledge."

19. F. Kaeser, "Can People with Severe Mental Retardation Consent to Mutual Sex?," *Sexuality and Disability,* 10 (1992): 33-42.

20. Ibid.

21. Sundram and Stavis, "Sexuality and Mental Retardation."

EYES ON THE HORIZON: THREATS TO SEXUALITY-RELATED SERVICES HIDE IN PLAIN SIGHT

Daniel Daley
Director, DC Policy Office, SIECUS

Betsy L. Wacker
Director, Public Policy, SIECUS

As conservative Republicans have taken the leadership positions within their political party and the Congress, they have brought with them a socially conservative viewpoint that will permeate major legislative initiatives in the 104th Congress. Proponents of sexuality education and sexual health services have grown adept at challenging conservatives' attacks against these services and at responding to the resulting controversies. But they must now acquaint themselves with the profound ways in which general efforts—such as attempts to diminish the role and size of federal agencies and programs, and to reform the welfare and education systems—could affect sexuality-related services, especially when these efforts are combined with an apparent trend of social conservatism in public policy. Proponents of sexuality education and sexual health services will have to be vigilant, perhaps more so than in the past, to keep abreast of the many ways in which the conservatives' agenda will likely encroach upon sexuality-related services.

DOWNSIZING THE FEDERAL GOVERNMENT

The first broad public policy initiative that should concern sexuality education and services advocates is the effort to downsize the federal government. House Speaker Newt Gingrich (R.-GA) and Senate Majority Leader Robert Dole (R.-KS) have called for reducing the spending, size, and role of the federal government. So have President Bill Clinton, in his 1995 State of the Union address, and Vice President Al Gore, in his book *Reinventing Government*. This notion is popular with the public, too, who are rightfully concerned about the impact of the deficit on future generations.

While the idea of this effort is laudable, it will likely be orchestrated by conservative policy makers to diminish programs they oppose. First, policy makers could use the call for a reduced federal government to justify eliminating or significantly reducing the funding for programs. The Senate Republicans plan to eliminate or reduce "100 programs in 100 days" as a response to their House counterparts' 100-day plan of action, the "Contract with America." According to some accounts, Republicans hope to eliminate or reduce as many as 300 federal programs. To date, there is no listing of the programs that could face the chopping block, but programs that have not received reauthorization (a multi-year commitment to the program passed as law) appear vulnerable. Moreover, the certainty of a recision bill for federal fiscal year 1995 (which would, in effect, reduce the funding for programs already operating) provides conservatives the opportunity to gut programs the 103d Congress supported. Even the move to reduce congressional committee staffs and the number of congressional committees, and to eliminate congressional caucuses, will affect a number of interests, including sexuality-related ones. Many of the committee staff who were terminated after the elections were the principal architects of current programs and policies addressing reproductive health and sexually transmitted diseases (STDs), including HIV, while the caucuses often provided a forum to articulate support for these programs.

Second, sexuality-related programs could suffer as a result of efforts to discontinue categorical federal programs (in which specific funding levels are designated for particular activities) and replace them with block grants to the states (in which states receive funds for specific services, but they decide how to allocate the expenditures). This shift poses threats because the amount given through a block grant typically is less than the funding for categorical programs; furthermore, block grants permit the states latitude to cut controversial programs, and they eliminate the opportunity for national leadership and coordination.

Only weeks into the 104th Congress, there have been many attempts to create block grant programs. Sen. Nancy Kassebaum (R.-KS) has introduced the Public Health and Enhancement Act of 1995, which would consolidate twelve grant programs at the Centers for Disease Control and Prevention into one block grant and combine twenty-eight

demonstration project funding streams into one flexible authority. These programs include prevention and control of STDs and infertility, breast and cervical cancer detection, and preventive health service programs for HIV. Outside Congress, but well inside the political power base, the thirty Republican governors have requested that the Congress consider rolling 300 federal programs into eight block grants. In exchange for increased flexibility to design and administer the programs, the governors would agree to forgo funding increases from the federal government for five years. One of the proposed block grants focuses on health programs, including the Title X family planning program, community health centers program, and Adolescent Family Life demonstration grants.

Efforts to expand block grant programs could shift the policy debates to the state level, where sexuality-related education and service programs could be dismantled. Even though forty-seven states mandate or recommend sexuality or HIV/AIDS education in the public schools,[1] state legislatures increasingly have been considering challenges to those mandates that would restrict the content. With the majority of the nation's governors espousing a more conservative viewpoint, they could construct budgets, issue executive orders, or suggest public policies to state legislatures that could restrict the content or scope of sexuality programs. For example, in late 1994, Republican Gov. George Allen of Virginia called for the repeal of his state's sexuality education mandate and suggested that sexuality education courses have a parental "opt-in" policy, though fewer than 5 percent of parents in the state have chosen to take advantage of the current opt-*out* policy. While the Virginia legislature has rejected the plan for the time being, the policy was clearly meant to curtail sexuality education. It would have made it administratively implausible to carry out a program because of the difficulty of obtaining and recording millions of parental opt-in forms, which the local education agency would need to do to avoid potential lawsuits. This, together with a block grant funding format, would diminish sexuality education because what little sexuality education funding was available would logically be applied to and exhausted by the administrative requirements of the parental opt-in. Shifting the emphasis to the state level would also further empower the well-organized and vocal minority opposed to sexuality education, who have created controversies in over 300 communities in forty-four states in the last four years.[2]

BLOCKING PROGRESS IN SEXUALITY

Conservatives in the Congress will have increasing opportunity to infuse broad and popular legislative efforts with punitive language regarding sexuality-related issues. With some of the most conservative Republicans chairing congressional committees, conservatives have the ability to imbed restrictive language into legislation even before it gets to the floor. The conservative chairs also have the authority to name the members participating in the conference of bills, making it even less likely that prohibitions could be softened or dropped, as they had been in the past.

Unfortunately, examples of this abound. The Contract with America includes troubling language in its welfare reform proposal, the Personal Responsibility Act of 1995, which would introduce—among other items—the policies of denying cash assistance to unwed teenage mothers and their children, denying benefits increases to welfare mothers who have additional children while on public assistance, and denying benefits to children whose fathers have not been identified to the state. However, conservatives may ultimately help make welfare reform less punitive for teenagers. For instance, some Republicans, including Senator Dole, are beginning to soften the rhetoric concerning teenage mothers. Also, groups that oppose abortion—such as the National Right to Life Committee, Catholic Charities, and Feminists for Life—are calling for less-severe penalties for young unwed mothers, because they believe, as teenage pregnancy prevention advocates do, that the punitive measures will not reduce the chance that teenagers will become pregnant. These antichoice activists feel that the punitive measures will only encourage abortion. Adding to the recent focus on teenage pregnancy, President Clinton reiterated during the State of the Union address his desire for a national media campaign concerning teenage pregnancy.

The Personal Responsibility Act also stipulates that "no funds received by a qualified State under this part shall be used for making abortion available as a method of family planning or for any counseling or advising with respect to abortion." Republicans contend that this is not a reinstatement of the "gag" rule, which prohibited agencies that receive Title X family planning funds from discussing abortion with their clients. It is true that this language is not attached specifically to the Title X family planning program, but it has the same restrictive intent as the "gag" rule.

Another part of the Contract, the Family Preservation Act, which is designed to "strengthen the rights of parents," provides that no program or activity funded (either in whole or in part) by the federal government shall require a minor to submit to a survey, analysis, or evaluation that reveals information concerning (among other things) sexual behavior or attitudes without the written consent of at least one of the minor's parents or guardians. (This limitation does not include tests of academic performance.) This is clearly an attempt to inhibit adolescent risk behavior surveys that provide data necessary for the design of prevention initiatives related to sexual activity. If interpreted in the extreme, this language could also potentially limit assessments of changes in students' knowledge and attitudes toward sexual behavior (including abstinence) as part of sexuality education, teenage pregnancy prevention,

STD prevention, and HIV/AIDS prevention programs.

Outside the Contract, the continuing education reform effort will again be lumbered by the debates—begun in the 103d Congress—on the content of sexuality education, particularly discussions regarding gay and lesbian issues. To the dismay of sexuality education proponents, all signs indicate that the issue will be spotlighted in the 104th Congress.

