

VOLUME 29 NUMBER 3

# SECTS

R E P O R T

SEXUALITY EDUCATION  
FOR PEOPLE WITH DISABILITIES

FEBRUARY/MARCH 2001

# SIECUS

## R E P O R T

VOL. 29, NO. 3 • FEBRUARY/MARCH 2001

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The *SIECUS Report* is published bimonthly and distributed to SIECUS members, professionals, organizations, government officials, libraries, the media, and the general public. The *SIECUS Report* publishes work from a variety of disciplines and perspectives about sexuality, including medicine, law, philosophy, business, and the social sciences.

Annual *SIECUS Report* subscription fees: individual, \$65; organization, \$135 (includes two subscriptions to the *SIECUS Report*); library, \$85. Outside the United States, add \$10 a year to these fees (in Canada and Mexico, add \$5). The *SIECUS Report* is available on microfilm from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106.

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Opinions expressed in the articles appearing in the *SIECUS Report* may not reflect the official position of the Sexuality Information and Education Council of the United States. Articles that express differing points of view are published as a contribution to responsible and meaningful dialogue regarding issues of significance in the field of sexuality.

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Design and layout by Alan Barnett, Inc.

Proofreading by Sheilah James and Sarah Donovan

Printing by Fulton Press

Library of Congress catalog card number 72-627361

ISSN: 0091-3995

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SIECUS POSITION STATEMENT

SEXUALITY OF PERSONS WITH DISABILITIES

The SIECUS Board of Directors has approved this position statement on “Sexuality of Persons with Disabilities”:

Persons with physical, cognitive, or emotional disabilities have a right to sexuality education, sexual health care, and opportunities for socializing and for sexual expression. Family, health care workers, and other caregivers should receive training in understanding and supporting sexual development and behavior, comprehensive sexuality education, and related health care for individu-

als with disabilities. The policies and procedures of social agencies and health care delivery systems should ensure that services and benefits are provided to all persons without discrimination because of disability. Individuals with disabilities and their caregivers should have information and education about how to minimize the risk of sexual abuse and exploitation.

SIECUS invites other organizations and individuals to join in affirming this statement and in working for its implementation.

WE MUST CREATE  
MORE OPPORTUNITIES FOR DISCOURSE

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Mac Edwards

**A**s I have worked on this issue of the *SIECUS Report* on “Sexuality Education for People with Disabilities,” I have enjoyed communicating with Scott Snedecor, a man from Oregon who has used his experiences with emotional disability to work as an advocate for others.

He first contacted me when he heard we were developing this *SIECUS Report* and said that he wanted to provide me with some personal observations of participants, including himself, on a panel held several years ago by a group called The Mind Empowered Inc. Our talks during the past several months have made me realize that we can best provide the sexuality education needs of people with physical, cognitive, or emotional disabilities if we listen to what they personally have to say.

“We, as survivors, must take responsibility to create opportunities for more discourse,” he said. “This will provide people with insight to help end discrimination and prejudice based on lack of understanding.” I thank Scott and wish him well. Comments from the panelists are on page 25. I think you will find them very interesting.

### TEACHING, SUPPORTING

This *SIECUS Report* begins with an article titled “Becoming Sexually Able: Education to Help Youth with Disabilities.” It includes a lesson plan that was developed by Mitch Tepper, founder of The Sexual Health Network and SexualHealth.com as well as a member of the SIECUS Board of Directors.

Mitch has taken his own physical disability and used it to help thousands of individuals through his work—especially his workshops and his Web site. He says in his article that he believes people of all abilities can benefit from focused and experiential learning relating to sexual health. I thank him for his insight and for the many hours he spent helping me develop this *SIECUS Report*.

Next, Michelle Ballan, who has just completed her doctoral work at the University of Texas and will soon become a professor at the Columbia University School of Social Work, talks about the role that parents must play in educating their children with disabilities. Her article titled “Parents As Sexuality Educators for Their Children with Developmental Disabilities” says that young people learn more when sexuality information is repeated and reinforced both at home and school.

Then, Judith Cook, director of the Mental Health Services Research Program at the University of Illinois at Chicago, talks in her article “Sexuality and People with Psychiatric Disabilities” about the position people with psychiatric disabilities hold in our society and the role that all of us can play in supporting their right for sexual expression. Unfortunately, she says, many internalize societal disapproval of their sexuality.

### FROM THE FIELD

I am happy to report that professional educators in both Kansas and New York City are currently involved in providing better sexuality education programs to students with cognitive, emotional, and physical disabilities. Both have written about their work in this *SIECUS Report*.

First, Darrel Lang, Jan Erikson, and Kristy Jones of the Kansas State Department of Education report in “Kansas Works to Meet the Needs of Special Education Students” about their providing workshops on this subject for special education teachers, nurses, counselors, administrators, and paraeducators. The sessions have proved so successful that they are going to provide more training. Their work is being conducted under a Cooperative Agreement with the Centers for Disease Control and Prevention.

Next, Melvyn Littner, Lorna Littner, and Mary Ann Shah write in their article “Sexuality Issues for the Disabled: Development of a Unified School Policy” about their project to attempt to address this issue. The article includes the guidelines eventually developed by administrative, staff, and parent representatives of P.721—Queens Occupational Training Center in New York City. Their work is very impressive.

### CONCLUSION

This *SIECUS Report* concludes with a Policy Update from SIECUS Director of Public Policy William Smith titled “Where is U.S. Health and Human Services (HHS) Secretary Thompson on the Issues?” He tells us that the new HHS Secretary will play a key domestic role in establishing health-related programs and policies across the country. He adds, however, that we are not yet certain what that role will be.

Finally, this *SIECUS Report* mailing includes the new SIECUS Annotated Bibliography on *Sexuality and Disability*. It includes information on books, videos, curricula, and organizations with information related to this subject.

SEXUALITY EDUCATION FOR THE DISABLED  
IS PRIORITY AT HOME AND SCHOOL

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Tamara Kreinin, M.H.S.A.

The need for sexuality education for people with disabilities first came to my attention many years ago. I was the director of a sexual abuse prevention project. Many of our most urgent requests were from schools and classes with children with some sort of disability; teachers feared others would sexually take advantage of these students and frighten them. They also feared these students would not know how to respond.

This same need became apparent to me many years later—actually quite recently—when I was working on teenage pregnancy prevention. I frequently received requests from people around the country seeking information and strategies to address sexuality-related issues with children with disabilities. Yet, I still had few good models to share.

#### POSITIVE SEXUALITY EDUCATION

While I am heartened that teachers are beginning to acknowledge the needs of disabled youth, I am sadly struck that many of their requests are based on preventing negative aspects of sexuality—sexual abuse, teenage pregnancy, and disease. This is critical, but we still want to provide our young people, including those with disabilities, with accurate information and skills to lead them to view sexuality as a natural and healthy part of life.

People with physical, cognitive, or emotional disabilities have a right to sexuality education and reproductive health care. They have the same emotional and physical needs and desires as people who are not disabled. As young children, they need touch and physical contact; as they grow older, their interests in love and relationships will emerge.

It is often true that people with disabilities are first identified by their disability rather than by their talents, intelligence, attractiveness, or by the fact that they are sexual. This makes sexuality education all the more important.

#### SUPPORT AT SCHOOLS, AGENCIES

Schools, social service agencies, and health care delivery systems must develop policies and procedures to address sexuality-related issues. The New York City School System and the Kansas State Department of Education each have excellent models that are described in this issue of the *SIECUS Report*. It is important to note that each involves a consultant or staff member with specific knowledge about disabilities.

This clearly points to the need for teachers and health care providers to have training to understand and support these students' needs for information, skills, and related health care. This includes understanding the medical aspects of a disability and its impact on a student's physical and emotional development.

When infants have developmental disabilities, their medical needs may impede some of the touch they would normally receive from family members. This lack of physical contact may impact their sexual development. Some young people experience difficulties with sexuality when their physical development does not correspond to their intellectual and social growth. This can cause anxiety and frustration. We all know that adolescents with disabilities experience sexual desires and interests even when no one is talking to them about their feelings. Teachers and health care providers must understand these issues and offer help.

#### SUPPORT AT HOME

Parents and caregivers need to start early to educate their children about sexuality-related issues and to continue the conversation well into their teen years. An important place for them to begin is to examine their own feelings and values about sexuality and about disabled individuals and sexual norms. Some parents have told me that they fear people will take advantage of their child. This makes them hesitant to provide information on sexuality issues. They say that they worry their child will not find reciprocated love and that someone will break their heart. This is what causes them to become overly protective. All of these concerns point to their need to receive information, skills, and support to educate their child. Ideally, schools, community agencies, and members of the medical community, such as a well-trained pediatrician, nurse, or other practitioner, will help.

#### CONCLUSION

Fortunately, we have more resources today than we had nearly two decades ago when I first started thinking about the sexuality education needs of young people with disabilities. It is my hope that this *SIECUS Report* will encourage teachers, providers, and parents to dispel myths, educate others, and continue to raise this important issue of sexuality education for young people with disabilities.

# BECOMING SEXUALLY ABLE: EDUCATION TO HELP YOUTH WITH DISABILITIES

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Pivotal legislation has been enacted over the past 20 years to enable people with disabilities to regain their rightful places as equal members of American society. The Rehabilitation Act of 1973, the 1975 Education for All Handicapped Children Act (Public Law 94-142), and the 1990 Americans with Disabilities Act have all added opportunities for inclusion and integration of people of all abilities.

Unfortunately, attitudes toward people with disabilities have not changed as fast as the laws enacted to support them. This is especially true in the area of sexuality and disability. Many people still deny that individuals with disabilities have sexual needs, and believe that people with disabilities should live their lives without fulfilling their sexual needs.<sup>1</sup>

## **SAME FEELINGS, NEEDS, DESIRES**

The fact is that people with disabilities have the same feelings, needs, and desires as people without disabilities. Still, many myths revolve around the sexuality or lack of sexuality of people with disabilities. This creates a double challenge for sexuality education among people with disabilities and their families.<sup>2</sup>

In the face of these challenges, sexuality educators need to work toward the ultimate goal of instilling a positive sense of sexuality among people with disabilities.<sup>3</sup> This is essential, for without assistance in dispelling the myths and without encouragement to develop sexual potential, people with disabilities sometimes come to believe these myths themselves.<sup>4</sup>

Kohlberg points out that children without disabilities learn “I am a girl” or “I am a boy,” and then adopt role attributes.<sup>5</sup> Children with disabilities, however, first learn that they are disabled before learning to see themselves as sexual people. Thus, sexuality educators need to affirm that people of all abilities, including those with early and late-onset disabilities, physical and mental disabilities, and disabilities that hinder learning, are sexual people.

Of course, educators must consider the point in life at which their students’ disabilities occurred and the subsequent effect the disabilities may have had on their psychosocial development. The needs of a student with

a congenital or developmental disability may vary tremendously from the needs of one who acquires a disability later in life. Wabrek, Wabrek, and Burchell note that, “In a personal sense, congenital handicaps seem to carry a greater stigma than traumatic injuries because individuals often feel as if they were meant to be that way.”<sup>6</sup>

The target population for this article includes adolescents and young adults categorized as having a developmental disability. Public Law 94-103 states that a developmental disability is a physical or mental impairment resulting in limitations of major life activities. It is manifested before 22 years of age and is likely to continue.

The categorization, developmental disability, by itself, is of little use for planning and implementing a developmentally appropriate curriculum, since children with developmental disabilities have a wide range of physical and mental abilities. A thorough understanding of the medical aspects of a

specific disability and the resultant impact on the child’s psychosocial development is required before an educator can design an effective sexuality education curriculum.

The extent of physical and mental problems varies with the disability; some children with physical disabilities have relatively few functional problems while others have multiple disabilities. Wolraich details the possible implications of such problems on education with respect to children with spina bifida:

The constant occurrence of acute problems—such as shunt malfunction, urinary tract infections, and repeated hospitalizations and surgery—combines with the socially limiting nature of such problems to affect almost every aspect of the child’s performance in an educational setting.<sup>7</sup>

Students with developmental disabilities may or may not have overlapping difficulties with learning. For example, a child with spina bifida may experience difficulties as the result of hydrocephalus, which is an increase in pressure on the brain from unabsorbed spinal fluid or other insult or trauma to the brain during development. Other problems

*“Children with disabilities first learn that they are disabled before learning to see themselves as sexual people.”*

may include lack of control of the leg muscles, lack of control of the bladder and bowels, lack of sensation in the skin, and/or a curvature of the spine. Because these children are less active than “normal children,” they are prone to obesity and may be following certain nutrition recommendations. An excess weight can impede ambulation and contribute to the development of pressure sores.<sup>8</sup>

Spina bifida generally has no effect on a child’s stamina, although the accompanying hydrocephalus may cause attention disorders, learning disorders, and even mental retardation. Educational assessments are necessary to determine what type of learning problems, if any, a child may have.

In addition to being conscious of the medical aspects of disability and the range of abilities among individuals, the sexuality educator should be aware of the psychosocial developmental issues of this population. In order to understand how disability affects a child’s psychosocial development, the sexuality educator must first understand psychosocial development in children without developmental disabilities. A review is provided in this article from various perspectives.