In January 1995, Speaker Gingrich revealed that he will honor the request of the Rev. Lou Sheldon, leader of the far right Traditional Values Coalition, and hold a one-day hearing this spring or summer on whether schools receiving federal funds should be banned from presenting homosexuality in a "positive light." During a town meeting in his home district, Gingrich told his audience that he does not want their tax dollars "to go to have first-graders being taught a set of values that, in fact, have no place in the first grade." He also related that Sheldon and his activist daughter, Andrea Sheldon, reportedly claimed to have "serious evidence of, both in AIDS education and in the education program, of things being taught that are clearly propaganda and clearly recruitment." Then, revealing his misunderstanding of the content of age-appropriate, school-based, comprehensive sexuality education, Gingrich added: "I don't believe that the taxpayers should pay a program to teach you effective methods of sadomasochistic interaction."[3]

DIFFUSING THE THREATS

While opponents of comprehensive sexuality education and sexual health services now have greater ability than before to chip away at these programs, proponents should take heart. Many policy makers still support sexuality-related services. Proponents of sexuality education and sexual health services are the mainstream of America—the overwhelming majority of adults support the provision of comprehensive sexuality education.[4] It is critical, however, while the vocal minority opposing sexuality education and programs have the ear of congressional leaders in the majority, that proponents of these services speak out and let their elected officials—in Congress, in the White House, in the state house, and on the school board—know that they demand to have their viewpoints represented. Opponents of sexuality-related services have ardently and diligently communicated with policy makers about their views on and prescriptions for programs. Not only is it imperative that proponents let their elected officials know that support for comprehensive sexuality education and service programs is the majority, mainstream position, but it also is critical for proponents to demonstrate that they are as committed to seeing their viewpoint represented in policy as their opponents are.

Sadly, recent antichoice violence has provided an example of how the outcry from supporters of sexuality-related concerns can be translated into constructive legislative action. On December 30, 1994, an antichoice activist allegedly used a .22-caliber semiautomatic rifle to kill two receptionists and wound five clinic workers and volunteers at women's health centers in Brookline, Massachusetts. Within days, the same individual allegedly continued his violent spree by firing more than twenty rounds of ammunition at a building housing a women's reproductive health clinic in Norfolk, Virginia. The shock and outrage of the prochoice community left policy makers little option but to address the issue. On December 30, President Clinton and Attorney General Janet Reno both made statements condemning the action. On January 2, the president ordered the Department of Justice to instruct "each U.S. Attorney immediately to head a task force...to formulate plans to address clinic security for all clinics in their jurisdiction" and to "direct each U.S. Marshal to consult with clinics in their jurisdiction."[5] Although not stating support for sexuality-related services, even conservative members of Congress like Speaker Gingrich and Rep. Henry Hyde (R.-IL) spoke out against the violence. Eight Democratic members of the House held a press conference and called for the Justice Department to get involved in the incident and to be more vigilant in enforcing the Freedom of Access to Clinic Entrances (FACE) law. One of them, Rep. Marty Meehan (D.-MA), subsequently introduced a resolution in the House condemning violence and urging federal action to safeguard clinics, which the House will consider after its work on the Contract with America. Sen. Barbara Boxer (D.-CA), along with nineteen other senators, introduced a similar Senate resolution, which passed unanimously, 99–0.

Supporters of sexuality-related services cannot afford to wait for senseless tragedy to strike before making their voices heard. It is crucial that they speak out about their concerns regarding all sexuality-related issues, their opposition to targeted attacks on sexuality, and the threats to sexuality in broader policy decisions. One way is to join the SIECUS Advocates. Contact SIECUS, 130 West 42nd Street, Suite 350, New York, NY, 10036; 212-819-9770.

REFERENCES

1. A. E. Gambrell and D. Haffner, *Unfinished Business: A SIECUS Assessment of State Sexuality Education Programs* (New York: Sex Information and Education Council of the U.S., 1993): 7.

2. SIECUS Community Advocacy Project, unpublished data, 1995.

3. "What Newt Gingrich Had to Say," *Washington Blade,* Jan. 20, 1995, p. 27.

4. D. W. Haffner and D. de Mauro, *Winning the Battle: Developing Support for Sexuality and HIV/AIDS Education* (New York: Sex Information and Education Council of the U.S., 1991).

5. Center for Reproductive Law and Policy, "Special Report: Year's End Brings Anti-choice Violence," *Reproductive Freedom News,* 4, no. 1 (1995): 3.

AN OPEN LETTER TO MEMBERS OF THE 104TH CONGRESS

Dear Honorable Members of Congress:

The November 1994 elections reflected the desire of many Americans to send a message to the federal government. As President Clinton said in his State of the Union address, it was not Americans singing, but Americans shouting for change.

In your position, you will be called on to deal with a number of sexuality-related issues. Like most adults in America, you probably have strong convictions about these issues. You also probably received very little sexuality education from your parents and learned little beyond the facts of reproduction and puberty while you were in school. If you are a parent, as I am, you undoubtedly have deep concerns about how to educate and protect your children in this complex and difficult world.

I hope you will approach these most important and intimate of matters with an open mind. I hope you will support research on sexuality-related issues and dedicate yourself to making public policy based on sound information and proven theoretical constructs. I hope you will commit yourself to upholding the proposition that in a pluralistic society like the United States, people should respect and accept a diversity of values and beliefs about sexuality, and that you will demonstrate tolerance for people whose values you do not share.

Our young people need adult guidance and support. Children and teenagers today are growing up in a world that is probably very different from the world you knew as a child. All children should be raised by families who will love them and support them, but this is not always the case.

The goal of comprehensive sexuality education is to help young people become sexually healthy adults, a goal that parents across the country support for their children. You will not be asked to vote directly on comprehensive sexuality education, as federal law requires state and local control of education program content. But several pieces of legislation may arise that address components of sexuality education programs. I hope you will support comprehensive programs that help young people protect themselves against pregnancy and sexually transmitted diseases by teaching them the skills they need to delay sexual involvement and to use contraception and condoms effectively and consistently. Comprehensive programs can help young people abstain from sexual activity *and* protect themselves, but fear-based, abstinence-only programs do neither.

Teenage pregnancy is a very complex problem, and sexuality education alone is not the answer. Young people need to have hope for their futures; they need both comprehensive sexuality education and high-quality reproductive health care. But they also need much more. And so, I hope you will support education reform, job training programs, guaranteed student loans, and other youth opportunities.

As you debate health and welfare reform, I hope you will remember that behind every statistic is a real person who has the same wants and needs as you and your family. I hope you will reject simplistic solutions that will penalize women and children. I hope you will remember that more than 70 percent of the fathers of the children of teenage mothers are adult men, who must be held responsible. I hope you will read the studies that demonstrate that teenage women do not get pregnant for welfare benefits. Perhaps most important, I hope you will remember that enabling low-income women to prevent unintended pregnancies and unwanted births by making reproductive health care services accessible to them is a critical first step toward reducing the number of families on welfare.

Even as abortion is becoming less accessible to American women, I ask that you remember that the right to choose legal abortion is constitutionally protected. You must do everything you can to assure that health care professionals and others who work in reproductive health clinics can do so without fear of harassment and violence. Five abortion clinic workers have been killed in the past two years; this violence must end.

Violence against gay men and lesbians also is increasing, and young people who have concerns about their sexual orientation are likely to attempt suicide when they have no place to turn. I hope that when you are asked to consider legislation related to gay and lesbian Americans, you will remember that sexual orientation is an essential quality of personality, and that each individual—whether bisexual, heterosexual, or gay or lesbian—should have the right to live without violence and discrimination.

Know that SIECUS is here to be of assistance to you and your staffs. The staff of our Washington, DC, office is eager to assist you. We look forward to working with you.

Debra W. Haffner, M.P.H.
Executive Director, SIECUS

Women Who Love Sex

Gina Ogden
New York: Simon and Schuster, 1994,
259 pp., $21.00

In *Women Who Love Sex,* Gina Ogden presents female sexuality as inner-directed, offering the possibility of ecstatic release, and a powerful source of energy. This message, delivered by a therapist with a passion for her subject and great caring for her patients and the other women she describes, is one of celebration and intended to empower women in their journeys of sexual discovery.

It is not simply having orgasms easily, often, in various ways and various places that defines women who love sex. It is also that they "are warm, embodied and capable of enjoying a full range of experiences in the bedroom and beyond" (p. 224). In other words, they are self-actualized. For example, Ogden tells of Rosa, who realized that "years of sicko sex" (p. 199) with many partners had not met her needs. In time, a therapist helped Rosa to give up an obsessive focus on intercourse, orgasm, and performance, and to discover that her deepest need was to be *known* in all her uniqueness.

This book has much to offer, but it has drawbacks. Ogden apparently sees her view of sexuality in stark contrast, even opposition, to the "scientific" (her quotation marks) one, which "narrows sex to a genital act" (p. 162). She believes that sex therapists and researchers consider foreplay "a second-rate activity that precedes the 'real thing'" (p. 75). I think Ogden has been talking to the wrong sex therapists. I and the other sex therapists I know teach that the word "foreplay" should be dropped from the language. Furthermore, the terms "sex" and "making love" are *not* synonymous with intercourse, which is one way among many that couples can "have sex" or "make love." I did not invent this distinction. I learned it from William Masters and Virginia Johnson in 1971.

Ogden also criticizes sex researchers from Richard Von Krafft-Ebing in the 1930s to Helen Singer Kaplan in the 1990s for "pathologizing sexuality." Of course, the mothers and fathers of modern sexology made mistakes. Of course, they saw things through the cultural lenses of their own times. But they broke the ground and seeded the earth where we now toil and reap.

No review of the book can omit discussion of women who can come to orgasm via fantasy *only*—by, in Ogden's words, "thinking off." Ogden did a laboratory study to prove that this is possible, and the description of one participant, Suzanne (p. 137), is very convincing, even amazing. But the study, as presented here, has serious shortcomings, most notably its failure to state how many of the volunteers were able to "think off."

Kinsey showed that about 40 percent of women experience orgasm while asleep and that very few can fantasize to orgasm while awake. Ogden seems to believe that "thinking off" may be much more common than research has suggested. She may well be correct; in the future, I plan to include a question about it in sexual histories.

Women Who Love Sex breaks some new ground, although it is somewhat redundant with Sandra Scantling's 1993 book *Ordinary Women, Extraordinary Sex.* I like it best for its generous appreciation of women's sexual potential and its focus on the psychological, emotional dimensions of sexual interactions. I like this book also for its glimpses of Ogden at work as a therapist—one I would refer patients to without hesitation. Finally, there are a few very funny moments, such as the mention of a button that trumpets "Guilt without Sex" (p. 177). I recommend this book for sex therapists and counselors and for women who would like to enlarge the sphere of their own sexual experience.

Reviewed by Lorna Sarrel, M.S.W., lecturer in psychiatry, Yale University School of Medicine.

GAY DOCTORS LAUNCH CAMPAIGN TO FIGHT DISCRIMINATION IN MEDICINE

The Gay and Lesbian Medical Association (GLMA)—formerly the American Association of Physicians for Human Rights—has announced a major project aimed at combating discrimination against gay men and lesbians in health care. The project is a response to a survey among GLMA members that documented widespread discrimination directed at gay and lesbian patients and physicians.

GLMA is asking 200 medical and other health organizations to take five steps to combat bias: adopt nondiscrimination policies and educate both patients and physicians about lesbian and gay health issues; urge training institutions to train health care workers about lesbian and gay health needs and about avoiding bias; press managed care plans to help health consumers identify nonbiased and knowledgeable providers; encourage licensing agencies to consider bias in evaluating providers' ability to offer care; and demand that any health reform legislation include nondiscrimination protections. GLMA has also asked the Department of Health and Human Services to create a task force to examine lesbian and gay health needs.

Copies of the survey are available for $9.00 from GLMA, 273 Church Street, San Francisco, CA 94114; 415-255-4547.

A SIECUS Annotated Bibliography of Available Print and Audiovisual Materials

Over the past twenty years, pivotal legislation has gone into effect that has enabled people with disabilities to gain their rightful place as equal members of American society. The Rehabilitation Act of 1973, the 1975 Education for All Handicapped Children Act, and the Americans with Disabilities Act of 1990 have added opportunities for the inclusion and integration into the community of people of all abilities. With inclusion and integration come greater opportunities for sexual expression. Thus, there is a need for greater access to information and educational material that affirms the sexuality of people of all abilities, including those with early- and late-onset disabilities; physical, sensory, and mental disabilities; and disabilities that hinder learning.

SIECUS advocates that all persons, including persons with disabilities, receive sexuality education, sexual health care, and opportunities for socializing and sexual expression. This necessitates sexuality education and training programs for teachers, health care workers, and family members to help them understand and support the normal sexual development and behavior of persons with disabilities. Social agencies and health care delivery systems must develop policies and procedures that will ensure the provision of services and benefits on an equal basis to all persons without discrimination because of disability.

SIECUS does not sell or distribute any of the publications listed here. However, these resources are available for use by SIECUS members in the Mary S. Calderone Library at SIECUS.

Copies of this bibliography can be purchased from the SIECUS Publications Department at the following costs: 1–4 copies, $2.00 each; 5–49 copies, $1.75 each; 50–99 copies, $1.50 each; 100 or more copies, $1.25 each. SIECUS is located at 130 West 42nd Street, Suite 350, New York, NY 10036; 212-819-9770.

This bibliography was prepared by Shelley Ross, special projects associate, SIECUS, and Mitchell Tepper, M.P.H., Ph.D. candidate, Program in Human Sexuality, University of Pennsylvania.

GENERAL BOOKS

Living and Loving: Information about Sexuality and Intimacy

Arthritis Foundation

This book offers tips for solving problems when arthritis interferes with sexuality. It includes illustrations of comfortable sexual positions for individuals with arthritis. 1993, 17 pp. Single copies free from local chapters; bulk rates available.
Arthritis Foundation, PO Box 19000, Atlanta, GA 30326; 800-283-7800.

Sexuality and Multiple Sclerosis, Third Edition

Michael Barrett

This book covers research findings, communication skills for sexual enhancement, information resources, and positive approaches to sexual adjustment with multiple sclerosis. It includes sections specifically for unmarried individuals, gay men, lesbians, and married couples. It discusses the effects of medication on sexual function. *Also available in French.* 1991, 80 pp. Single copies free; orders of multiple copies subject to postage and handling costs.
Multiple Sclerosis Society of Canada, 250 Bloor Street East, Suite 1000, Toronto, Ontario, Canada M4W 3P9; 416-922-6065.

Learning to Love: A Set of Simple Booklets on Sexuality

Brook Advisory Centres

These five publications provide accurate information about sexuality and reproductive health for young people with learning disabilities. Titles in the series are *Contraception, From Child to Adult, How a Baby Is Born, Sex and Making Love,* and *Health & Infections.* 1991, 23 pp. each, £12.95 for the series, bulk rates available.
Education & Publications Unit, Brook Advisory Centres, 153 A East Street, London SE17 2SD England; 011-44-71-708-1390.

The Sensuous Heart: Sex after a Heart Attack or Heart Surgery

Suzanne Cambre

This cartoon-style booklet explains the emotional and physical needs of persons who have had heart attacks or heart surgery. It answers questions about frequency of sexual activity; suggests comfortable positions; and covers the effects of alcohol, prescribed drugs, stimulants, and illegal drugs. 1990, 21 pp., $5.75 plus $1.50 postage and handling.
Pritchett and Hull Associates, 3440 Oakcliff Road NE, Suite 110, Atlanta, GA 30340-3079; 800-241-4925.

The Baby Challenge: A Handbook on Pregnancy for Women with a Physical Disability

Mukti Jain Campion

This book describes the impact, effect, and outcome of a range of physical disabilities on pregnancy and childbirth, and of

pregnancy and childbirth on physical disabilities. It outlines how various disabilities affect fertility, the role of genetics, implications of medication, remission of symptoms, precautions to take during pregnancy and labor, possible interventions during delivery, and what to expect in a postnatal ward. A resource list accompanies each chapter. The book includes a chapter specifically geared for health care professionals. 1990, $15.95.
Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001; 212-244-3336.

Sexuality and Spinal Cord Injury

Sylvia Eichner McDonald, Willa M. Lloyd, Donna Murphy, and Margaret Gretchen Russert

The authors explore a number of topics regarding sexuality and reproduction before and after a spinal cord injury, including the physiology of sexual response and reproductive health. One chapter outlines the steps individuals with spinal cord injuries may take to prepare for sexual activity. Another is devoted to different ways to give hugs from a wheelchair. There is also a general discussion about sexual attitudes, relationships, parenthood, contraception, and sexually transmitted diseases. The book concludes with a list of myths about sexuality and spinal cord injury and a resource list. 1993, 34 pp., $14.95 plus postage and handling.
The Spinal Cord Injury Center, Froedtert Memorial Lutheran, 9200 West Wisconsin Avenue, Milwaukee, WI 53226; 414-259-3657.