## HUMAN DEVELOPMENT

Human development is a complex process that many psychologists and theorists have tried to explain and predict. Their theories and models appear to cluster in four categories: (1) psychosocial development, (2) cognitive development, (3) maturity, and (4) typology.<sup>9</sup>

**Psychosocial development.** Many of the traditional psychosocial developmental theories are based on Erikson’s epigenetic principle, whereby an individual advances through predictable stages or *seasons* in life. Under this principle, physical growth and the cognitive maturation that follows interact with external societal demands to influence an individual’s psychosocial development.<sup>10</sup>

Some psychosocial developmental theories have focused on specific stages in development. For example, Chickering’s seven vectors of development occurring in young adulthood are: (1) developing competence, (2) managing emotions, (3) developing autonomy, (4) establishing identity, (5) freeing interpersonal relationships, (6) developing purpose, and (7) developing integrity.<sup>11</sup>

Arriving at an accurate, realistic picture of self seems to encourage experimentation in the realms where decisions are required: relationships, purpose, and integrity.<sup>12</sup>

**Cognitive development.** Moving to the cognitive realm, Piaget focuses on how students think about things, while Kohlberg, Gilligan, and Murphy examine moral development and the shifts in reasoning that take place.<sup>13</sup> According to Piaget, factors that affect the rate at which children progress through the four stages of intellectual development include maturation, physical experience, social experience, and the child’s own internal coordinating activity.<sup>14</sup>

Models such as Erikson’s and Piaget’s focus on the developmental process of people without physical or cognitive disabilities. The unique challenges faced by those with developmental disabilities are not represented. Whether individuals ascribe to Erikson, Piaget, or Chickering, all theories include “normal” development of physical/motor skills or cognitive ability. The effects of a physical and/or cognitive disability will most likely alter this process.

**Maturity.** Using “normal” development based on epigenetic principles as a framework, we can begin to see how a disability may impact the maturation process.

While some limitations may be due to the disability, others are the result of external physical and attitudinal barriers that impair equal access to experiences in the environment during crucial developmental periods and throughout the lifespan.

Cole makes a direct connection between developmental challenges faced by children and sexual development:

In many situations, chronological age of the child will not be consistent with the maturational or emotional age. Many factors can influence this delay—mobility limitations which require a great deal of physical assistance in all or many activities, lack of privacy, including the area of personal hygiene, and other daily living experiences which can interfere with spontaneous learning about sexuality... A congenitally disabled child can experience a great lack of privacy due to excessive personal care needs and perhaps unrealistic assistance or protection from family who wish to protect the child from emotional injury by an insensitive society. The child may experience isolation from peers because interaction takes organization, planning, effort, and assistance. Mobility limitations and lack of privacy are significant factors in alerting or limiting natural sexual development, education, and values.<sup>15</sup>

In addition to being overly protected by family, isolated from peers, and mobility-impaired, those with disabilities may have difficulty learning, may have limited genital and other tactile sensations, may have communication problems, and may be uncertain about their sexual function and fertility status.<sup>16</sup> Poor body image and self-conception also limit natural sexual development. Issues that may hinder the development of a healthy body image and self-conception include:

- Use of braces, crutches, wheelchairs, and other assistant devices
- Bladder and bowel management routines/ostomies and other collective devices
- Physical differences from peers, including underdeveloped limbs and atrophy

- Diminished gender-role expectations from society (being treated as asexual)<sup>17</sup>
- Mistrust of own body

It becomes easy to see how growing up with a disability creates roadblocks to establishing a firm sexual identity and healthy relationships for those with disabilities.

**Typology.** Taking these factors into consideration, Cole and Cole developed a typology for purposes of a construct of disability and sexuality for people with early-onset physical disabilities, suggesting important differences that may affect the developmental process.<sup>19</sup> They grouped these disabilities into categories, depending on the age of onset and the progressive or stable nature of disability. Those that begin before puberty and are not progressive are classified as a *Type I Disability—Preadolescent Nonprogressive*. People with Type I disabilities experience a lifetime of being different from their nondisabled peers:

Protective or guilt-laden attitudes by society or parents may have an inhibiting effect on sexual maturation. They may be deliberately or inadvertently deprived of important adolescent experiences. Such individuals may emerge from adolescence with maturational deficits and lack of social skills. They may find themselves in an adult world, wanting to be sexual but lacking the requisite education.<sup>20</sup>

By tracing the development of a child with physical disabilities such as spina bifida from early infancy through young adulthood and incorporating various developmental theories and models, we can begin to get a better idea of his or her specific developmental needs. Because Erikson's psychosocial stages of development are well recognized and widely accepted, I will use them as a framework for discussion of the development of children with physical and/or mental disabilities, further dividing Erikson's Stage 6—puberty and adolescence—into early adolescence and adolescence.

### EARLY INFANCY (BIRTH TO 1 YEAR)

According to Erikson, the first developmental crisis any human being faces is that of trust versus mistrust. Successful resolution of this crisis results in hope, the first psychosocial strength. Hope is the enduring belief in the attainability of primal wishes in spite of the anarchic urges and rages of dependency. The resolution of this crisis is performed primarily by maternal care. If the child receives affection and has needs promptly satisfied, he or she will develop a sense of trust and the basis for hope. During this exchange,

the child's demeanor also inspires hope in adults. Unavoidable pain and delay of satisfaction make this stage prototypical for a sense of abandonment.<sup>21</sup>

The establishments of trust and hope between parent and child may be hampered from the very start when a child is born with a disability. The child may face unavoidable pain and delay in satisfaction in the form of surgery, medical treatment, and hospitalization. This adds an extra burden to the development of a sense of trust and hope. The parents' hopes for their child are often shattered when they learn their child will have a physical and/or mental disability.

### TODDLER YEARS (1 TO 2 YEARS)

During the toddler years, the unimpaired child begins to creep, then crawl, then finally walk. He or she is toilet trained, learns to interact verbally, and starts to play. Rapid gains in muscular maturation, locomotion, verbalization, and discrimination set the stage for the child to develop a sense of either autonomy or shame and doubt. Erikson states that "a sense of self-control without loss of self-esteem is the ontogenetic source of confidence in free will; a sense of over-control and loss of self-control can give rise to a lasting propensity for doubt and shame."<sup>22</sup>

The child with a physical disability may have paralysis of the lower limbs that interferes with or totally interrupts the process of learning to walk. Without the ability to move about freely, the child is at a developmental disadvantage. According to pediatric physiatrist Lurna Wilner, unless parents and rehabilitation specialists adapt ways for the child to move about and experience his or her environment in different ways, the child may experience delays in speech and language skills and in his or her ability to learn. The child with a disability often has less access to experiences throughout all developmental stages.<sup>23</sup>

In addition, a child with a physical disability that includes neurological impairment of bowel and bladder function may experience a delay in toilet training, sometimes indefinitely. The child may never gain voluntary control of these functions, and may depend on others to catheterize him or her and/or to change his or her ostomies and/or protective undergarments throughout his or her adolescent years. Thus, the child with a disability has fewer opportunities to develop a sense of autonomy. For some, this may result in compulsive over-compliance or impulsive defiance.<sup>24</sup>

### EARLY CHILDHOOD (3 TO 5 YEARS)

Erikson sometimes refers to this period as the "play age."<sup>25</sup> The developmental crisis during this time is initiative versus guilt. The unimpaired child is able to move about independently and vigorously and begins to develop an increased sense of expected gender roles and the differences in

genders. The child tries new roles, including gender-role identity conveyed by parents, and social roles and norms of behavior. For this reason, these years are often called the “years of magic.” Although the child’s ability to think logically is growing, the child still makes heavy use of his or her imagination in reasoning.<sup>26</sup>

The child with a disability is at a competitive disadvantage when it comes to options for play, which can hinder initiative and sense of purpose. The child with a disability, socialized into a disabled, asexual role, does not receive the same messages as his or her nondisabled peers, which may slow the development of his or her sexual curiosity and imagination.<sup>27</sup>

### MIDDLE CHILDHOOD (6 TO 11 YEARS)

School is the predominant force at this stage in life. A child begins to receive formal instruction in the skills needed to prosper in society. He or she may also have more opportunities to interact and learn from other children. Freud referred to this stage as the “latency period.” Others have demonstrated, however, that children are highly interested in sexual matters.<sup>28</sup> At this age, children learn a great deal from their playmates about sex. Because of lack of privacy and isolation from peers, the child with a disability often misses out on these important opportunities to gain sexual information.

Piaget pointed to the development of knowledge at this stage as opposed to learning. He said that knowledge is gained through life experiences as opposed to formalized learning. The child begins to develop a sense of altruism and begins to understand the feelings of others. The child with a disability has fewer opportunities to gain knowledge than children without disabilities.<sup>29</sup>

The Eriksonian crisis here is industry versus inferiority, with industry leading to a sense of competence. Erikson warns that the danger of this stage lies in the development of a sense of inadequacy. “If the child despairs of his skill or his status among his school partners, he may be discouraged from learning.”<sup>30</sup> The child with a disability often has difficulty learning or has an impaired mental capacity. Difficulty in learning can set him or her up for developing a sense of inferiority. Societal influences also gain importance. If the child learns through experience that his or her disability will determine his or her opportunities in society, he or she may begin to internalize a feeling of unworthiness. This child is at special risk of developing “learned hopelessness,” believing that personal failures are caused by his or her lack of ability and cannot be remedied.<sup>31</sup>

During this stage of development, friendships are of primary importance. Egocentrism is on the decline while intimacy and a renewed sense of self are on the rise.<sup>32</sup>

### EARLY ADOLESCENCE (12 TO 14 YEARS)

Early adolescence is marked by the onset of puberty. The maturing youngster begins to undergo rapid physical and emotional changes and becomes concerned with his or her psychosocial identity. He or she needs education about pubertal issues at this time.

Early adolescents begin the process of separating from family and establishing connections with peers. There are increasing sexual attractions. The early adolescent begins to ponder what is logically possible for his or her life. The early adolescent develops an erroneous “belief that others are pre-occupied with his [or her] appearance and behavior.”<sup>33</sup> This egocentrism results in self-consciousness and a need for greater privacy and independence. This leads him or her to the compelling question, “Am I normal?”

A young person who is different because of a disability may become more aware of his or her differences at this stage. A person with a disability who requires a lot of personal care from parents or caregivers may not succeed in separating from family and achieving independence. The need for privacy becomes a central issue.

The early adolescent is just beginning to think abstractly but is still curious about sexual facts. Possible questions may include: “Why do some girls have their period at 10 and others do not have it until 13 or 14?,” “What is a wet dream?,” “Is it okay if I don’t have one?,” “What do *heterosexual* and *homosexual* mean?,” “What is oral sex?” The early adolescent with a disability may also wonder: “Can I have sex?,” “Can I have children?,” “Will I have a baby with a disability like mine?”

### ADOLESCENCE (15 TO 18 YEARS)

During this stage, the adolescent is continuing to develop a sense of “Who am I?” and “What am I capable of doing?” His or her conflict is between identity and identity confusion, with fidelity the particular psychological strength that he or she seeks. According to Erikson, fidelity is:

...the opportunity to fulfill personal potentialities (including erotic vitality or its sublimation) in a context which permits the young person to be true to himself and true to significant others. “Falling in love” also can be an attempt to arrive at a self-definition by seeing oneself reflected anew in an idealized as well as eroticized other.<sup>34</sup>

Erikson points out that adolescents in this stage can be clannish and cruel in their exclusion of all those who are different. This exposes a child who uses a wheelchair or braces or who is still wearing diapers at serious risk of being excluded.

According to Piaget, the adolescent is also developing formal reasoning and moral development.<sup>35</sup> The middle

adolescent (13 to 17 years of age) has begun to establish a separate identity from parents, is strongly influenced by peers, is striving for independence, is idealistic and altruistic, is interested in dating, is establishing his or her own values, is experimenting sexually, falls in love intensely, and continues to develop abstract thinking.

The late adolescent (16-plus years of age) has achieved at least some independence from parents; has established a more stable body image; loves more realistically; chooses friends more selectively; has developed a framework of values, morals, and ethics; thinks abstractly; is defining life goals, careers, and relationships; and, perhaps most important to him or her, is driving.

Sexual topics of interest include dating, relationships, sexual activity, contraception, abortion, and safe sex. Questions include: "How am I going to get a date if I can't drive?," "Why won't so-and-so go out with me?," "How do I know if so-and-so really loves me?," "Is it okay to go all the way if so-and-so does?," "Can someone with a disability have sex?," and "How does sex work if you have a disability?"

### YOUNG ADULTHOOD (19-PLUS YEARS)

According to Erikson, the young adult is ready for intimacy and solidarity. Inability to form intimate bonds results in isolation, and success results in love. "True genital maturity is first reached at this stage; much of the individual's previous sex is of the identity-confirming kind."<sup>36</sup> In the case of the young adult with a disability, the issue is less an avoidance of contacts that commit to intimacy than one of others avoiding intimate contacts with him or her.

Questions regarding sexuality may include: "How do we move a relationship from friendship to romance?," "How do I tell someone about my ostomy without having him or her reject me?," "How do I protect myself against HIV and STDs in the face of a high rate of latex allergies?," and "When is it time to get married?"

### DEVELOPMENTAL LESSONS

According to Sanford, "development involves an upending which brings about new, more differentiated responses. However, if the challenge or disequilibria is too great, the individual will retreat; if the supports are too protective, the individual will fail to develop."<sup>37</sup> Finding the right balance for a child with a disability is not a simple task. A developmentally based introduction to sexuality education for teenagers with disabilities should promote maturation as a

sexual person and provide an opportunity to develop social skills. In customizing a program, specific attention should be placed on sexual questions and concerns specific to disability.

### ROLE OF PARENTS

As mentioned earlier, the child with a disability is often more protected than a child without a disability by parents or family members who wish to shield the child from emotional injury by an insensitive society. Cole and Cole point out that the family's efforts to protect the child from rejection or exploitation may lead to avoidance of the topic of sexuality and normal family interactions.

The child may thus be insulated from exposure to sexual situations and may be thought of by peers as "less than" other children. The gaps in sex education of a child may lead to problems that can become insurmountable in later years. Parents, in turn, may be isolated by the child's fear of admitting ignorance or of revealing fantasies and concerns.<sup>39</sup>

Cole and Cole suggest that the parents may not understand the critical importance of information itself. Being overprotected by family or infantilized can contribute to stunting the sexual maturation and development of appropriate social skills for the adolescent with a developmental disability.