Women with Disabilities: Essays in Psychology, Culture, and Politics

Michelle Fine and Adrienne Asch, editors

Drawing on law, social science, folklore, literature, psychoanalytic theory, and political activism, the contributers to this volume describe the experience of women with disabilities. The essays consider the impact of social class, race, the age at which disability occurs, and sexual orientation on the disabled woman's self-esteem, as well as on her life options. Topics include sex roles and culture, bodies and images, the constructions of gender and disability, and women with disabilities in relationships. 1988, 347 pp., $19.95.
Temple University Press, University Service Building, Room 305, Broad and Oxford Streets, Philadelphia, PA 19122; 215-204-8787.

Past Due: A Story of Disability, Pregnancy, and Birth

Anne Finger

The author, who was disabled by polio during childhood, explores the complexities of disability and reproductive rights through an account of her pregnancy and home birth experience. Disability rights, motherhood, and reproductive freedom are among the issues she raises. 1990, 200 pp., $10.95.
The Seal Press, 3131 Western Avenue, Suite 410, Seattle, WA 98121-1028; 206-283-7844.

Love: Where to Find It, How to Keep It

Elle Friedman Becker

This self-help book describes ways for people with disabilities to meet and discusses communication skills, dating, and terminating relationships. It is written from the personal experiences and professional observations of a single woman with an acquired disability who works as a counseling psychologist. 1991, 104 pp., $6.95 plus $1.25 postage and handling.
Accent Special Publications, Cheever Publishing, PO Box 700, Bloomington, IL 61702; 309-378-2961.

Marriage and Disability

Betty Garee and Raymond Cheever, editors

In this collection of articles from *ACCENT* magazine, people with a variety of physical disabilities tell how they met and married, and discuss the happy, successful lives they are living with their spouses. 1992, 80 pp., $7.95.
Accent Special Publications, Cheever Publishing, PO Box 700, Bloomington, IL 61702; 309-378-2961.

Reproductive Issues for Persons with Physical Disabilities

Florence P. Haseltine, Sandra S. Cole, and David B. Gray, editors

This resource features contributions from both consumers with disabilities and health professionals from a variety of backgrounds. Chapters focus on dispelling myths about sexuality and disability and exploring sexual issues that challenge people with disabilities. Topics include basic information about congenital and acquired physical disabilities, reproductive rights and opportunities, sexual dysfunctions, sexually transmitted diseases, reproductive physiology, sexual development, health care needs, fertility, birth control, adoptions, pregnancy, labor and delivery, and parenthood. Personal stories of people with disabilities appear throughout the book, and various clinical and policy issues are discussed. 1993, 400 pp., $33.00.
Paul H. Brookes Publishing, PO Box 10624, Baltimore, MD 21285-0624; 800-638-3775.

Sex and Back Pain

Lauren Andrew Hebert

A physical therapist describes various types of back pain and sexual positions for maximum comfort. Line drawings and photographs illustrate recommended exercises and sexual positions for people who experience back pain. All individuals in the photographs are clothed. In an accompanying video, a partially clothed man and woman demonstrate the various sexual positions described in the book. Book: 1992, 121 pp., $12.95. Video: 1993, 21 min., $149.00 (comes with three 21-page professional manuals; additional manuals are available for $6.00 each).
IMPACC, 1 Washington Street, PO Box 1247, Greenville, ME 04441; 800-762-7720; from outside the United States, 207-695-3354.

Understanding and Expressing Sexuality: Responsible Choices for Individuals with Developmental Disabilities

Rosalyn Kramer Monat-Haller

The author draws on her experience in counseling to discuss sexuality issues for people with developmental disabilities. Topics include anatomy and physiology, physical maturation, contraception, marriage, parenthood, AIDS, sexually transmitted diseases, and sexual exploitation and abuse. The book includes a bibliography, resource list, and therapeutic intervention tools. The author conducts in-service training and workshops on this book. 1992, 240 pp., $26.00 plus $2.50 postage and handling. Residents of South Carolina add 5 percent sales tax.
Paul H. Brookes Publishing. Place orders through Rosalyn Kramer Monat-Haller, PO Box 2103, Summerville, SC 29484; 803-873-6935.

Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled (And People Who Care about Them)

Ken Kroll and Erica Levy Klein

This book contains information on the sexual abilities and limitations of amputees and individuals with spinal cord injuries, multiple sclerosis, blindness, hearing impairments, and neuromuscular disorders. It includes guidelines for overcoming stereotypes and offers advice on family planning, safer sex, and establishing intimacy. 1992, 209 pp., $22.50.
Harmony Books/Crown Publishers, 201 East 50th Street, New York, NY 10022; 800-733-3000.

Sexual Rehabilitation of the Spinal-Cord-Injured Patient

J. F. J. Leyson, editor

Twenty-eight experts in the fields of sexuality, sexual dysfunction, and spinal cord injury contributed to this practical guide to the management of every type of sexual dysfunction arising from spinal cord injury. The book also explores fertility, pregnancy, and sexual orientaiton among individuals with spinal cord injury. 1991, 560 pp., $89.50.
Humana Press, 999 Riverview Drive, Suite 208, Totowa, NJ 07512; 201-256-1699.

Survivor: For People with Developmental Disabilities Who Have Been Sexually Assaulted

Los Angeles Commission on Assaults against Women

This publication is made up of two spiral-bound booklets. Booklet 1 is written for individuals with minimal reading levels, to be read with the assistance of a teacher or parent. Booklet 2 is designed for parents, teachers, advocates, and others. 1986, single copies free, $1.50 postage and handling.
Los Angeles Commission on Assaults against Women, 6043 Hollywood Boulevard, Suite 200, Los Angeles, CA 90028; 213-462-1281.

Finding Love and Intimacy

Robert Mauro

From the editor and publisher of *PeopleNet*, the personals newsletter for unmarried persons with disabilities, comes this compilation of essays, poems, short stories, and book reviews on love, relationships, and sexuality. Topics include dealing with protective parents, arranging dates, and coping with shyness. 1994, 190 pp., $8.95.
Accent Special Publications, Cheever Publishing, PO Box 700, Bloomington, IL 61702; 309-378-2961.

A Guide to Bladder Cancer, Urostomy and Impotence

Roni Olsen

This book offers guidance to people who have recently received a diagnosis of bladder cancer or who are contemplating a urinary diversion (or an ostomy of any type). The author shares her husband's experience with bladder cancer and the results of her own extensive research. 1994, 140 pp., $6.95 plus $1.50 postage and handling.
Highline Editions, 6400 Southwood Drive, Littleton, CO 80121; 303-798-8281.

Smooth Sailing into the Next Generation: The Causes and Prevention of Mental Retardation

Diane Plumridge and Judith Hylton

This manual defines mental retardation, discusses its known causes, and outlines several discussion points and possible choices one might make that could influence the risk of producing children with a cognitive disability. Personal responsibility is emphasized, along with the importance of planning pregnancy and parenthood within a lifestyle of mature behavior. 1989, 139 pp., 19.95 plus $2.00 postage and handling, bulk rates available.
R & E Publishers, 468 Auzerais Avenue, Suite A, San Jose, CA 95126; 408-866-6303.

The Sensuous Wheeler, Sexual Adjustment for the Spinal Cord Injured

Barry Rabin

This sexuality guide for men and women with spinal cord injuries covers sexual response, adjustment, and functioning. It also outlines ideas for attracting a partner, preparing for sexual activity, sexual positions, and nondemand pleasure techniques. 1980, 153 pp., $14.95 plus $3.00 postage and handling.
New Mobility, Miramar Communications, PO Box 8987, Malibu, CA 90265-8987; 800-543-4116, ext. 454.

The Right to Control What Happens to Your Body: A Straightforward Guide to Issues of Sexuality & Sexual Abuse

The Roeher Institute

This easy-to-read, large-print book discusses the risk and incidence of sexual abuse of people with mental disabilities. It includes definitions of abuse and assault, as well as suggesting ways of recognizing, treating, and preventing sexual abuse. This guide

includes a glossary and lists of referral sources and legal resources. 1991, 29 pp., $7.00 (Canadian) plus 15 percent postage and handling.
The Roeher Institute, Kinsmen Building, York University, 4700 Keele Street, North York, Ontario, Canada M3J 1P3; 416-661-9611.

Sexual Abuse Prevention Programs and Mental Handicap: A Report Prepared by the G. Allan Roeher Institute

The Roeher Institute

This Canadian study analyzes several prevention programs in terms of their suitability or adaptability for use with people who have a mental impairment. It explores what information is appropriate and required in a prevention program that deals with people with a disability, summarizes findings and general trends across programs studied, and presents recommendations for future development. 1989, 70 pp., $6.00 (Canadian) plus 15 percent postage and handling.
The Roeher Institute, Kinsmen Building, York University, 4700 Keele Street, North York, Ontario, Canada M3J 1P3; 416-661-9611.

Vulnerable: Sexual Abuse and People with an Intellectual Handicap

The Roeher Institute

This study addresses the problems of society's denial of sexual feelings and of sexual abuse among persons with intellectual disabilities, the prevalence of sexual abuse among such individuals, and risk factors of developmental disability as related to sexual abuse. It discusses treatment and effects of abuse, accessibility of services, prevention, legal issues, and sex offenders who have an intellectual disability. 1989, 115 pp., $14.00 Canadian plus 15 percent postage and handling.
The Roeher Institute, Kinsmen Building, York University, 4700 Keele Street, North York, Ontario, Canada M3J 1P3; 416-661-9611.

Mother-to-Be: Guide to Pregnancy and Birth for Women with Disabilities

Judith Rogers and Molleen Matsumura

This book discusses all aspects of pregnancy in the context of disability, from making the decision to have a child to the problems that women with disabilities confront after giving birth. It begins with interviews with thirty-six women who have a range of disabilities, including cerebral palsy, lupus, ataxia, multiple sclerosis, spina bifida, postpolio syndrome, and arthritis. Other chapters discuss nutrition, exercise, labor, and delivery. Appendices include dietary plans, a glossary, an extensive index, and lists of important resource organizations and suggested reading materials. 1991, 410 pp., $24.95 plus $4.00 postage and handling.
Demos Publications, 386 Park Avenue South, Suite 201, New York, NY 10016; 212-683-0072.

The Illustrated Guide to Better Sex for People with Chronic Pain

Robert W. Rothrock and Gabriella D'Amore

This self-help booklet provides information about frequent problems that interfere with sexual enjoyment for individuals who suffer from chronic pain and suggests simple, basic solutions. It includes six illustrations showing comfortable sexual positions for persons with various pain disorders, and stresses the importance of communication between partners. 1991, 37 pp., $8.95 plus $3.00 postage and handling, bulk prices available.
R. Rothrock & G. D'Amore, 201 Woolston Drive, PO Box 1355, Morrisville, PA 19067-0325; 215-736-1266.

Sexual Concerns When Illness or Disability Strikes

Carol Sandowski

This book discusses the possible effects of various medical conditions (arthritis, diabetes, spinal cord injury, alcoholism) on sexual functioning, relationships, self-esteem, and communication. The author explores treatments for sexual dysfunction. 1989, 281 pp., $56.75 plus $5.50 postage and handling.
Charles C. Thomas Publisher, 2600 South First Street, Springfield, IL 62794-9265; 217-789-8980, 800-258-8980.

Sexuality & Cancer: For the Woman Who Has Cancer and Her Partner

Leslie R. Schover

This booklet offers information about cancer and female sexuality. Information includes the effects of cancer and treatment on sexuality, keys to staying sexually healthy during cancer treatment, how to seek professional help, and a list of resources. 1991, 40 pp., free.
The American Cancer Society, New York, NY. All orders are taken by local chapters; consult your local telephone directory.

Growing Up: A Social and Sexual Education Picture Book for Young People with Mental Retardation

Victor Shea and Betty Gordon

This book is designed to be read to students ages twelve and older who have moderate to severe mental impairments, although many parts may be suitable for younger students with mild learning problems. The book is looseleaf, providing basic information and illustrations on the right, and ideas for discussion and further learning activities on the left. This format allows for tailoring the program to individual needs. 1991, 147 pp., $22.00 plus $3.00 postage and handling.
Clinical Center for the Study of Development and Learning Library, UNC-CH, BSRC, CB#7255, Chapel Hill, NC 27599; 919-966-5171.

Changes in You: A Clearly Illustrated, Simply Worded Explanation of the Changes of Puberty for Boys

Changes in You: A Clearly Illustrated, Simply Worded Explanation of the Changes of Puberty for Girls

Peggy C. Siegel

These books explain changes of puberty in a simple, positive manner. They cover such topics as physical development, menstruation, erections, masturbation, wet dreams, and sexual abuse prevention. A parent guide accompanies each book. 1994, 47 pp. each, $8.95 each.
Family Life Education Associates, PO Box 7466, Richmond, VA 23221; 804-262-0531.

Fact Sheet: HIV/AIDS Prevention for People with Disabilities

Sharon Wachsler

This comprehensive fact sheet covers HIV/AIDS prevention and testing information, and includes a list of resources and agencies. 1991, 20 pp., single copies free, multiple copies $1.00 each for Massachusetts residents and $2.00 each for others.
Information Center for Individuals with Disabilities, Fort Point Place, 27-43 Wormwood Street, Boston, MA 02210-1606; 617-727-5540; TDD 617-345-9743.

Intimacy and Disability

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

Written by and for individuals with disabilities, this guide assists people in overcoming barriers to developing intimate relationships. Topics include self-image, body image, sexuality, dating, intimacy, contraception, and sexual abuse. The book includes a resource list. 1982, 110 pp., $5.50.
National Rehabilitation Information Center, 8455 Colesville Road, Suite 935, Silver Spring, MD 20910-3319; 800-346-2742.

Signs of Sexual Behavior: An Introduction to Some Sex-related Vocabulary in American Sign Language

James Woodward

This introduction to sexuality-related American Sign Language vocabulary offers clear illustrations of more than 130 signs. Comprehensive explanations and notes on derivation are included. A video illustrating the signs is also available. Book: 1993, 81 pp., $7.95. Video: 1993, 30 min., $24.95. Book and video: $29.95.
T.J. Publishers, 817 Silver Spring Avenue, Silver Spring, MD 20910, 301-585-4440.

BOOKS FOR PARENTS

HIV & AIDS Prevention Guide for Parents

The Arc

Developed to assist parents and caregivers in talking about HIV/AIDS with their children who have developmental or learning disabilities, this guide includes illustrations, resource lists, and position statements. 1991, 14 pp., 1–9 copies, $3.50 each; 10–29 copies, $2.50 each; 30 or more copies, $1.50 each.
Publications, National Headquarters of the Arc, PO Box 1047, Arlington, TX 76004; 817-261-6003.

Sexuality and People with Intellectual Disability

Lydia Fegan, Anne Rauch, and Wendy McCarthy

This book candidly discusses sexuality and the attitudes of both individuals with intellectual disabilities and their caregivers. Sample dialogues and case situations, discussion of sexual rights for people with intellectual disabilities, and policy guidelines for organizations also are included. 1993, 144 pp., $30.00.
Paul H. Brookes Publishing, PO Box 10624, Baltimore, MD 21285-0624; 410-337-9580, 800-638-3775.

Shared Feelings: A Parent's Guide to Sexuality Education for Children, Adolescents, and Adults Who Have a Mental Handicap

Diane Maksym

This book is intended to help parents of children with mental impairments learn how to teach their sons and daughters about relationships and sexuality. A parent guide includes tips for facilitating support networks, goal setting, and working in groups. Outlines for seven meetings are included. 1990, 181 pp. Parent guide: $16.00. Discussion guide: $14.00 (Canadian) plus 15 percent postage and handling.
The Roeher Institute, Kinsmen Building, York University, 4700 Keele Street, North York, Ontario, Canada M3J 1P3; 416-661-9611.

How to Thrive, Not Just Survive: A Guide to Developing Independent Life Skills for Blind and Visually Impaired Children and Youth

Rose-Marie Swallow and Kathleen Mary Huebner, editors

This book is a guide for parents, teachers, and others involved in helping children with visual impairments develop skills for daily living. Topics include sexuality education, motor development, personal hygiene and grooming, clothing selection, self-esteem, social behavior, communication, and low-vision devices. 1987, 93 pp., $16.95 plus $3.50 postage and handling.
American Foundation for the Blind, c/o American Book Center, Brooklyn Navy Yard, Building 3, Brooklyn, NY 11205; 718-852-9873.

An Easy Guide for Caring Parents: Sexuality and Socialization—A Book for Parents of People with Mental Handicaps

Lynn McKee and Virginia Blacklidge

This book addresses the social needs of children with mental impairments and other developmental disabilities. It discusses the crucial role of parents in their children's

sexuality education and contains a comprehensive discussion of sexual development, addressing topics such as growing up, responsible sexual behavior, masturbation, social life, sexual orientation, fertility and birth control, sexual abuse, and marriage. 1986, 56 pp., $7.25, bulk rates available.
Planned Parenthood/Shasta-Diablo, 2185 Pacheco Street, Concord, CA 94520; 510-676-0505.