While much of the physical care the child with a disability may need necessary, denying a child's sexuality can be helped. Parents of children with disabilities are members of a society that still holds many myths surrounding sexuality and disability, and they are not immune to these myths. Cole and Cole state that:

Parents should be encouraged to learn and teach their disabled children about sexuality at an early age in order to provide them with information, decision-making and risk-taking skills which will enable them to more fully experience natural sexual development in an insensitive society. Parents of adult disabled persons need to view their children as sexual individuals. This perception will validate the sexuality of the disabled family member and may be one step to removing a barrier or social restriction.<sup>40</sup>

Considering what we know about some of the medical aspects of disability, the psychosocial developmental issues, the social and environmental issues, and the parental issues, I will lay out the blueprint for a lesson plan that is developmentally appropriate for young people with disabilities.

*"Sexuality education for teenagers with disabilities should promote maturation as a sexual person and provide an opportunity to develop social skills."*

## THE LESSON PLAN

This lesson plan was originally created for a one-and-a-half hour workshop addressing the questions and concerns of 40 to 50 young people ranging from 12 to 24 years of age, all with spina bifida. It addressed sexuality issues they would face from childhood through adolescence to young adulthood.

It would have been developmentally inappropriate for one educator to work with such a large group of young people with spina bifida that spanned several developmental stages and various levels of learning abilities. People who have difficulty learning need the eye contact and close supervision available in small groups.

Because of their wide range of ages and abilities, I recruited volunteer sexuality educators from the Program in Human Sexuality Education at the University of Pennsylvania Graduate School of Education to serve as facilitators. I assigned each to a small group of individuals of the same age and made certain each educator was capable of discussing sensitive sexual issues and prepared to provide information on anatomy, physiology, socialization, privacy, appropriate and inappropriate touch, refusing unwanted sexual activity, and the basic language of sexuality as recommended by Cole and Cole.<sup>41</sup> The key messages that each educator relayed was that all people are sexual and sexual feelings are natural.

I built the lesson plan around developmental models without disabilities, specifically, Chickering's seven vectors of development. I then applied the model to young people with disabilities and focused on helping them develop competence and establish identity. Specifically, I focused on providing them knowledge of sexuality, interpersonal or social competence through the development of basic interactive or communication skills, the establishment of sexual identity through perceptual and attitudinal change, and coming to terms with one's physical and sexual self.

Arriving at an accurate, realistic picture of self seems to encourage experimentation in the realms where decisions are required: relationships, purpose, and integrity.<sup>42</sup> Developing competencies and establishing sexual identity help to impel the student to establish healthy relationships.

Along these lines, Kempton suggests that the ultimate goal of sexuality education is the positive perception of individual sexuality.<sup>43</sup> Cole and Cole recommend that the goals of education should focus on social abilities.<sup>44</sup> "A good sex education program generates confidence by developing self-understanding, thereby promoting a better self-image."<sup>45</sup>

## GOALS

This lesson plan was designed to help the participants achieve three interrelated goals.

**Knowledge: Early adolescents, adolescents, and young adults with disabilities will increase their knowledge of**

**human sexuality.** The rationale behind this goal is to compensate for the limited access that these young people have to sexuality information and sexual experiences as compared with their nondisabled peers. Cole reports that women with disabilities may have special concerns regarding sexuality, sexual functioning, and sexual health—partly because they may have physical differences from nondisabled women and partly because their circumstances may have prevented them from acquiring basic sexuality information and education when they were developing.<sup>46</sup> The same concerns hold true for men with disabilities. Young adults with disabilities will advance their sexual development when they acquire information about sexuality.

**Attitude: Early adolescents, adolescents, and young adults with disabilities will affirm their identity as sexual people.** This goal is important because young people with disabilities often may have greater difficulty establishing sexual identities.<sup>47</sup> Too often, they are first identified with their disability. Cole notes that "if a disability is congenital (such as spina bifida), then the child from birth or early childhood will integrate this disability into all aspects of sexual development."<sup>48</sup> By providing these young people with sexuality information, we can begin to affirm their sexual identity. This will help them to dispel myths about sexuality and disability (and asexuality) and to encourage them to develop their sexual potential. Sexuality is not dependent on the ability to walk, to control the bowels and bladder, or to learn. Each human being is inherently sexual and has the capacity to love and be loved, both physically and emotionally.

**Behavior: Early adolescents, adolescents, and young adults with disabilities will increase their social and interpersonal competence.** Social and interpersonal competence is a prerequisite for establishing healthy sexual relationships. Children who grow up with disabilities are often deprived of opportunities to develop such competence because of their limited access to sexual experiences. Such development is slowed through lack of privacy to be sexual because of personal care needs, overprotection from parents, and isolation from peers because interaction requires organization, planning, and assistance.<sup>49</sup> The lesson plan provides them with the opportunity to develop these social skills.

## BEHAVIORAL OBJECTIVES

The lesson plan incorporates measurable behavioral objectives. The purpose of the objectives is to expand the concept of sexuality beyond sex and intercourse so that these individuals (1) will realize that they are sexual regardless of their ability to have sexual intercourse; (2) will develop language skills so they can discuss sexuality with parents, health providers, and peers; (3) can assess their own attitudes about people with disabilities while dispelling

myths about sexuality and disability; and (4) will have an opportunity to practice interpersonal communication skills.

### COLLABORATIVE LEARNING

The lesson plan is based on the philosophy of collaborative learning. Such learning is experiential, active, student-centered, and interdependent. It provides a level of stimulation needed by young people with disabilities, many of whom have attention deficits and difficulty learning. In a collaborative learning environment, everyone's contribution is valued and is important to the educational process. This helps contribute to the development of a student's self esteem. A high level of student-student and student-teacher interaction also provides opportunities for students with disabilities to improve their social and communication skills on the subject of sexuality. At the same time, this helps the students to develop active listening and feedback skills.

### METHODOLOGY: THE 4-I MODEL

The lesson plan was developed based on the "4-I" model, which allows young people to learn who they are and how they relate to others, in four stages: (1) initiation, (2) interaction, (3) investigation, and (4) internalization.

**Initiation.** During this stage, the facilitator starts with a warm-up exercise to help the group distinguish between *sex* and *sexuality*. He or she then reviews the subject matter and encourages individual interaction to help the young people acquire information to begin to explore their feelings.

This may include a "Clap Your Hands" warm-up session during which individuals are asked to clap if they agree that they ever wished they could drive, had a crush on someone, had a sexual fantasy, felt rejected, wished their body were different, got a hug that made them feel good, had to kiss a relative they did not want to, wished it was easier to get a date, had a question about sex but were afraid to ask, wished they had more privacy, had a sexual feeling that felt good, wished people would stop treating them like a child, wished life were more spontaneous, wished they could pee like everyone else, loved someone, felt proud, and so forth.

In the process, the facilitator asks them to discuss sexuality, sex, feelings about themselves, feelings about others, relationships, dating, kissing, hugging, and intercourse, among other things.

**Interaction.** During this stage, the facilitator divides the group into small discussion groups. Groups of eight to 10 people are usually small enough to allow all individuals to participate without difficulty and learn from everyone's perspective. Smaller groups may prove necessary if many individuals have a high level of cognitive impairment.

Once they are in the small discussion groups, the students are divided into pairs and asked to interview each

other, including where they come from and what they hope to learn. They then introduce their partners to everyone. This helps them to know each other and gently eases them into discussion around sexual issues. After the students finish their introductions, the facilitator reviews a sexuality questionnaire that was handed out earlier in the day and polls group members on their true/false answers to the questions. Students then discuss their differences of opinion on questions that are of most importance or that generate a lot of disagreement.

Through this process, the facilitator can assess the group's knowledge. At the same time, the students have the opportunity to develop their confidence in discussing sexuality issues with peers and adults. Practice in communicating is a vital goal of this stage because it is through such practice that the students will develop a more realistic understanding of their own sexuality and an appreciation of the other and same gender.

**Investigation.** After group discussion of the questionnaire, the facilitator shifts to investigation and asks each group member which question generated an interest for more information. The facilitator also raises questions about any myths or misinformation, and invites discussion on sexual concerns beyond the questionnaire topics.

Throughout this stage, the subject should be dealt with in a manner which helps young people to begin to think through their attitudes toward sexuality and how these attitudes relate to their personal value systems.

**Internalization.** At this final stage of the session, the facilitator summarizes and evaluates goals. He or she also encourages students to think of personal situations to which they might apply their new knowledge and attitudes. Because of limited time, this is accomplished in a wrap-up period, during which each student is given the opportunity to share something he or she learned. Additional feedback is requested through an evaluation.

### CONCLUSION

Sexuality educators interested in developing lessons for disabled individuals should realize that the lesson plan in this article is just a start. For my own use, I have adapted and expanded the lesson plan to create a six-session workshop titled *Relationships, Purpose, and Integrity in the Lives of Young People with Disabilities*® held each year for young adults with various disabilities (including physical, cognitive, and sensory impairments) who participate in the Mentoring Project for Persons with Disabilities at the YWCA in New York City. The six sessions work together to:

- Ensure that all participants have a basic understanding of sexuality, sexual anatomy and physiology, and the possible effects various disabilities may have on sexuality

- Affirm participants' status as sexual beings worthy of love, relationships, and self-protection
- Improve participants' ability to negotiate privacy, make dates, and establish meaningful relationships
- Ensure that participants have an understanding of their sexual rights and how to minimize physical and emotional risks of sexual expression
- Critically examine messages received from the media and other sources about body image
- Critically examine messages received from the media and other sources about gender roles

I hope other sexuality educators will use the ideas in this article to design their own lessons to help individuals become sexually able, even in the face of disability. I believe that students of all abilities can benefit from such focused and experiential learning.

Dispelling myths, providing a solid foundation in human sexuality and relationships, adding disability-specific information, and providing opportunities for individuals to build communication skills in a developmentally suitable manner is a true prescription for sexual health.

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## DEAF STUDENTS USUALLY LACK SPECIALLY-DESIGNED SEXUALITY EDUCATION CURRICULA

*Dr. Yvette Getch of the University of Georgia's Department of Counseling and Human Development Services has extensively studied the need for specialized sexuality education curricula for students who are deaf. This article is based on a recent conversation where she discussed this need based on her findings. —Editor*

### **Q: Why are students who are deaf not as knowledgeable about sexuality-related issues?**

**A:** Unlike their hearing peers, many students who are deaf do not have the opportunity to learn about sexuality by overhearing their parents, watching (and listening to) television, or reading materials. In addition, their first language is American Sign Language (ASL) rather than English. Most sexuality education materials are written for an eighth-grade reading level while most students who are deaf read English at or below a fourth-grade level.

Several studies indicate that students who are deaf can name significantly fewer internal body parts than their hearing peers. They typically lack knowledge about human anatomy, birth control, sexually transmitted diseases (STDs), emotions, and responsibilities in relationships. Although they appear to have a general knowledge of HIV/AIDS, they have little knowledge of its transmission and the behaviors that cause risk for HIV infection.

### **Q: Can't deaf students learn from curricula developed for hearing students?**

**A:** Videotapes developed for hearing students are also not very accessible to students who are deaf. These students often don't have the skills to read captions, they have difficulty watching the action while simultaneously reading closed captions, and, they have difficulty watching an ASL interpreter and a video at the same time.

### **Q: What are teachers doing?**

**A:** The most recent survey in which I participated showed that over half of the responding teachers spent one to two hours per week modifying materials for their students who are deaf and that 27 percent spent three to four hours per week. Ninety percent of the teachers said they used visually-based materials but most reported they were "verbally loaded." Eighty-two percent said they used written texts or workbooks and 50 percent used videotapes signed in ASL. Over 80 percent reported using videotapes, overheads, diagrams/charts, handouts, and written materials. Nearly 90 percent of teachers said that they would like to see more materials on videotape with persons who are deaf discussing relationships and other sexuality issues.

### **Q: What needs to be done?**

**A:** First, teachers need access to a comprehensive list of sexuality materials they can use with their students who are deaf. This would help them when they are ordering materials and developing sexuality education curricula for these students. If a comprehensive curriculum were developed that was specifically designed for students who are deaf, teachers would be able to quickly access materials that needed little modification.

**Editor's note:** Additional information is available in these two surveys: (1) "Sexuality Education for Students Who Are Deaf: Current Practices and Concerns" by Yvette Q. Getch, Mike Young, and George Denny, *Sexuality and Disability*, vol. 16, no. 4, 1998, and (2) "A Sexuality Curriculum for Deaf Students: A Cause for Concern and Action, by Yvette Q. Getch and Kamielka O. Gabriel, *Deaf Worlds*, vol. 14, no. 2, 1998.

# PARENTS AS SEXUALITY EDUCATORS FOR THEIR CHILDREN WITH DEVELOPMENTAL DISABILITIES

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**H**istorically, the sexuality of individuals with developmental disabilities has been both feared and denied. For centuries, numerous myths prevailed, alleging that people with developmental disabilities were asexual, oversexed, sexually uncontrollable, sexually animalistic, subhuman, dependent and childlike, and breeders of disability.<sup>1</sup>

Despite research that contradicts such myths, parents of children with developmental disabilities are still susceptible to these falsehoods; it is, therefore, not surprising that many experience anxiety regarding their children's sexual development and expression.<sup>2</sup>

## PARENTAL CONCERNS

Although parent groups frequently have been the first to advocate for sexuality education for their children with developmental disabilities,<sup>3</sup> few parents are adequately preparing their children for the socio-sexual aspects of life.<sup>4</sup>

Parents of children with developmental disabilities tend to be uncertain about the appropriate management of their children's sexual development.<sup>5</sup> They are often concerned with their son's or daughter's autoerotic behavior, overt signs of sexuality, physical development during puberty, and genital hygiene.<sup>6</sup> Fears of unwanted pregnancy, STDs, and embarrassing or hurtful situations are persistent realities.<sup>7</sup>

Some parents of children with developmental disabilities also fear that their children will be unable to express their sexual impulses appropriately, will produce children (thereby adding unwelcome responsibilities), and will be targets of sexual abuse or exploitation.<sup>8</sup> Parental anxiety over sexual exploitation often results in overprotection, thus depriving children with developmental disabilities of their sexual rights and freedom.<sup>9</sup> To alleviate fears and anxiety, parents may suppress their children's sexuality, and thus fail to equip them with the knowledge to deal appropriately with the sexual experiences they will encounter.<sup>10</sup>

The problem most frequently mentioned by parents regarding sexuality education is an inability to answer questions.<sup>11</sup> They are also often uncertain of what children know or should know.<sup>12</sup> Parents fear opening a Pandora's box of problems for themselves and their children by talking.<sup>13</sup> They often equate learning with intentions to perform sexual activities.<sup>14</sup> Professionals have found that parents have confused, anxious, and ambivalent attitudes

toward the sexuality of their children and that they claim both limited knowledge of sexuality and feelings of inadequacy in providing information.<sup>15</sup>

Through professional guidance, support, and education, mothers and fathers can gain a clearer understanding of their son's or daughter's sexuality. To assist parents with their role as sexuality educators, professionals should debunk popular misconceptions about sexuality and disability, provide information on children's psychosexual development, and address strategies to promote appropriate childhood behavior through comprehensive sexuality education.