BOOKS FOR PROFESSIONALS

The HIV Guide: Resources for Board Members and Administrators

The Arc

This practical guide is intended to help local and state chapter executives develop and adopt policies and procedures necessary to address HIV/AIDS issues with staff, consumers, and volunteers. 1991, 48 pp., $6.00.
Publications, National Headquarters of the Arc, PO Box 1047, Arlington, TX 76004; 817-261-6003.

Summary of the National Forum on HIV/AIDS Prevention Education for Children and Youth with Special Needs

Association for the Advancement of Health Education (AAHE)

This report of an assessment of HIV/AIDS prevention education for special education students summarizes findings, presents conclusions and recommendations, and includes a reading list. 1989, 38 pp., single copies free.
Association for the Advancement of Health Education (AAHE), 1900 Association Drive, Reston, VA 22091; 703-476-3437.

The Sexual Assault Survivor's Handbook for People with Developmental Disabilities and Their Advocates

Norma J. Baladerian

This book can be used as a guide and support after a sexual assault of an individual with a developmental disability. It walks the reader through the events following an assault, and provides guidelines for counseling survivors and their families. The book can also be used to teach professionals about how to prevent the sexual assault of people with developmental disabilities. 1991, 34 pp., $11.95 plus $2.50 postage and handling.
R & E Publishers, 468 Auzerais Avenue, Suite A, San Jose, CA 95126; 408-866-6303.

HIV Infection and Developmental Disabilities: A Resource for Service Providers

Allen C. Crocker, Herbert J. Cohen, and Theodore A. Kastner, editors

This text looks at the medical, social, legal, and educational issues involved in providing appropriate HIV-related services to people with developmental disabilities. It includes discussion of the developmental needs of children and youth with congenital and acquired HIV infection, special concerns of staff, and policy considerations. 1992, 320 pp., $47.00.
Paul H. Brookes Publishing, PO Box 10624, Baltimore, MD 21285-0624; 410-337-9580.

Socialization and Sexuality: A Comprehensive Training Guide for Professionals Helping People with Disabilities that Hinder Learning

Winifred Kempton

This guide outlines a sexuality education course for persons with developmental disabilities. It describes teaching strategies that have proven successful with such individuals and details the process of training professionals to become sexuality educators for students with cognitive disabilities. A list of print, video, and multimedia resources is included. 1993, 348 pp., $39.95.
James Stanfield Company, PO Box 41058, Santa Barbara, CA 93140; 800-421-6534. Or Planned Parenthood of Southeast Pennsylvania, 1144 Locust Street, Philadelphia, PA 19107-5740; 215-351-5590.

Teaching Persons with Mental Retardation about Sexuality and Relationships

June Kogut and Susan Vilardo

This manual offers educators of persons with mental retardation guidance for the development and implementation of sexuality education programs. The authors are sexuality educators for Planned Parenthood of Connecticut. 1994, $49.95.
Publications Department, Planned Parenthood of Connecticut, 129 Whitney Avenue, New Haven, CT 06510; 203-865-5158.

Sexuality and the Mentally Retarded: A Clinical and Therapeutic Guidebook

Rosalyn Kramer Monat-Haller

This guide to sexuality counseling and education for individuals with developmental disabilities presents ethical challenges, suggestions, and ideas for debate. It covers the role of sexuality counseling, the development of healthy psychosocial and sexual attitudes, and public relations for sexuality education and counseling. The author also provides in-service training and workshops on this book. 1982, 150 pp., $21.50 plus $2.50 postage and handling. Residents of South Carolina add 5 percent sales tax.
College Hill Press. Place orders through Rosalyn Kramer Monat-Haller, PO Box 2103, Summerville, SC 29484, 803-873-6935.

Barrier Free: Serving Young Women with Disabilities

Linda Marks and Harilyn Rousso

This training manual for groups that provide services to teenagers with physical or sensory disabilities examines some important issues that young women with such disabilities face, including career exploration, independent living, and sexuality. 1991, 52 pp., $8.00.
Education Development Center, Women's Educational Equity Act Publishing Center, 55 Chapel Street, Newton, MA 02158-1060; 800-225-3088, 617-969-7100.

Choices: A Guide to Sex Counseling with Physically Disabled Adults

Maureen E. Neistadt and Maureen Freda

Written for rehabilitation professionals who provide sexuality counseling, this book contains guidelines for limited sexuality counseling and examines issues of intimacy and communication, as well as the sexual response cycle. This book discusses functional and sexual difficulties caused by disabilities and the impact of disability on social issues such as privacy, dating, marriage, and childbearing. Reading and resource lists are included. 1987, 132 pp., $14.50.
Robert E. Krieger Publishing, PO Box 9542, Melbourne, FL 32902-9542; 407-724-9542.

No More Victims: Addressing the Sexual Abuse of People with a Mental Handicap

The Roeher Institute

This series of four manuals can be used by police, social workers, counselors, families, and members of the legal community concerned about the sexual abuse of people with a mental disability. The series explores factors that put people with mental impairments at risk of sexual abuse, and discusses detection, appropriate responses, and prevention. Each manual includes a two-day training curriculum. 1992, $15.00 per manual.
The Roeher Institute, Kinsmen Building, York University, 4700 Keele Street, North York, Ontario, Canada M3J 1P3; 416-661-9611.

Sexuality and Chronic Illness: A Comprehensive Approach

Leslie R. Schover and Soren Buus Jensen

Using an integrative biopsychosocial approach, this volume reviews basic skills needed to comfortably discuss sexuality with chronically ill patients, assess sexual problems through both psychological and medical approaches, and create a systematic treatment plan. 1988, 347 pp., $47.50 plus $3.50 postage and handling.
Guilford Publications, 72 Spring Street, New York, NY 10012; 800-365-7006.

Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?

Dick Sobsey

This guide to understanding and preventing abuse includes accounts of abuse from the perspectives of both victims and offenders, a conceptual framework for understanding the nature of abuse and why it occurs, and practical strategies for abuse detection and prevention. Part 1 is devoted to understanding abuse and includes a section on sexual abuse and assault. Part 2 focuses on abuse prevention and discusses the importance of sexuality education—as well as sexual abuse prevention programs—in the prevention of sexual abuse. An annotated list of individuals and organizations is included. 1994, 480 pp., $27.00.
Paul H. Brookes, PO Box 10624, Baltimore, MD 21285-0624; 410-337-9580.

Disability, Sexuality, and Abuse: An Annotated Bibliography

Dick Sobsey, Don Wells, Diane Pyper, and Beth Reimer-Heck

Containing over 1,100 entries, this comprehensive reference book brings together literature from a wide range of disciplines relevant to the sexual abuse, assault, and exploitation of persons with disabilities. It includes research studies, position papers, program descriptions, clinical reports, and media accounts. 1991, 208 pp., $26.00.
Paul H. Brookes Publishing, PO Box 10624, Baltimore, MD 21285-0624; 410-337-9580.

CURRICULA

Not a Child Anymore

Brook Advisory Centres

This twelve-module training program designed for use with young adults with mental impairment covers topics such as human relationships, anatomy, physiological development, reproduction, pregnancy and childbirth, child care, sexual relationships, contraception and sexually transmitted diseases. Each module is self-contained, enabling presenters to follow the interest and needs of the group. A teacher manual, evaluation kit, illustrations, flip folder of the human body, and fabric kits to make anatomically correct three-dimensional models are included. 1991, £189.00 for complete program.
Brook Advisory Centres, Education & Publications Unit, 153A East Street, London SE17 2SD England; 011-44-71-708-1390.

CIRCLES: A Multi-media Package to Aid in the Development of Appropriate Social/Sexual Behavior in the Developmentally Disabled Individual

Marklyn Champagne and Leslie Walker-Hirsch

This three-part series includes curricula, videos, photos, wall chart, and discussion guide. *CIRCLES I* deals with intimacy and relationships, and includes twelve live-action videos. *CIRCLES II* deals with sexual abuse prevention. *CIRCLES III* covers sexually transmitted diseases, including HIV/AIDS. *CIRCLES I* (revised): 1993, $599.00. *CIRCLES II:* 1987, $399.00. *CIRCLES III:* 1988, $399.00. Discounts available for sets.
James Stanfield Company, PO Box 41058, Santa Barbara, CA 93140; 800-421-6534.