## DEBUNKING MYTHS

Myths concerning sexuality and people with developmental disabilities stem from various beliefs. Some believe these individuals need protection from their sexuality because they appear dependent and childlike. Others believe that those with developmental disabilities must not be exposed to sexuality because they are lifelong children.<sup>16</sup> Still others perceive people with developmental disabilities as "sexually innocent" individuals who do not possess the maturity to learn about sexuality.<sup>17</sup> In reality, maturity occurs within several matrices: intellectual, physical, social, emotional, sexual, and psychological.<sup>18</sup> People with developmental disabilities are capable of maturing, even when one or two matrices are delayed.

The pervasive myth regarding the asexual nature of people with developmental disabilities originated from the belief that individuals who are disabled in one way are disabled in every way.<sup>19</sup> Many assume that a person who is developmentally disabled is also socio-sexually disabled.<sup>20</sup> Regarding people with developmental disabilities as asexual is also based on the rationale that these individuals are not fully human,<sup>21</sup> and therefore sexuality is of no concern. In essence, the person with developmental disabilities is regarded as a neuter who does not possess the same needs, desires, and capabilities of other individuals.<sup>22</sup> Research shows, however, that there is little or no difference between the sexual desires and interests of people with developmental disabilities and the nondisabled.<sup>23</sup>

A contradiction to the myth of asexuality is the myth perhaps most detrimental to this population: that people with developmental disabilities are oversexed and possess uncon-

trollable sexual urges. This myth accuses men with developmental disabilities of being sexually aggressive and women with developmental disabilities of being sexually promiscuous.<sup>24</sup> The frequency of sexual activity, however, is actually lower among people with developmental disabilities than in their nondisabled peer groups.<sup>25</sup>

The above myth is based on the assumption that the sexual drive of individuals with developmental disabilities is often uncontrollable due to a lack of sexual opportunities. This belief may be attributed to the increased likelihood that this population will participate in inappropriate, nonassaultive sexual behavior such as public masturbation<sup>26</sup> or that they will exhibit unacceptable social behaviors such as disrobing in public or wearing inappropriate clothing.

These actions are often regarded as demonstrating a lack of inhibitions and an indication of immoral behaviors; however, they are typically the result of a wish to please, limited judgment in social situations, and a lack of comprehensive sexuality education.<sup>27</sup> Such inappropriate sexual behaviors are also due to isolation, segregation of the sexes, and sexual ignorance.<sup>28</sup>

The majority of adults with developmental disabilities are not significantly different from nondisabled adults in the exploration and control of their sexual impulses.<sup>29</sup> Many behaviors viewed as deviant in people with developmental disabilities are considered appropriate for the general public. Thus, sexual behaviors that are considered problems for people with developmental disabilities may actually be normal sexual behaviors.<sup>30</sup> The perception that normal sexual behavior is deviant sexual behavior in this population has encouraged parents to believe that any interest in sexuality among people with developmental disabilities is an indication of perversion.

Some believe the sexuality of people with disabilities is animalistic. Thus, people with disabilities are often suspected whenever a sex crime is committed.<sup>31</sup> Society believes that the rate of sexual offenses among people with developmental disabilities is higher than that of the general population. Most studies do not, however, support this belief.<sup>32</sup> When people with developmental disabilities are arrested, there is an increased likelihood that the offense is of a sexual nature.<sup>33</sup> Their actions are, however, often due to lack of information and training as opposed to malicious intent.<sup>34</sup> They may also be due to the fact that people with developmental disabilities have restricted or limited opportunities to engage in normal, appropriate sexual behaviors.<sup>35</sup> Without opportunities for sexuality education and appropriate sexual expression, people with developmental disabilities will engage in inappropriate

sexual behavior often resulting in remittance to institutions or prison.

Finally, there is the myth that sexuality education will cause people with developmental disabilities to become overly stimulated and to engage in sexual activity when normally they would not.<sup>36</sup> This myth is based on the belief that sharing information will unleash desires and conflicts that would otherwise have remained dormant<sup>37</sup> and that knowledge will trigger uncontrollable and insatiable urges.

There are no empirical data to support the belief that sexuality education will result in experimentation among

people with developmental disabilities or motivate adolescents to engage in sexual activity.<sup>38</sup> Rather, sexuality education acts as a deterrent by teaching responsibility and control.<sup>39</sup> Studies have shown that sexuality education conducted by trained individuals who provide accurate information reduces inappropriate sexual behaviors by people with developmental disabilities.<sup>40</sup>

Myths about the sexuality of people with developmental disabilities have led to individuals avoiding, ignoring, discouraging, or distorting the sexual concerns of this population.<sup>41</sup> As a result, people often view the sexuality of individuals with developmental disabilities

as problematic rather than as a positive human attribute.<sup>42</sup>

*“Many assume that a person who is developmentally disabled is also socio-sexually disabled.”*

## PSYCHOSEXUAL DEVELOPMENT

Children with developmental disabilities may learn at slower rates than their nondisabled peers, but their physical maturation typically occurs at the normal stages of development. The sexual maturation of children with disabilities does, however, have some noted differences. As a result, their parents need to understand what to expect at different stages of psychosexual development, from infancy onward, in order to understand the appropriateness of their children's sexual behaviors and expression.

Infants possess the physiology for arousal and orgasm and the capacity for a variety of sexual behaviors beginning at or before birth.<sup>43</sup> During infancy, the experience of sucking and being cradled is of critical importance to the child's sexual development.<sup>44</sup> When infants have a developmental disability, this experience may be delayed or restricted due to their medical needs.<sup>45</sup> When infants have a disability that interferes with their capacity to give appropriate cues to their parents, parental bonding and subsequent attachment are often inhibited.<sup>46</sup> Regardless of their level of bonding and stimulation, infants with developmental disabilities demonstrate delays in distinguishing body feelings from other feelings, in differentiating among parts of the body, and in engaging in distinctive genital sexual play.<sup>47</sup>

As children with developmental disabilities move from infancy to the toddler and preschool years, a myriad of issues emerge concerning psychosexual development. Toilet training often occurs at a later age and over a longer period of time, thus causing delays in their developing self-control and a sense of self.<sup>48</sup>

The sense of self of children with developmental disabilities is further delayed as a result of an elongated period of dependency on parents or caregivers for personal care and hygiene. This often leads to their inability to differentiate between the sexual and nonsexual parts of their bodies. As a result, children with developmental disabilities may not firmly understand body ownership since they are not allowed to *own* even the nonsexual parts of their bodies.<sup>49</sup>

Such lack of body ownership may result in children with developmental disabilities being confused about their sexual selves. This developmental lag in distinguishing the self as separate from parent/caregiver is reflected in the delayed rate at which children develop perceptions of themselves as either boys or girls.<sup>50</sup> At later developmental stages, children with developmental disabilities are able to self-identify as male or female and to develop sex-role identity.

Upon reaching preschool age, children with developmental disabilities exhibit a heightened level of curiosity about others and about sexual differences between males and females. Their curiosity is, however, less intense than their nondisabled peers.<sup>51</sup> Children with developmental disabilities may not be allowed to resolve their curiosity due to prolonged supervision. At this stage of psychosexual development, they often experience problems differentiating between private and public places and actions<sup>52</sup> and therefore may engage in publicly unacceptable sexual behaviors. Children with developmental disabilities are often unaware of what sexual behaviors are appropriate due to limited social interactions and lack of opportunities to observe or model behaviors of their nondisabled peers.<sup>53</sup>

As a result of the media and their peers, children with developmental disabilities confront the school years with an increased awareness of their sexuality.<sup>54</sup> However, during this time, their social activities remain closely supervised, and normal sexual expressions of behavior are often discouraged.<sup>55</sup> They tend not to ask questions about sexuality, but when they do, they often articulate the questions poorly due to an undeveloped sexual vocabulary.<sup>56</sup> At this stage of their sexual maturation, children with developmental disabilities frequently masturbate. Parents of these children have reported that their children between the ages of six and ten “frequently” touch their genitals.<sup>57</sup> Children with developmental disabilities are often overcorrected for masturbating,<sup>58</sup> and later may experience guilt and uneasiness.

The sexual development of older children with

developmental disabilities is varied. The majority exhibit normal development,<sup>59</sup> others show delayed development, and some have little or no development of secondary sexual characteristics.<sup>60</sup> Typically, when children experience normal physical maturation, their sexual development follows chronological rather than cognitive development.<sup>61</sup> They experience difficulties with sexuality when their physical development does not correspond to their intellectual and social growth.<sup>62</sup>

It should, therefore, not be surprising that children with developmental disabilities experience adolescence in the same way as nondisabled children. During adolescence, all children, whether they have disabilities or not, should learn to strengthen their sense of identity and secure a measure of independence.<sup>63</sup>

Research indicates that adolescents with developmental disabilities have gender-role preferences similar to their nondisabled peers.<sup>64</sup> These preferences are most similar when the adolescent with developmental disabilities resembles his nondisabled peer in overall functioning.<sup>65</sup> Adolescents with developmental disabilities develop gender identities similar to adolescents without developmental disabilities.<sup>66</sup> The development of a socio-sexual identity for adolescents with developmental disabilities is, however, often hampered by the commonly experienced rejection by their nondisabled peers and their dearth of social opportunities to interact with members of the opposite gender.<sup>67</sup>

The majority of adolescents with developmental disabilities reach puberty chronologically on schedule despite delays in acquiring social awareness.<sup>68</sup> Girls begin the pubertal process between eight and 12 years of age, while boys begin the same process approximately two years later.<sup>69</sup>

Delays in the onset of puberty are primarily seen in adolescents whose developmental disabilities are prenatal or genetic in origin.<sup>70</sup> However, a small percentage of adolescents who have severe and profound disabilities also experience significant delays in sexual development.<sup>71</sup> Particular syndromes uniquely impact the onset of puberty, specifically among adolescent females. For example, research shows that adolescent females with Down syndrome reach puberty earlier than girls with other developmental disabilities.<sup>72</sup> Females with Prader-Labhart-Willi syndrome, however, experience late or absent menarche.<sup>73</sup> Adolescent females with hydrocephalus, regardless of the etiology, often experience precocious puberty.<sup>74</sup>

Adolescents with developmental disabilities experience sexual desires and interests even though they may not be informed about their emerging sexuality. The young person’s interest in sexual activity will tend to decrease as the severity of the developmental disability increases.<sup>75</sup>

Adolescent females with developmental disabilities who appear overly interested in sexual activity are often seeking

attention and may attempt to mimic the seductive behaviors they see depicted on television and in films. These behaviors may lead to sexual involvement due to their own desires and their need for approval and affection.<sup>76</sup>

Various behaviors such as participation in sex games, public displays of masturbation, and exaggerated use of makeup typically result from such adolescents yearning to please others, inadequate judgment in social settings, lack of opportunity for legitimate sexual expression, and limited knowledge of sexuality.<sup>77</sup>

To develop an understanding of an individual's sexual development and appropriate sexual behaviors, children and adolescents with developmental disabilities require comprehensive sexuality education.

### PROMOTING APPROPRIATE BEHAVIOR

Children with developmental disabilities establish appropriate sexual behaviors through repetitive learning and modeling. There are several strategies families can adopt to promote healthy sexuality among their children with developmental disabilities. They include:

**Teaching the difference between public and private.** In order to teach children the difference between public and private places and behaviors, parents should demonstrate consistency in their caregiving actions. They should encourage their children to disrobe and dress in the child's bedroom or bathroom with the door closed. By emphasizing privacy, children are taught modesty. Parents can demonstrate privacy by knocking on their children's doors before entering and pulling down the shades before their children disrobe.

**Teaching independence.** Parents should encourage their children to be responsible for their personal care and hygiene. They can encourage independence by allowing their children to wash their own genitals and wipe themselves after using the toilet. And when parents know their children need help, they should ask their permission. Such independence also allows children to gain a sense of body ownership.

**Teaching socialization.** Parents should schedule social outings where their children can interact with their peers. By understanding societal norms through increased social interactions and opportunities to observe appropriate conduct, children with developmental disabilities will learn to determine what behaviors are acceptable in accordance with time and place. Children with developmental disabilities should also have the opportunity to develop friendships with members of

the opposite gender through socialization in school and in their community. This will enhance their self-esteem.

**Preparation for puberty.** Parents should prepare their children in advance for the onset of puberty and possible bodily changes.

One goal of early female education is to prevent them from fearing the flow of menstrual blood. Menstruation is sometimes very upsetting to females who are not prepared because blood is typically associated with a problem. Young women will need to practice using sanitary napkins. Mothers can use their bodies to show their children about menstrual care. If self-modeling causes embarrassment, anatomically correct dolls and pictures can be used.

Males need information about puberty prior to their first erections and nocturnal emissions. Parents should explain the cause and normalcy of erections, as well as actions to take when an erection occurs in public. (For example, go to a nearby restroom to readjust the penis in private.) Parents also need to explain the difference between semen and urine so their sons will understand "wet dreams."

Parents should teach both males and females about the pubertal changes that occur in the opposite gender.

Other recommendations for parents:

- Assess your attitudes and beliefs before talking
- Recognize your children as sexual beings with emotions and desires
- Consider how you want your children's sexuality education to be similar or different from your own
- Acknowledge that sexuality extends beyond reproduction and intercourse.

Sexuality includes a range of emotions and interactions, including intimacy, love, and affection

- Provide information about sexuality without making the conversation a biology lesson. Nevertheless, use the correct names for body parts
- Use everyday opportunities to teach about sexuality. Do not wait for children to ask questions
- Think about your behaviors that might send messages contradictory to those you are trying to teach
- Develop individualized approaches to your children's sexuality education by tailoring the information to their specific needs
- Help children differentiate thoughts from behaviors. While many thoughts are acceptable, certain behaviors are not

*“Children with developmental disabilities learn more when sexuality information is repeated and reinforced both at home and school.”*

- Clearly communicate your values to your children. By personalizing your reactions, you will help your children remember how you want them to behave

When parents are uncomfortable talking with their children about sexuality, they should consult family planning and disability agencies for guidance and support. They may also want to consult their local public school to discuss sexuality education curricula. Children with developmental disabilities learn more when sexuality information is repeated and reinforced both at home and at school.

## CONCLUSION

As more children with developmental disabilities are included in society, they will require access to sexuality education to help them understand sexual norms.

The dangers of not providing children with developmental disabilities with sexuality education are serious and may result in self-doubt, fear and embarrassment, unacceptable socio-sexual behaviors, social ridicule, unplanned pregnancy, and STDs.<sup>78</sup> Without sexuality education, children with developmental disabilities are precluded from reaching their sexual potential, and their continued ignorance makes them vulnerable to sexual exploitation.<sup>79</sup>

The goal is for parents of children with developmental disabilities to offer sexuality information from early childhood and to continue through adolescence, preparing their children to become sexually responsible and knowledgeable young adults. To accomplish this goal, parents need education and support from sexuality educators and family service providers.

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# SEXUALITY AND PEOPLE WITH PSYCHIATRIC DISABILITIES

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The sexuality of people with psychiatric disabilities has increasingly become the focus of serious local and national research and advocacy. This article addresses the topic by:

- Identifying psychiatric disability and looking at the position that the provision of related services has in the disability rights movement
- Exploring societal and professional treatment of people with psychiatric labels, especially relating to their sexuality
- Discussing research findings that look at intimacy in the lives of a sample of individuals in California with serious psychiatric illnesses
- Reviewing research on barriers to sexual expression among individuals with psychiatric disabilities, along with what is known about their difficulties in using contraception and safer sex
- Describing issues relating to women; gay, lesbian, bisexual, and transgender individuals; and people who are HIV positive
- Suggesting ways in which multiple communities can support the efforts of people with psychiatric disabilities to express their sexuality freely and combat stigmatizing societal representations of their sexuality

## PSYCHIATRICALY DISABLED

Not everyone with mental health problems experiences disability. Individuals with psychiatric disabilities are those who have been labeled with a severe mental disorder as defined in the *Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV)*.<sup>1</sup> Typical Axis I and II diagnoses include severe depression, bipolar disorder (commonly known as manic depression), schizophrenia, personality disorder, posttraumatic stress disorder, and obsessive compulsive disorder, among others.

A diagnosis alone is, however, not enough to define this group of individuals. They also are people with severe levels of symptoms such as psychosis (hallucinations and delusional thinking), obsessions (ideas that one cannot stop thinking about), compulsions (behaviors one cannot stop performing), overwhelming and unpleasant emotions (feeling sad or

anxious most of the time on most days), and cognitive processing difficulties (hearing voices or an inability to concentrate or think clearly).

An individual is considered disabled when his or her symptoms are so severe that they interfere with the individual's ability to function in adult roles, creating difficulties living independently, maintaining employment, completing or advancing in education, and relating interpersonally to others. Some argue that an individual's psychiatric disorder itself is far less important than the disabling environment in which he or she must function.<sup>2</sup> In this view, disability does not stem from the individual's deficits or impairments but from the interaction between these and unsupportive, even hostile, environments.<sup>3</sup>

At the same time, however, people with psychiatric disabilities manifest considerable strengths. These include often being more accepting of difference among other people and more tolerant of diverse and alternative viewpoints. Many are very self-aware given that they receive so much feedback about their emotions and behavior from clinical and social service professionals. Those who have had years of experience with their disability often develop a set of *survivor skills* that stem from being forced to exist on very low levels of income, dealing with a fragmented, often under-funded social service system, and coping with highly inadequate resources. They often are people with a sensitivity to oppression and a strong desire not to oppress others, given their experiences with curtailment of their own civil rights in the name of treatment. Finally, some have a tendency to challenge "accepted reality," asking why things are as they are, and possess the ability to envision alternatives, some of which may make others uncomfortable or uneasy by upsetting the status quo.

## "DISABILITY RIGHTS" MOVEMENT

People with psychiatric disabilities are relative latecomers to disability rights activism.<sup>4</sup> To some extent, this is because, for much of this century, most have spent significant portions of their lives residing in state institutions. Only in recent decades, since their deinstitutionalization from public hospitals beginning in the 1950s and 1960s,<sup>5</sup> have they had the opportunity for social and political participation in society.<sup>6</sup>

People with psychiatric labels have experienced minimal self-determination since society has not provided them with adequate mental health services or choices in how to use services that are available.<sup>7</sup> Moreover, as will be argued later, there is still a great deal of societal ambivalence about whether people with psychiatric disabilities are capable of knowing what is best for themselves and making informed choices. However, some people with psychiatric disabilities were active participants in lobbying for the passage of the Americans with Disabilities Act,<sup>8</sup> and have been involved in recent disability-related legislation such as the Ticket to Work and Work Incentives Improvement Act.<sup>9</sup>

Many of these individuals also are engaged in building increased acceptance for peer support and self-help among policymakers and mental health/rehabilitation professionals. While peer counseling is a central feature of the independent living movement and was even a mandated service in the Rehabilitation, Comprehensive Services, and Developmental Disabilities Act of 1978,<sup>10</sup> peer support and self-help did not become a major policy issue for the mental health community until the 1980s and 1990s.<sup>11</sup> The notion of individually controlled self-help (that is, without professional supervision or involvement) has been neglected or rejected by many clinicians who feel that the individuals are too unstable to assist each other without supervision from others.<sup>12</sup>

During the past decade, representations of recovery versus cure have been constructed where recovery refers to a process by which one reenvisioning one's life following the onset of a psychiatric diagnosis.<sup>13</sup> The emphasis here is not so much on curing symptoms and impairments but, instead, on controlling them as much as possible in order to fashion an existence with dignity, maximal self-determination, and the highest possible level of role functioning. It is the thesis of this analysis that *expressing sexuality and establishing intimacy are part of the recovery process for these individuals.*

Perhaps because of the supposed mental rather than physical nature of their disorders, this disability group lacks an independent living movement such as that established among the physical disability community.<sup>14</sup> Perceptions persist that they are not as deserving as other groups of housing assistance and support.<sup>15</sup> These individuals are organizing politically and focusing on presenting a united front while allowing for diversity and acceptance of multiple viewpoints in their movement. Given that they value their unique perspectives on reality, they are unwilling to homogenize in order to gain power.<sup>16</sup> They allow room in their movement for dissenters and for those with psychiatric symptoms and impairments.

## SOCIETY'S VIEWS, TREATMENT

It is important to understand the larger context in which changes are occurring. People with disabling mental disorders, particularly during the acute and florid phases of their illnesses, often are deprived of their civil rights by being placed in institutional settings in the name of treatment and public safety.<sup>17</sup> Mental illness is one of the few disabilities that place people at risk of losing their freedom in order to receive inpatient treatment; one is considered legally committed (either voluntarily or involuntarily) to a psychiatric inpatient setting. Increasingly, this is occurring in community settings as well, as evidenced by the recent passage of "Kendra's Law" in New York State<sup>18</sup> and a lessening of the severity of commitment criteria nationwide.<sup>19</sup>

Strong examples of social control of individuals with mental illness are the stigma and fear they experience, partly because of cultural representations in the media of their "dangerousness." Their medical treatment has been shown to include coercion involving emotional intimidation, threats, and bullying, as well as occasional forced restraint, forced seclusion, and chemical restraint. Many argue<sup>20</sup> that such treatment victimizes or revictimizes individuals, perpetuating illness rather than enhancing health and well-being, and preventing many from ever seeking formal treatment again.

Outside the clinical realm, individuals with disabling psychiatric disorders are objects of culturally acceptable humor, scorn, and humiliation. It is still socially acceptable in the United States, even in today's atmosphere of supposed political correctness, to mock people with psychiatric problems, make fun of psychiatric symptoms, and use stigmatizing language.

Examples of all of these abound in the media, including joking about, imitating, and making light of symptoms and behaviors that are painful and humiliating for those who experience them.<sup>21</sup> Some have argued that institutionalized discrimination against people with mental illness is one of the last socially acceptable, government-sanctioned threats to the rights of a large group of vulnerable individuals.

Finally, people with severe mental illness are not perceived as legitimately disabled by large segments of society, but instead as malingerers or whiners whose expression of their discontent and insistence on protection of their civil rights is viewed as evidence of insanity itself. To a large extent, this may be due to the well-documented episodic nature of many severe psychiatric disorders, making it difficult for uninformed citizens to believe that individuals can decompensate and recover rapidly, events that enhance perceptions that individuals are faking their problems.

*“Many  
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of their  
sexuality.”*

## WHAT ABOUT SEXUALITY?

While U.S. society prefers to view people with mental illness as asexual,<sup>22</sup> studies show that many are sexually active, with from one third to three quarters reporting that they engaged in sexual relations, depending upon the time frame about which they are asked.<sup>23</sup> In addition, research shows that most people with mental illness do not practice safer sex<sup>24</sup> or have not been given information about pregnancy or STD prevention.<sup>25</sup> A series of studies in the 1990s showed that many mental health clients (66 to 75 percent) did not use condoms during sexual activity. In a survey of over 750 individuals at a community-based rehabilitation program in Chicago, 72 percent said they did not use condoms or dental dams regularly during sexual activity.<sup>26</sup> Many have difficulty using contraception for reasons that are economic, interpersonal, and situational.<sup>27</sup> While many report enjoying their sexuality, they also report less physical and emotional satisfaction than their nondisabled counterparts in some studies.<sup>28</sup> Many say they repress their sexuality, worry about its normalcy, and internalize societal disapproval of their sexuality. To some extent, sexual relations involve letting go, and this can be difficult to those who fear loss of emotional and behavioral control.

## CLIENT SURVEY

In 1990, a survey of 325 individuals receiving mental health services was conducted by peer researchers in the California Department of Mental Health led by Dr. Jean Campbell and associates.<sup>29</sup> Just over half (51 percent) of the mental health clients surveyed said they lacked a satisfying sex life; just under half (47 percent) said they lacked a satisfying social life. Two fifths (40 percent) said they lacked warmth and intimacy. Interestingly, there was a connection between clients' housing situations and opportunities for intimacy. Over 50 percent of board-and-care residents reported a lack of privacy in their everyday lives, which impeded their ability to establish intimate relationships. However, there was some evidence that lack of privacy was only part of the problem, since 50 percent of respondents felt that people with serious mental health problems were incapable of having satisfying intimate relationships.

## BARRIERS TO SEXUAL EXPRESSION

Even though many people with psychiatric disabilities are sexually active and view sexual relations and intimacy as essential for their well-being and self-determination, a series of barriers often prevents them from expressing their sexuality. As mentioned earlier, lack of privacy in many residential settings, including mandatory room sharing and “no sex between residents” policies, create few opportunities for healthy sexual self-expression.<sup>30</sup> Histories of childhood and adult abuse and trauma constitute another barrier.<sup>31</sup> In fact,

a growing literature shows that anywhere from 36 to 85 percent of women receiving mental health services in the public system have experienced traumatic abuse, including physical and sexual abuse as children or adults.<sup>32</sup>

Partly due to their disorders and partly due to societal stigma, many people with psychiatric disabilities lack self-confidence and experience very low self-esteem that can impair their ability to establish intimacy with others.<sup>33</sup> Sexual relations involve a degree of risk-taking and vulnerability that is often difficult for everyone but especially so for those with low self-confidence. Psychiatric medication side effects also can diminish sexual performance and desire, causing impotence in men and inorgasmia in women.<sup>34</sup> Certain symptoms (paranoia, withdrawal) inhibit a person's ability to form and maintain relationships. But beyond symptoms, individuals may find that their interpersonal relationships are impaired; for example, some may avoid eye contact and may not talk casually with people. Lack of such social skills critical to establishing intimacy can be related to some forms of psychiatric disability. As a result, some individuals may appear less desirable to potential partners. Finally, most people with psychiatric labels receive very little assistance and support from service providers for expressing their sexuality, especially practical assistance with social skills and support for sexual activity.<sup>35</sup>

## DIFFICULTIES WITH SEXUALITY

Successful contraception and safer sex practices can prove difficult for all sexually active individuals. One of the most serious barriers to contraceptive use and safer sex among people with psychiatric disability is lack of knowledge and information. Since case managers and clinicians often feel uncomfortable discussing sexuality with their clients,<sup>36</sup> these individuals usually receive very little education on this subject.<sup>37</sup> Because families may feel ambivalent about or disapprove of their disabled relative's sexual activity,<sup>38</sup> they may not support the disabled relative using contraception or having information about safer sex. In addition, birth control pills or IUDs—among the most effective methods of contraception—are usually not affordable for those on limited incomes.<sup>39</sup> Lack of privacy in residential settings may also lead to hurried, unprepared sexual activity that is not protected. Finally, the social skills needed for negotiating safer sex (such as persuasion or limit-setting) are especially challenging for many people with emotional difficulties, particularly when they are having sexual relations with individuals facing the same sorts of emotional problems.