Janet's Got Her Period

Judi Gray and Jitka Jilich

This curriculum for girls and young women with severe developmental disabilities, consisting of a video and an illustrated storybook with full-color photographs, tells the story of a young girl who learns menstrual self-care from her mother and sister. The program includes a detailed task analysis of behaviors required for using sanitary pads. This curriculum is suitable for home instruction. 1990. Guidelines: 40 pp. Storybook: 24 pp. Pictograph chart and twenty-four laminated pictograph cards: $279.00.
James Stanfield Company, PO Box 41058, Santa Barbara, CA 93140; 800-421-6534.

Being Sexual: An Illustrated Series on Sexuality and Relationships

Dave Hingsburger and Susan Ludwig; illustrated by James F. Whittingham

This clearly written and richly illustrated sixteen-book series presents important information about sexuality and relationships for adolescents and adults with developmental disabilities or problems with literacy, learning, or communication. The books address the personal feelings, individual rights, and social expectations associated with a variety of sexuality-related topics. Key concepts and definitions on each page are translated into Blissymbols, with new symbols highlighted. 1993, $60.00 for individuals, $80.00 for organizations.

Sex Information & Education Council of Canada, 850 Coxwell Avenue, East York, Ontario, Canada M4C 5RI; 416-466-5304.

SAFE: Stopping AIDS through Functional Education

Judith Hylton

This comprehensive instructional package for use with adolescents and adults with developmental or learning disabilities contains guidelines for developing a comprehensive HIV/AIDS prevention program. It includes videos, brochures, slides, and illustrations. 1992, 200 pp., $75.00.

Child Development and Rehabilitation Center, CDRC/OHSU, Publications Department, PO Box 574, Portland, OR 97207-0574; 503-494-8699. Or Publications, National Headquarters of the Arc, PO Box 1047, Arlington, TX, 76004; 817-261-6003.

Life Horizons I & II

Winifred Kempton

This two-part curriculum, consisting of slides and instructor handbooks, is a revised version of *Sexuality and the Mentally Handicapped*. Part 1 (over 500 slides) discusses anatomy, puberty, reproduction, contraception, and HIV/AIDS. Part 2 (over 600 slides) deals with the psychosocial aspects of sexuality, including self-esteem; moral, legal, and social issues; dating; marriage; parenthood; and sexual abuse. 1988, $399.00 each, $699.00 for both.

James Stanfield Company, PO Box 41058, Santa Barbara, CA 93140; 800-421-6534.

Sex Education for Persons with Disabilities that Hinder Learning: A Teacher's Guide

Winifred Kempton and Frank Caparulo

This resource for educators covers effective techniques and strategies for teaching sexuality education to people with cognitive disabilities. The book outlines the major components of a comprehensive sexuality program. It includes an extensive bibliography. 1989, 200 pp., $29.95 plus 15 percent postage and handling.

James Stanfield Company, PO Box 41058, Santa Barbara, CA 93140; 800-421-6534.

No-Go-Tell!: Protection Curriculum for Young Children with Special Needs

Elisabeth J. Krents and Dale Special Atkins (second edition)
Elisabeth J. Krents and Shella Brenner (curriculum guide, revised edition)

This curriculum, made up of seventy-six illustrated teaching panels, deals with preventing abuse of children in preschool and early elementary school who have communication and language limitations. It features guidelines for developing a school child abuse policy and includes sections on parental involvement, curriculum implementation, and up-to-date information on physical and sexual abuse research. The curriculum is divided into three sections: interpersonal relationships, appropriate touch, and inappropriate touch. Personal safety issues are illustrated through the use of black-and-white drawings. Role-play exercises are included. This curriculum avoids "stranger-danger" messages. The complete program includes two dolls. 1991, 69 pp. plus seventy-six teaching panels, $299.00 ($199.00 without dolls).

James Stanfield Company, PO Box 41058, Santa Barbara, CA 93140, 800-421-6534.

Human Sexuality: A Portfolio for Persons with Developmental Disabilities, Second Edition

Victoria Livingston and Mary E. Knapp

This portfolio can be used by any group in need of basic knowledge about human sexuality. It consists of ten large color drawings illustrating anatomy and sexual functions, discussion suggestions, and a script for the teacher printed on the back of each plate. 1991, $24.95 plus 15 percent postage and handling.

Bookstore, Planned Parenthood of Seattle–King County, 2211 East Madison, Seattle, WA 98112-5397; 206-328-7716.

Sexuality: A Curriculum for Individuals Who Have Difficulty with Traditional Learning Methods

Susan Ludwig

Developed by a teacher of individuals with developmental disabilities, this manual includes topics on feelings, self-esteem, anatomy, puberty, reproduction, social behavior, contraception, and sexually transmitted diseases. Each section presents information on several levels, from simple and concrete to more difficult and abstract, and includes activities that can be adapted to students' prior knowledge and the individual needs of the group. This curriculum includes sessions for parents and caregivers. 1989, 145 pp., $38.00 (Canadian).

The Regional Municipality of York Public Health, Community Health Nursing, 4261 Highway 7 East, Suite 202, Unionville, Ontario, Canada L3R 9W6; 905-940-1333.

Positive Approaches: A Sexuality Guide for Teaching Developmentally Disabled Persons

Lisa Maurer

This guide provides a format for teachers, parents, and caregivers to assist persons with developmental disabilities in acquiring knowledge and skills for understanding and expressing their individual sexuality in a

safe and appropriate manner. Background information is coupled with a variety of exercises, fact sheets, and programs concerning anatomy, physiology, contraception, relationships, pregnancy, and parenthood. 1991, 91 pp., $40.00.
Education Department, Planned Parenthood of Delaware, 625 Shipley Street, Wilmington, DE 19801; 302-655-7293.

Signs for Sexuality: A Resource Manual for Deaf and Hard of Hearing Individuals, Their Families, and Professionals, Second Edition

Marlyn Minkin and Laurie Rosen-Ritt

This curriculum contains information on sexual abuse, sexually transmitted diseases, and reproductive health, with more than 600 photographs to illustrate 250 vocabulary terms associated with sexuality. Appendices include contraception information and anatomical drawings. 1991, $24.95 plus 15 percent postage and handling.
Bookstore, Planned Parenthood of Seattle–King County, 2211 East Madison, Seattle, WA 98112-5397; 206-328-7716.

The Project Action Curriculum: Sexual Assault Awareness for People with Disabilities

Carolyn S. Paige, Sarah Wright, and Melanie Schaefer

This curriculum is designed for use with persons who have mild to moderate cognitive disabilities. Sections 1–4 give background information on sexual assault, sexuality, and disability, and present a variety of strategies and suggestions for teaching sexual assault awareness. Sections 5–9 make up the body of the curriculum, covering different kinds of touching, sexual exploitation, and disclosure. Sections 10–15 include behavior assessment forms, role-plays, case studies, a glossary, body maps, a caregiver packet, and values exploration exercises for staff. 1991, 128 pp., $99.95 plus $5.00 postage and handling.
Seattle Rape Relief, 1905 South Jackson, Seattle, WA 98144; 206-325-5531 (TTY at same number).

Changes in You: An Introduction to Sexual Education through an Understanding of Puberty

Peggy Siegel

This family life education program for young people with cognitive disabilities is intended to help students in grades 4–9 develop strong, positive feelings about themselves as they make the transition into puberty. The complete program includes seventy-three laminated teaching pictures; illustrated student manuals; parent guides; and a curriculum guide with teaching activities, objectives, lesson plans, and tests. 1991, $299.00.
James Stanfield Company, PO Box 41058, Santa Barbara, CA 93140; 800-421-6534.

The Family Education Program Manual

Katherine Simpson, editor

This manual includes complete curricula for teaching sexuality, self-esteem, and abuse prevention to students with developmental and learning disabilities. Areas covered include working with schools, setting up educational plans, working with parents, and dealing with teachers' concerns. The manual contains training outlines and resources, a complete section on audiovisual instruction, reproducible teaching graphics, and pretest and posttest evaluations. 1990, 300 pp., $35.00.
Planned Parenthood/Shasta-Diablo, 2185 Pacheco Street, Concord, CA 94520; 510-676-0505.

LIFEFACTS: Essential Information about Life for Persons with Special Needs

James Stanfield Company

Of these seven programs designed to provide health education professionals with essential materials and information to teach adolescents and adults with developmental and learning disabilities, three specifically address sexuality: *AIDS* (1991), *Sexuality* (1990), and *Sexual Abuse Prevention* (1990). Each curriculum is designed to enable educators to choose the appropriate level of presentation, depending on students' needs and community attitudes. Each kit includes a curriculum guide, laminated pictures and 35mm slides, worksheets, and evaluation material. 1991, $199.00 each, $893.00 for the set. Discount rates available for combinations of curricula.
James Stanfield Company, PO Box 41058, Santa Barbara, CA 93140; 800-421-6534.