## SPECIAL ISSUES FACED BY WOMEN

Women with mental disabilities encounter special needs and issues regarding intimacy and sexuality. As mentioned earlier, rates of childhood and adult physical, sexual, and emotional abuse are especially high for these women. As a result, many

women have trauma-related needs that remain unaddressed in adulthood and can interfere with their ability to establish relationships or engage in fulfilling sexual activity. Domestic violence is also a concern. In one rare study<sup>40</sup> of the topic, 26 percent of female psychiatric inpatients reported abuse by a spouse or partner at some time, with 19 percent reporting partner abuse within the past year. Studies of domestic violence against homeless adults indicate that women are more likely to become victims of domestic violence than men,<sup>41</sup> and such domestic violence often contributes to a woman's homelessness due to her need to terminate the relationship.<sup>42</sup> Lesbian, bisexual, and transgender individuals also usually encounter limited understanding and support from clinicians and society in general, as discussed later. A documented lack of health care for women with mental disabilities (such as gynecological and breast care) can also create problems.<sup>43</sup> Some medications may also inhibit sexual desire or arousal, interfering with sexual functioning. Finally, societal repression of women's sexuality in general<sup>44</sup> can affect women with psychiatric disabilities as well, causing them to internalize negative attitudes about themselves as sexual beings with sexual needs.

### GAY, LESBIAN, BISEXUAL, TRANSGENDER ISSUES

Using epidemiologic data regarding the incidence of severe mental illness as well as homosexual self-identification in the general population, R. E. Hellman estimates that anywhere from 200,000 to half a million gay men and lesbians have severe psychiatric disorders.<sup>45</sup>

Studies show that a large majority of the members of gay, lesbian, bisexual, and transgender communities have been the target of verbal abuse (92 percent) and that nearly a quarter (24 percent) report having been physically attacked.<sup>46</sup> Heterosexism and homophobia also persist in the therapeutic community, resulting from gaps in the education and clinical training of therapists.<sup>47</sup> Aware of overwhelmingly negative societal attitudes, many clients hide their sexual orientation from health care providers.<sup>48</sup> This creates a need for affirmative treatment models in both inpatient and outpatient settings, including psychoeducational approaches, support groups, and day treatment.<sup>49</sup> Without such services, sexual minorities face unnecessary barriers to the establishment of intimacy and sexual expression.

### SPECIAL HIV-POSITIVE ISSUES

Another vulnerable population with specific sexuality needs are those mental health clients who are HIV positive. HIV infection rates are notably high among this population,<sup>50</sup> ranging as high as 40 percent in homeless groups.<sup>51</sup> Lack of coordination between the mental health and HIV/AIDS care systems makes integrated services difficult to obtain.<sup>52</sup>

Disclosure regarding multiple statuses (HIV/AIDS and mental disability) adds to the burdens faced by these individuals.

Special prevention services are needed by sexually active HIV-positive clients. These include the need for peer support groups and peer counseling,<sup>53</sup> the need to address any co-occurring substance abuse issues,<sup>54</sup> and the need to support adherence to complex treatment regimens for HIV.<sup>55</sup>

A final point worth mentioning is the fact that many clinicians lack training in the combined issues of mental disability and HIV/AIDS. As a result, clients often face discomfort or homophobia in mental health service provider communities and stigmas relating to mental illness in the HIV/AIDS field. Individuals may thus face a "double whammy" of discrimination in accessing services and support.

### WHAT CAN WE DO?

There are many ways in which people working with individuals who have psychiatric disabilities can support them. First, they must stand solidly in support of this group's right to sexual self-determination and expression of sexual identity. They must also work with the disability rights movement to help reduce the stigma associated with mental illness. These individuals need empowering environments and care providers in the areas of both cognitive and physical disability. They also need affordable contraception and safer sex materials from the medical and rehabilitation communities. They can also move forward by incorporating sexual expression and intimacy goals into the agenda of their empowerment and disability rights movements.

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*This article is based on a paper presented at a plenary session at a conference on Disability, Sexuality, and Culture: Societal and Experiential Perspectives on Multiple Identities, San Francisco State University, San Francisco, CA, March 17-18, 2000.*

*The preparation of the paper was funded by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research, and the Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (Cooperative Agreement H0163478). The opinions expressed herein are not the official position of either agency, and no official endorsement should be inferred.*

*The author wishes to acknowledge Jessica Jonikas, Lisa Razzano, and Pamela Steigman for their intellectual contributions.*

—Editor

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## PERSONAL INSIGHTS FROM PEOPLE WITH COGNITIVE, EMOTIONAL DISABILITIES

The best insight into relationship needs of people with cognitive or emotional disabilities often comes from the people themselves.

These comments from participants in a *SEEDS Program*\* panel discussion at The Mind Empowered Inc. are perfect samples:

- Being institutionalized can cause learned helplessness that decreases our ability to function on the social level necessary to develop relationships. We are not encouraged to develop our sexuality in a healthy way.
- Being labeled with an emotional disability makes it difficult to overcome the resulting shyness and low self-esteem. This makes it difficult to connect with other individuals. The more we can feel like humans the better we will be able to relate to others.
- Many people with emotional problems also struggle with poverty issues. It is hard to have confidence if you can't take a date for a cup of coffee.
- The shame related to emotional disability is difficult to surmount. A person wouldn't say, "I like long walks on

the beach, and I like to dance. By the way, I have schizophrenia." People are not adequately educated on the subject of mental health to discuss the issue openly.

- The unpredictability in the lives of people with emotional disabilities makes us leery of taking new steps in our growth and may make us balk at taking the risks necessary in forming relationships.
- People in recovery from emotional disabilities become open to the possibility that they will continue to grow as human beings. This openness can serve as a template for the openness we will need to develop future relationships.

\**SEEDS* is an acronym for "Spreading Enlightenment and Empowerment with Dignity and Support."

—Scott Snedecor with thanks to Steve Walker, Faye George, and The Mind Empowered Inc.

## FROM THE FIELD

# KANSAS WORKS TO MEET THE NEEDS OF SPECIAL EDUCATION STUDENTS

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There are many reasons individuals give for overlooking sexuality education for special education students. They include (1) the students do not need to know anything about sexuality because they will not have sex; (2) they cannot understand the information; (3) they are already excluded from sexuality education classes; and (4) there is no curriculum for them.

After several phone calls from the field requesting a curriculum, information, and/or resources for students with disabilities, we at the Kansas State Department of Education (KSDE) decided to investigate previous state efforts in this area and to determine what the state needed to do in the future.

### INVESTIGATION, RESEARCH

Darrel Lang, the health/physical education/HIV/AIDS program consultant with the KSDE, began by searching through files and resources left by previous program consultants in his position. Jan Erikson, a KSDE educational program consultant as well as a former principal college sexuality educator, also started checking her files for information. Kristy Jones, another KSDE program consultant as well as a former special education teacher, began searching the Internet for resources to support the teaching of sexuality education to students with disabilities.

Our findings were miniscule and disappointing. We found that KSDE had held a workshop for special education teachers in 1987 when it mandated the teaching of sexuality and HIV/AIDS-prevention education. We found the handouts outdated and of limited use. We also noted that there were no follow-up meetings or workshops. We found Internet resources also very limited with many dating back to the 1980s. We were able, however, to find some current resources and we ordered them to start a new resource library. (See the current *SIECUS Annotated Bibliography on Sexuality and Disability* for information on new resources.)

### WORKSHOP DESIGN

After determining the limited scope of education efforts in this area, we decided to design a workshop on this subject. We felt this was important because Kansas has a mandate to teach comprehensive sexuality education to all students, including those with developmental disabilities.

Our efforts also supported the state's Individuals

with Disability Education Act (IDEA), which emphasizes that all students with disabilities must have the same opportunity for general education curriculum, to the maximum extent possible, as their nondisabled peers.

We decided that workshop attendees should include special education teachers, coordinators, and directors, as well as general education teachers, nurses, paraeducators, social workers, and possibly other health agency personnel.

Based on the varied backgrounds of the prospective attendees, we decided it was important to start by providing basic information on sexuality education and how it would impact special education populations.

We then looked at the specific needs of both special and general educators. We realized that special educators needed to know more about content and laws/regulations while general educators needed to know how to modify and adapt current curricula. Both needed to understand their roles and responsibilities in working with students with disabilities as well as the challenges they would face in meeting the needs of *all* of their students. We knew the educators would need more information than we could provide in a one-day workshop. We, therefore, decided to schedule a second workshop where we would provide hands-on, practical classroom information.

### WORKSHOP CONTENT

The workshop started by considering the need to include special education students in sexuality education programs. We discussed both the myths and misconceptions about students with disabilities as well as the history of exclusion and neglect that they have faced. We then discussed the rationale and goals for including all students in sexuality education programs. We also discussed the following subjects during the workshop.

***Are you an askable teacher?*** By using a 13-item inventory, we asked participants to assess how “askable” they were about topics relating to sexuality education. We also shared with them a six-component model for sexuality education that included discussion of sensuality, sexualization, identity, intimacy, reproduction, and society/culture.

***Laws and guidelines.*** We provided everyone with a copy of Kansas's mandate for sexuality education and provided guidelines for teaching developmentally appropriate information to students in kindergarten through the twelfth grade.

**Considering resisters.** Participants also discussed how they would proactively work with individuals who resisted the teaching of comprehensive sexuality education. The audience discussed potential controversial issues and considered how they would handle each of them in their respective communities.

**How and where to provide services.** Individuals were asked to read and discuss a variety of scenarios where they would discuss the roles and responsibilities of those involved in human sexuality education classes that included students with developmental disabilities.

**Identifying different needs of different exceptionalities.** Individuals participated in disability awareness activities where they learned how to modify sexuality education programs to meet the needs of students with disabilities. This included modifying instruction methods, materials, and assessments.

**Teachable moments.** Participants were asked to consider and discuss “teachable moments” where they could use their newly gained knowledge and experience to bring information about sexuality and disabilities into the classroom.

**Materials and resources.** Participants were given the opportunity to review the sexuality education resources/materials in the resource library of the KSDE. They were also given a notebook that contained presentation materials and related information from other professional sources.

## WORKSHOP EVALUATIONS

KSDE held eight workshops titled *Meeting the Needs of Special Education Students in Human Sexuality Education* throughout the state from October 1999 through March 2000. A total of 239 individuals attended and 178 submitted evaluations.

Of those who submitted evaluations, 40 percent were special education teachers; 22 percent were general education teachers; 14 percent were nurses; 12 percent were unidentified; five percent were mixed categories; three percent were counselors; three percent were administrators; and two percent were paraeducators. (Some participants had dual classifications.)

The evaluation consisted of a three-point Lickert Scale with “1” indicating “not helpful/valuable”; “2” indicating “somewhat helpful/valuable”; and “3” indicating “helpful/valuable.” Overall, the scores indicated the workshops were successful. Scores ranged from 2.62 to 2.87.

## SURPRISES AND CHALLENGES

One of the special surprises of the workshop was the attendance of some parents who had children with disabilities. These parents shared challenges they faced when dealing with the topic and behavior as they related to sexuality. This led to discussion and collaboration between parents and teachers in solving challenging problems.

Another surprise was the lack of importance placed upon the topic of sexuality education for all students, not just those students with disabilities. This was shown through the teachers’ lack of knowledge about their own school’s sexuality education curriculum. This workshop has resulted in many general and special education teachers investigating their own sexuality education curriculum.

A major challenge came from the findings of the workshop evaluations. The majority of workshop participants indicated they wanted more information and training. The major request was for more hands-on teaching techniques based upon the sexuality model that was shared in the workshop. Participants also wanted their colleagues and administrators to attend future workshops to help support the teaching of sexuality education. Participants also indicated they needed financial resources to assist them in purchasing materials/curricula to use in teaching sexuality education.

## NEXT STEP

Based on participants’ input, we have decided to offer more workshops covering these issues: (1) developing practical lessons related to the six areas covered in the sexuality model (previously discussed); (2) modifying those lessons to address the needs of their students with disabilities; (3) linking the lessons to learning styles and multiple intelligences; and (4) tying sexuality education to other curricula so it does not stand alone.

Under our Cooperative Agreement with the Centers for Disease Control and Prevention, the KSDE funds six regional resource centers to assist school districts with curricular materials and resources. We have asked each of them to develop a purchasing plan for the procurement of special education curricula and materials on sexuality education.

— Darrel Lang, Ed.D.  
Jan Erikson, M.S.  
Kristy Jones, M.S.

# SEXUALITY ISSUES FOR THE DISABLED: DEVELOPMENT OF A UNIFIED SCHOOL POLICY

Melvyn Littner, M.P.H.  
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It is a well-known but little-discussed fact that physically, emotionally, cognitively, socially, and multiply disabled\* children and youth often exhibit a propensity toward inappropriate sexual behavior. It is also true that many of the individuals who live or work with this population are unprepared to deal with these behaviors. More importantly, many have never been educated to view them in the context of normal developmental issues related to physical maturity and sexuality. This article will describe a project that attempted to address this challenge through the development and implementation of a set of policies that facilitated a uniform response to sexuality issues in a New York City (NYC) public school special education setting.

## LITERATURE REVIEW

Although many institutions and programs that provide residential services for disabled adults have developed policies that address sexuality issues and behaviors for the residents and the staff who work with them,<sup>1</sup> it is noteworthy that only one other project relating specifically to a similar public school population<sup>2</sup> has been reported in the professional literature.

Organizations such as the National Information Center for Children and Youth with Disabilities have published guidelines for parents to help them understand, educate, and supervise their children's sexual development.<sup>3</sup> Experts in the field have also written extensively on the subject, arguing strongly for the need for formal sexuality education for disabled students. They have developed curricula, guidelines, and other materials for use in a wide range of settings with a range of disabled populations.<sup>4</sup> The work of this project, however, is the first attempt to create a policy in a New York City special school setting that is relevant for all students, staff, and parents concerning sexuality issues and behavior. A description of the process will be presented in order to serve as a model to others who work in the area of sexuality with disabled children and youth.

## POLICIES NEEDED

Ideally, every central board of education (BOE) would have in place a set of written policies or codified regulations that would guide school personnel in the provision of sexuality education and the handling of any sexual acting-out

behaviors. However, this is not the case in most settings. Therefore, it is not unusual for the reactions (on the part of the pedagogical staff, the administration, or those who interface with parents) to be haphazard, contradictory, and ultimately ineffective.

As one would expect, the NYC BOE has policies in place that guide its overall functioning. Some of these policies relate to sexuality education for all students, sexual conduct, and student behavior. As such, the Chancellor's regulations address sexual harassment among students and condom availability in the high schools. The special education policy developed and described herein, however, addresses the unique task of working specifically with students who are emotionally, physically, cognitively, or socially disabled.

## THE SETTING

The Queens Occupational Training Center (QOTC) is one of several hundred sites in a district that serves the most severely disabled children in the NYC public school system. District 75 provides educational and support services to approximately 20,000 disabled students and their families. The QOTC is a Special Instructional Environment that serves approximately 450 students, who range in age from 14.9 to 21, and has a staff of 186. All of the students are cognitively disabled, and many of them have multiple disabilities. The ultimate goal of the QOTC is to prepare students for entry-level employment as well as semicompetitive and noncompetitive employment. The latter is usually sponsored in sheltered agency settings. To this end, the QOTC attempts to prepare students in job readiness, social skills, independent living skills, and some academic skills. Ultimately, the mandate is to prepare students who, upon graduation, are prepared to assume roles in society that afford them a degree of independence. For many of these students, this encompasses the ability to be gainfully employed.

## THE CHALLENGE

Some of these disabled children and youth do, on occasion, demonstrate inappropriate sexual behaviors in the home and/or classroom, which must be dealt with by teachers, parents, and administrators, many of whom are ill-equipped to handle such behaviors. Obviously, such sexual activity is not unique to this group of students; but the likelihood that

it will be exhibited in a public forum makes it potentially problematic because of its impact on students' employability, thereby requiring a unified response on behalf of the entire school community.

This policy development project evolved out of the recognition of a need for guidelines to formulate consistent responses to behavioral issues that occur in settings such as this one. Public masturbatory behavior is a common problem that causes anxiety for parents and school staff. It is not unusual, for example, for a student to be engaged in self-stimulating behavior such as touching his or her genitals, rubbing against an object, or rubbing himself or herself against the floor in a public part of the building, such as a classroom or the lunchroom. In the absence of a uniform policy, different staff members would respond to these incidents haphazardly and often counter-productively. A typical staff member's or parent's response might be to:

- Say, "Look, that little so-and-so is doing it again"
- Avert his or her eyes, pretending he or she does not even see the behavior
- Giggle and laugh but, in essence, do nothing
- Make a very strong, negative statement, which often fosters embarrassment and guilt
- Respond instinctively by trying to get the young person to understand that private parts are not touched in public places

The last example would be the most helpful response, of course. The challenge: how to encourage all staff and family members to respond in that way when confronted with public self-stimulating behavior.

Other typical improper behaviors involve unacceptable touching of others, including peers and staff members, couples engaging in intimate behaviors in public places, and and provocative dress unsuitable for the work place. Also of concern is the inability to recognize, deflect, and report uninvited sexual attention from others. Obviously, these behaviors have to be addressed in order for disabled students to make the transition successfully from a protected home or school environment to the world of work.

## THE PROCESS

The sexuality education consultant (SEC) was perfectly positioned to assume a leadership role in the policy creation process. He is a certified sexuality educator and, for the majority of his professional life, has worked for the BOE with school administrators, pedagogical and clinical staff, students (in elementary, middle, and high school special education and regular settings), and parents.<sup>5</sup> He is currently District 75's expert in human sexuality education and works as a consultant to the administrators of the district. He had worked in the

QOTC for several years prior to the project and, although not a regular school staff member, was known and respected by most of the school personnel and the families of the students. His work there had focused on human sexuality education for the parents and staff of the school. He was asked to address students and parents regarding issues of inappropriate sexual behavior on an ad hoc basis. As this aspect of the SEC's work was fairly common and, by definition, reactive, it was ultimately unhelpful on an institutional level.

Since the SEC had to deal with these behavioral issues fairly constantly, he decided to approach the school administration with the idea that a proactive approach, the cornerstone of which would be the development of a uniform policy on sexuality, was needed. In addition to the short-term benefit of having uniform staff and family responsiveness to these behaviors, there were also long-term issues that would be addressed by the creation and implementation of such a school-wide policy. His work with parents was also critical in his decision to undertake the project. They had been asking him for help in how to deal with these behaviors in their homes and understood instinctively that anything they did at home would have to be reinforced by similar reactions at the school.

In the initial planning meeting with school administrators, it was decided that the policy would represent the views of a cross-section of the entire school, and the policy creation committee would include teachers, paraprofessionals, clinicians, parents, and administrators. The SEC was to serve as a facilitator as well as a process and content supervisor to the committee. He would, therefore, not only facilitate the actual work of the committee and subcommittees but also serve as the resident expert for the cognitive and training aspects of the project. In this initial stage of the process, the parents' participation was especially crucial so that their views would be represented and that the policy created would reflect their experience.

It is widely recognized that consistency of response is an essential component in an attempt to alter maladaptive behavior in cognitively disabled youngsters.<sup>6</sup> In order to ensure that the home environment was reinforcing the learning in school, and vice versa, parents' participation in the entire process, including the initial writing phase, was key.

Following the announcement of the administration's intent to create a school-wide policy on sexuality-related issues, volunteers were sought to participate. Only people who had been previously trained by the SEC, and therefore had a similar baseline of information and some experience in exploring attitudes and practicing skills development, were asked about their interest. One parent, active in the PTA, and several staff members volunteered to participate in the committee's work. A manageable-sized group was formed and met one morning a week for the duration of the policy cre-

ation, which occurred over a period of two months.

The first task of the committee was to identify the issues that needed to be addressed. Once these were identified, committee members volunteered to write initial drafts of the policy based on their own area of interest. These first drafts were discussed and edited by the entire committee and served as the foundation of the policies that emerged. Policy was written to cover the following topics:

- A definition of sexuality
- A statement of philosophy about normative sexual development
- Inappropriate self-touch
- Menstruation
- Toileting skills
- Allowable sexual expression
- Sexual orientation
- Sexual exploitation
- Allegations of sexual contact
- STDs and HIV/AIDS infection
- Contraception
- Public and private places
- Inappropriate dress for work

The draft of the comprehensive policy statement was disseminated to all parents and staff for their review and input. The final draft was used as the basis for the next stage of the project, which centered on training.

It was clear that the training component of this process was going to be an even bigger challenge than writing the policy. In order to enable everyone to respond uniformly to sexuality-related issues that would naturally arise in the school or home setting, a large number of very diverse (in terms of their knowledge base and their religious and cultural backgrounds) professionals and parents were going to have to be trained using a design that would resonate with all. With this in mind, the training design included several components. First and foremost was the distribution of the policy statement to the entire school population in advance of their participation in any formal program so that they would read and become familiar with its content. Cognitive, affective, and skills components were built into the design.<sup>7</sup> The SEC worked separately with school personnel and parents. He began the staff-training program by talking about the history of the policy project and the rationale for the development of this policy in particular. The nature of the project, as a work-in-progress, was emphasized throughout this discussion. It was explained that nothing in the policy statement was “written in stone” and that there was a basic understanding that the policies would

be refined and fine-tuned as more people in the school community had the opportunity to provide input and, more importantly, as the policies were applied to situations that arose with students.

The affective work allowed participants to listen to and share views and experiences concerning sexually-related situations they had observed in the school. They were encouraged to discuss their feelings about and reactions to anything they had observed. The group then analyzed the range of feeling and reactions that had been identified. This provided a natural segue into the skills-building part of the training.

In the skills-building component, small groups representing a cross-section of the staff were constituted. Each of these groups was facilitated by someone who was a member of the policy committee and had participated in writing the statement. Each group’s task was to role-play situations that typically occur in the school and that had been identified as important and pervasive enough to be included in the policy statement. For example, a role-play concerning self-stimulation in a public place was utilized to illustrate the policy for dealing with inappropriate masturbatory behavior. The same five role-play scenarios were given to each small group.

The facilitators, who had been previously trained by the SEC to lead the groups, began the process by modeling an inappropriate response to behavior in the role-play situation. The group was then instructed to play the situation out in dyads using more constructive and facilitating responses that, hopefully, mirrored their understanding of the basics outlined in the written policy. After all five situations were played out and discussed in the small groups, the participants came back together in an auditorium setting. They shared with their colleagues the responses that they had identified as being the most helpful. As in the example above, a clear communication about public versus private behavior without any admonition or negative message about self-stimulation was identified as the most facilitating response. This final large group sharing resulted in a reaffirmation of the importance of the policy statement and a recognition that it will continue to be modified as staff and parents begin to integrate the concepts in the document into their interactions with their students and children.

## CONCLUSION

The project described in this brief overview continues. A parent’s training experience is underway and the training of school staff, including teachers, clinicians, and paraprofessionals, is ongoing as well.

The model of policy development that evolved in this particular setting can be used as a paradigm for similar work in other school and institutional environments. Essential to the success of the work is the facilitation by a skilled sexuality

educator/consultant. Equally important is the willingness of staff to address such sensitive issues as inappropriate sexual behaviors. The ongoing support and participation of administration at all levels, local and district, is also crucial as is the involvement of parents in every step of the process.

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*The program described herein was a pilot project and continues to be a work in progress within one school setting. As such, it has not been officially endorsed by the New York City Board of Education for city-wide implementation.*

—**Editor**

\*Terms such as “handicapped” and “challenged” have purposely been avoided. The more generic term “disabled” has been used throughout this report in accordance with the recommendation of Dr. Simi Linton.<sup>8</sup>

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## SEXUALITY ISSUES, POLICY, AND GUIDELINES: QUEENS OCCUPATIONAL TRAINING CENTER

This document represents the collective efforts of administrative, staff, and parent representatives of P.721-Queens Occupational Training Center (QOTC), who serve on an ad hoc committee under the guidance of the District 75 sexuality education consultant. The policies that follow were specifically designed for the QOTC and reflect the special needs of the student population. Every effort was made to ensure that the basic tenets are in accord with existing federal, state, and local ordinances, and that they fully comply with all guidelines and regulations set forth by the Chancellor concerning sexuality education for the New York City Board of Education. This includes the new regulation (A-831) concerning student-to-student sexual harassment.

### SEXUALITY DEFINITION

Sexuality is a composite term referring to the totality of a person's being. It is concerned with the biological, psychological, sociological, and spiritual variables of life, which affect personality development and interpersonal relations. It encompasses bodily changes, feelings, gender identification, and an array of behavioral manifestations.

Genital activity is but one small part of human sexuality. How does it feel to be a woman? How does it feel to be a man? What are the implications of these feelings on the way that we feel about ourselves and the way that we relate to others, personally and professionally? The committee believes that a comprehensive concept of human sexuality must address such authentic parameters and is a reality for all people—the young, the adolescent, the adult, the aged, and the developmentally disabled.

### STATEMENT OF PHILOSOPHY

The QOTC strives to teach skills that are a prerequisite to the world of work. Intrinsic to these skills is recognition of students' future employability. As such, the center maintains that learning to manifest students' sexuality properly is an important component to the education of all youngsters.

This relates directly to the areas of personal hygiene, gender, dress, and behavior. Students' success in learning these skills will determine whether they will be able to be employed in the future.

Therefore, we at the QOTC:

- **Recognize that all people, including people with physical and/or mental disabilities, are sexual beings with sexual needs.** Therefore, we advocate that people with physical and/or mental disabilities receive sexual education and sexual health care, with opportunities for socialization and sexual expression, without regard to sexual orientation. We believe all students have a right to a comprehensive sexuality education that takes into consideration: (1) the cognitive domain (facts and data); (2) the affective domain (feelings, values, and attitudes); and (3) the skills domain (the ability to communicate effectively and to make responsible decisions).
- **Believe that parents are and ought to be the primary sexuality educators of their children and that schools can help parents fulfill this important role.** Educators have their own personal beliefs and religious values but ought not impose them on students; rather, it is their responsibility to educate all students about facts, alternatives, choices, and ways to make informed decisions based on school policy and sound principles.
- **Further believe that young people should be encouraged to delay becoming genitally active with a partner.** Our school policy, curriculum, and counseling models reflect that belief. We are cognizant of the fact, however, that youngsters may not always heed the counsel of their parents, teachers, and clinical personnel, especially when it concerns delaying sexual intimacies. We are, therefore, committed to providing the information and skills necessary to help our students be responsible to their partners and to themselves.
- **Acknowledge the need for a uniform approach to dealing with our students' sexuality.** While we do not expect staff to go against culture, religion, or personal beliefs, we do expect students' needs to be addressed in a consistent and professional manner. This statement of philosophy contains phrases and suggestions for handling a variety of situations, which may help staff respond appropriately to our students. Those who are unable or uncomfortable with handling these issues may call upon a designated staff member for assistance.
- **Believe that each individual learns about sexuality from birth until death.** Parents, peers, schools, religion, the media, friends, and partners all influence one's learning about sexuality. Unfortunately, the vast majority of our youth get their sexuality information primarily from friends and from the media. As a result, youngsters receive conflicting, incomplete, and inaccurate

information that often leads to confusion and health risk. The situation can be even worse for boys and girls with developmental disabilities, whose sexuality needs are generally overlooked or denied.