Special Education: Secondary F.L.A.S.H. (Family Life and Sexual Health): A Curriculum for 5th through 10th Grades

Jane Stangle

This comprehensive program is designed to provide practical teaching experiences and functional tools to adolescents in special education programs. It addresses the physical, emotional, and safety aspects of sexuality education; encourages parent and family involvement; and includes a section on preparing community-based sexuality education programs. Lesson plans cover relationships, communication, avoiding exploitation, anatomy, reproduction, sexually transmitted diseases, and AIDS. The curriculum includes resource lists, guidelines for answering students' questions, recommended audiovisuals, teacher preparation suggestions, and masters for all transparencies and student handouts. 1991, 301 pp., $40.00 plus 10 percent postage and handling.
Family Planning Publications, Seattle–King County Department of Public Health, 110 Prefontaine Place South, #500, Seattle, WA 98104; 206-296-4672.

The GYN Exam Handbook: An Illustrated Guide to the Gynecological Examination for Women with Special Needs

Maria Olivia Taylor

This curriculum takes students through the process of a routine gynecologic examination and provides the opportunity to understand the procedure with comfort and confidence, while easing anxiety and promoting responsible female health care.

The program includes an illustrated handbook and a two-part video. Part 1 is an uninterrupted demonstration of the examination. Part 2 discusses scheduling an appointment, the breast examination, and the pelvic examination. 1991, 103 pp., two videos, $129.00.
James Stanfield Company, PO Box 41058, Santa Barbara, CA 93140; 800-421-6534.

JOURNALS/NEWSLETTERS

Connections: The Newsletter of the National Center for Youth with Disabilities

National Center for Youth with Disabilities, University of Minnesota, Box 721, 420 Delaware Street SE, Minneapolis, MN 55455-0392; 800-333-6293.

CYDLINE Reviews: Issues in Sexuality for Adolescents with Chronic Illness and Disabilities

National Center for Youth with Disabilities, University of Minnesota, Box 721, 420 Delaware Street SE, Minneapolis, MN 55455-0392; 800-333-6293.

Disability, Pregnancy and Parenthood International

Auburn Press, 9954 South Walnut Terrace, #201, Palos Hills, IL 60465.

The Disability Rag & ReSource

The Disability Rag & ReSource, PO Box 145, Louisville, KY 40201; 502-459-5343 (phone, fax, TDD).

It's Okay!: Adults Write about Living and Loving with a Disability

Phoenix Counsel, 1 Springbank Drive, St. Catharines, Ontario, Canada L2S 2K1; 905-685-0496.

NICHCY News Digest, Volume 1, Number 3: Sexuality Education for Children and Youth with Disabilities

National Information Center for Children and Youth with Disabilities, PO Box 1492, Washington, DC 20013-1492; 800-695-0285; 202-884-8200.

Resourceful Women: Women with Disabilities Striving Toward Health and Self-Determination

Rehabilitation Institute of Chicago, 345 East Superior Street, Room 1562, Chicago, IL 60611; 312-908-7997.

Sexuality and Disability

Human Sciences Press, 233 Spring Street, New York, NY 10013-1578; 212-620-8466.

Spinal Network's New Mobility

Miramar Publishing, 613 Bristol Parkway, PO Box 3640, Culver City, CA 90231-3640; 310-337-9717, 800-543-4116.

TEACHING AIDS

Anatomically Detailed Models: For Teaching Concrete Learners

These models feature legs, buttocks, anus, and genitalia. The penis model can go from flaccid to erect. The female reproductive anatomy model can be used to demonstrate a pelvic examination and tampon insertion. Both models can be used to demonstrate safer sex methods. Each model is $145.00 plus $7.00 postage and handling and is available in tan or dark brown.
Adagio, 450 Lloyd Place, Cincinnati, OH 45219; 513-721-1842.

Reproductive Anatomy Charts

These charts consist of life-size heavy paper male and female body charts with detachable parts to demonstrate erection, ejaculation, urination, menstruation, pelvic examinations, fertility, and fetal development. $90.00 prepaid plus 15 percent postage and handling.
Planned Parenthood of Minnesota, 1965 Ford Parkway, St. Paul, MN 55116; 612-698-2401.

Reproductive Anatomy Models

These are three-dimensional cross-sectional models of the female and male reproductive systems, including flaccid and erect penis models. Instructor guides to reproductive anatomy models and a catalog of anatomical models are available. Prices vary.
Jim Jackson and Company, 33 Richdale Avenue, Cambridge, MA 02140; 617-864-9063, 800-827-9063.

Teach-a-Bodies

These soft-bodied, anatomically correct dolls can be used with young children and people with developmental disabilities. A catalog of dolls, clothes, accessories, puppets, paper dolls, and instructional books is available. Prices vary.
Teach-a-Bodies, 3509 Acorn Run, Fort Worth, TX 76109; 817-923-2380.

DATABASES

Exceptional Child Education Resources

Council for Exceptional Children, 1920 Association Drive, Arlington, VA 22091; 703-620-3660.

National Resource Library

National Center for Youth with Disabilities, University of Minnesota, Box 721, 420 Delaware Street SE, Minneapolis, MN 55455-0392; 800-333-6293.

ORGANIZATIONS

Agency for Instructional Technology

PO Box A
Bloomington, IN 47402
800-457-4509

Alliance of Genetic Support Groups

1001 22nd Street NW, Suite 800
Washington, DC 20037
800-336-GENE

American Foundation for the Blind

15 West 16th Street
New York, NY 10011
212-620-2000; 800-543-5463

The Arc: A National Organization on Mental Retardation
500 East Border Street, Suite 300
Arlington, TX 76010
817-261-6003; TDD 817-277-0553

Arthritis Foundation
PO Box 19000
Atlanta, GA 30326
800-283-7800

The British Columbia Coalition of People with Disabilities AIDS & Disability Action Project
204-456 West Broadway
Vancouver, British Columbia
Canada V5Y 1R3
604-875-0188

DisAbled Women's Network (DAWN) Toronto
180 Dundas Street West, Suite 210
Toronto, Ontario
Canada M5G 1Z8
416-598-2438; TDD and TTY 416-598-5059

Gallaudet University Library
800 Florida Avenue NE
Washington, DC 20003
202-651-5220

Information Center for Individuals with Disabilities
Fort Point Place, First Floor
27-43 Wormwood Street
Boston, MA 02210-1606
617-727-5540; 800-462-5015;
TDD 617-345-9743

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
914-428-7100

National Center for Children and Youth with Disabilities
PO Box 1492
Washington, DC 20013-1492
Voice and TT 800-695-0285 or 202-884-8200

National Center for Youth with Disabilities
University of Minnesota
Box 721
420 Delaware Street SE
Minneapolis, MN 55455-0392
800-333-6293; TDD 612-624-3939

National AIDS Hotline for Deaf and Hearing-Impaired People
TDD and TTY 800-243-7889

National Chronic Pain Outreach Association
7979 Old Georgetown Road, Suite 100
Bethesda, MD 20814
301-652-4948

National Genetics Foundation
555 West 57th Street
New York, NY 10019
212-586-5800

National Society of Genetic Counselors
Clinical Genetics Center
Children's Hospital of Philadelphia
34th and Civic Center Boulevard
Philadelphia, PA 19104
215-596-9802

The Project on Women and Disability
1 Ashburton Place, Room 1305
Boston, MA 02108
617-727-7440; voice and TDD 800-322-2020

Sexuality and Developmental Disability Network Sex Information & Education Council of Canada (SIECCAN)
850 Coxwell Avenue
East York, Ontario
Canada M4C 5RI
416-466-5304

Sexuality and Disability Training Center
University Hospital
75 East Newton Street
Boston, MA 02118
617-638-7358

Sexuality Information and Education Council of the United States (SIECUS)
130 West 42nd Street, Suite 350
New York, NY 10036
212-819-9770

Special Interest Group on Social and Sexual Concerns
American Association on Mental Retardation
444 North Capitol Street NW, Suite 846
Washington, DC 20001
202-387-1968; 800-424-3688

Women in Spinal Cord Evolution (WISE)
1798 Valley Side Drive
Frederick, MD 21702
301-694-7519

YWCA Networking Project for Disabled Women and Girls
610 Lexington Avenue, Room 209
New York, NY 10022
212-755-2700, ext. 767