- **Are committed to educational and training programs for staff and for family members to help them understand and support the normal sexual development and behavior patterns of persons with disabilities.** We, the members of the staff at P.721-QOTC support the Chancellor's Regulation A-750, which states that staff members who have reasonable cause to suspect that a child is abused, maltreated, or neglected must notify the principal or the principal's designee immediately.
- **Strongly encourage those who are disabled and those who care for the disabled to receive sexual abuse prevention education.** Curriculum and curriculum materials should be appropriate to the age and the developmental level of the students.

In the event that circumstances require a parent to be notified about a student's sexual behavior in school, the following steps should be taken: (1) notify the student advisor or crisis intervention teacher (CIT) about the incident; (2) submit a written narrative describing the incident to the CIT; and (3) arrange for the student advisor or the CIT to schedule and facilitate a meeting with the family, the student, and the staff member involved.

### PUBLIC/ PRIVATE PLACES

The staff at the QOTC believe that teaching behaviors appropriate to public and private places encourages responsible social and sexual behavior. We believe that our students are capable of learning how to behave appropriately in public and private places, and we recognize that many inappropriate actions and activities reflect confusion, lack of awareness, and limited judgment. We are committed to providing our students with personalized guidance and assistance in understanding these concepts. Our ultimate objective is to ensure that our students blend in as much as possible with the greater society.

We acknowledge that many of our students' social problems indicate a limited understanding about public and private places, private parts of the anatomy, and public and private behaviors. Students are discouraged from publicly engaging in such activities as exposing private parts of the anatomy by undressing, pulling down or lifting up clothing, scratching or touching genitals, fixing or adjusting underclothing, and self-stimulation. The staff

offers support by gently explaining that performing these activities is inappropriate in social settings and will be embarrassing and humiliating to students. Students are told that these are private behaviors, which should always be performed in a private place. The students are also directed to discuss sexual issues in an environment that provides privacy. We emphasize role-playing and role-modeling to present the information realistically. Students with difficulty understanding concepts of appropriate behavior in public places are assisted by verbal and physical prompts. Family involvement is indicated when a more intensive behavior modification program is needed.

### **INAPPROPRIATE DRESS**

The goal of the QOTC is to provide students with the skills they need to become independent, contributing members of their communities. In preparation for employment, we stress appropriate dress for both school and the workplace. Any student wearing inappropriate clothing will meet with a member of the administrative team or CIT/student advisor/guidance counselor to discuss why such attire is not appropriate for the school/work setting. Contact will be made with the parent(s)/caregivers to explain school policy.

### **ALLOWABLE SEXUAL EXPRESSION**

We at QOTC believe that there should be a uniform manner in which all faculty and students physically interact with each other. The underlying principle for this should be behavior that is appropriate to the world of work. In this regard, students should not be hugged, caressed, massaged, kissed, or embraced by a member of the staff, nor should students be allowed to interact with a staff member in any of these ways. It is understood that during crisis situations, the need for physically calming a distraught student may sometimes be necessary; however, such behavior should only be used at these times and in the presence of another staff or crisis team member. Understanding that there are situations that do not fit this mold, the staff needs to be aware of individual student needs and should respond in a way that is both appropriate and supportive.

In the event that a staff member is inappropriately touched by a student, the staff member must first *firmly* let the student know that the touch is inappropriate, making the distinction between touching public parts (such as hands, shoulders, and so forth) and private parts (such as breasts, rear ends, and so forth). Then staff must contact the student advisor, who will make

contact with a parent and submit a written anecdotal report to the CIT. Documentation of any sexually-related incident is imperative for the protection of both student and staff members.

We also recognize that during the course of the development of cognitively disabled adolescents, an interest in having a relationship with a peer may occur. It is important for us to remember when interacting with the cognitively disabled that their concept of what constitutes a relationship may vary greatly from the social norm. Since we are working toward developing skills for the world of work, we have chosen to use what is appropriate in the workplace as our guideline for monitoring student behavior. This means at the QOTC that there will be no hugging, kissing, or other sexual contact among students during the course of the school day. Since handholding and hugging are appropriate in a social setting, we allow this behavior during such social functions as school parties and dances, under the close supervision of the staff.

### **INAPPROPRIATE SELF-TOUCH**

Sexual self-stimulation, or masturbation, is, according to current medical and mental health standards, normal, natural, and nonharmful behavior for individuals of all ages and genders throughout the life cycle. Self-stimulation can be a way of learning to be more comfortable with and/or enjoying one's sexuality by getting to know and like one's body. However, self-stimulation is a private behavior, and students must be taught that it is inappropriate in public places.

At the QOTC, if a student is inappropriately touching himself/herself while in public, he or she will be assisted to recognize the inappropriateness of such an activity in a public setting. ("This is a public place. We do not touch our private parts in a public place.") If a staff member does not feel comfortable, he or she may call upon a designated staff member for assistance. For some youngsters, verbal cues are not enough to help them learn appropriateness; a more intensive behavior-modification plan may be necessary and should include family support.

### **MENSTRUATION**

The staff at the QOTC recognizes that our female students experience the same patterns of physical development as all women. Under the guidance of teachers and nurses, we make every effort to provide information concerning menstruation, adapted to each student's cognitive level of understanding. We are aware that our female students may not have the skills needed

for personal care nor understand the importance of good personal hygiene during menstruation.

We believe the responsibility of menstrual care should reside with the family and family members. When a young woman demonstrates inadequate menstrual care, our role is to work with the student and her family. When a student presents distress by continually staining her clothes, having an odor, or not bringing pads/tampons to school, the staff provides immediate assistance by correcting the problem and taking the opportunity to teach the student about hygiene. In addition, the staff informs the social living teachers and CIT/student advisor so these specialists can maximize the student's successful outcome through direct parent involvement. We believe that we, along with family members, carry the responsibility of developing appropriate health behaviors and attitudes.

### **TOILETING SKILLS**

The students at the QOTC display many different levels of skills. Some students still require assistance with simple toileting skills. Every attempt is made to have a student assisted by a staff member of the student's gender. Under no circumstance is a male staff member responsible for assisting a female student with toileting. Staff uses verbal prompting to assist students in proper toileting skills. If physical assistance is needed, staff members are encouraged to have another staff member present.

### **SEXUAL ORIENTATION**

A person's sexual orientation, whether bisexual, homosexual, or heterosexual, is an essential quality of his or her humanness. Each person has the right to be accepted, acknowledged, and given the opportunity to live according to his or her orientation. In New York City, under Local Law #2, protection from discrimination is guaranteed to all people, regardless of their sexual orientation. Our students are afforded these same human rights.

### **SEXUAL EXPLOITATION**

We believe that sexual relationships should be consensual and that exploitative and coerced sexual acts and behaviors, including rape, incest, sexual harassment, and sexual abuse, should be condemned. We believe that forcing anyone to participate without consent in a sexual act is by definition exploitative.

The staff at QOTC supports all efforts to prevent all forms of sexual exploitation by providing information and education as well as by supporting the laws that deter and punish such acts.

### **ALLEGATIONS OF SEXUAL CONTACT**

All members of the staff at the QOTC understand that on occasion an allegation, ranging from inappropriate touching to sexual abuse, will be made by a student. We further realize that an allegation may be accurate, exaggerated, minimized, or unfounded. At QOTC, we are also sensitive to the fact that our cognitively impaired students can be easier targets than the general population; conversely, they are sometimes prone to distortions of interpersonal interactions. Thus, staff must be alert to any subtle cues of possible abuse, while maintaining professional demeanor at all times.

If a staff member is presented with an allegation, he or she should refer it to an administrator or the CIT at once. In an effort to resolve the allegation, our school will conduct an investigation by a team composed of the CIT/student advisor and an administrator. The team will conduct its investigation by collecting evidence and by taking statements from witnesses, the alleged perpetrator, and the alleged victim. The results of the investigation will be forwarded to the principal, who will then determine whether or not disciplinary action in the form of a suspension of the accused or a report to the police is warranted. The principal or the principal's designees will also be responsible for communicating the findings to the parents and the district office. Our school will complete this investigation, findings, and communication on the day an allegation is made.

At P.721-QOTC, we will emphasize education over punishment. Instead of blaming, scolding, or criticizing an offender, we accept each student's developmental level and bring him or her along from that point. There are students who are too developmentally disabled to benefit from the teaching of coping skills. For them, we recommend the intervention of a behavioral psychologist to work with the student and the student's family.

### **STDs AND HIV INFECTION**

STDs and AIDS are major health concerns affecting all segments of the population. In view of the health crisis, we strongly urge the development of a program to educate students and staff of the scientific facts involved, including the methods of transmission of STDs and HIV and how to prevent such transmission. We strongly oppose discrimination against HIV-positive persons and people with AIDS. The QOTC has a condom availability program, and we follow the

Chancellor's guidelines in providing the mandated six lessons in HIV/AIDS transmission and prevention.

### CONTRACEPTION

As reflected in our statement of philosophy, we believe that sexual abstinence is the ideal way for students to prevent pregnancy and STDs. However, recognizing that this advice may not always be realistic and that teenage pregnancies, STDs, and HIV are on the rise, it is imperative that all young people, regardless of mental or physical disability, become well informed as to the importance of protecting themselves from unplanned pregnancies and STDs.

We also feel that parents should be involved, whenever possible, in their children's family planning and health care decisions. We also feel that our students have the same rights to privacy as guaranteed under the law to all New York City teenagers. We are not encouraging our students to become sexually active; rather, we want to ensure that they have accurate contraceptive information and free access to family planning services when and if they choose to become genitally active with a partner.

The QOTC authors recognize that this document is a work in progress. We expect that after training takes

place and our staff begins to integrate the concepts in this document and apply them on the job there will be many suggestions for changes and additions.

The QOTC authors welcome all suggestions for changes, additions, and amendments.

### ACKNOWLEDGMENTS

Sexuality, as defined in this document, is as defined in a paper given by Dr. Michael A. Carrera in the lecture series "Mental Health in Teaching," 1977.

The 1990 *SIECUS Position Statements* provided the conceptual framework of this document.

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## CALL FOR SUBMISSIONS

The *SIECUS Report* welcomes articles, reviews, or critical analyses from interested individuals. Upcoming issues of the *SIECUS Report* will have the following themes:

#### Sexuality Issues Worldwide

*June/July 2001 issue*

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#### Sexuality Education in the United States

*August/September 2001 issue*

*Deadline for final copy: June 1, 2001*

#### Emerging Issues in STD Prevention

*October/November 2001 issue*

*Deadline for final copy: August 1, 2001*

#### Sexuality and Aging Revisited

*December 2001/January 2002 issue*

*Deadline for final copy: October 1, 2001*

## WHERE IS U.S. HEALTH AND HUMAN SERVICES SECRETARY THOMPSON ON THE ISSUES?

**William Smith**

SIECUS Director of Public Policy

**N**o single person or agency in Washington, DC, has a monopoly on issues related to sexual and reproductive health. Yet, the U.S. Secretary of the Department of Health and Human Services (HHS) plays a key domestic role in establishing health-related programs and policies that affect the heart of each community across this country.

For example, President Clinton declared teen pregnancy a national emergency in his 1995 State of the Union Address, but it was former HHS Secretary Donna Shalala who led efforts to address this crisis.

The United States' Senate has confirmed former Wisconsin Governor Tommy Thompson as the new HHS Secretary. During confirmation hearings, Senator Russ Feingold (D-WI) described Thompson as "someone we can rely on to address the tough issues by bringing Wisconsin's 'can do' attitude to Washington." But, that "can do" attitude possibly suggests mixed results for sexual and reproductive health.

### ABORTION

On the issue of abortion, Thompson opposes a woman's right to choose. While he does approve of exceptions in cases of rape, incest, and the protection of a mother's life, his moderate positions end there.

As governor, he signed three pieces of legislation curtailing reproductive rights. In 1998, he banned so-called "partial birth" abortions and mandated life imprisonment for providers performing the procedure (1997 Wisconsin Act 219). In 1996, he required that women receive in-person counseling on the procedure and then wait 24 hours before terminating a pregnancy (1995 Wisconsin Act 309). In 1992, he required a parental consent for unemancipated minors seeking an abortion (1991 Wisconsin Act 263).

### SEXUALITY EDUCATION

On the whole, Wisconsin does not have a mandate requiring schools to provide sexuality education even though it encourages instruction in both abstinence and contraception. There is also a statewide "opt-out" provision that allows parents to withdraw students from sexuality education instruction with a written request.

Thompson's own actions in this area are somewhat disjointed. On one hand, Wisconsin used its federal abstinence-only-until-marriage education dollars to undertake a media campaign when Thompson was governor. As a result, the National Coalition for Abstinence Education gave Wisconsin a not-so-embracing grade of "C." On the other hand, The National Abortion Rights Action League (NARAL) reports that in response to a 1998 survey by Project Vote Smart, Thompson said he supported sexuality education that stressed abstinence and did not indicate support for sexuality education that stressed safer sexual practices.

### FAMILY PLANNING

Thompson appears most friendly to sexual and reproductive health on the issue of family planning. During his confirmation hearings, reproductive health advocates were successful in requesting that Senator Patty Murray (D-WA) query Thompson on this issue. Having heard that he had "a really strong record in support of comprehensive family planning services," Senator Murray asked if he would give a top priority to Title X family planning services. He replied: "Absolutely, Senator Murray." He also said: "I believe Title X has a great deal of bipartisan support."

### CONCLUSION

The pressure is already underway for Secretary Thompson to make changes. For example, Focus on the Family wants him to direct Title X-funded family planning programs to notify parents when their children are receiving such services.

In a March 19 article, "Title X Changes Sought," Focus on the Family correspondent Stuart Shepard said that while such a regulatory change would be met with court action, "it's still the right thing to do." (Read the article at [www.family.org/cforum/fnif/news/a0015268.html](http://www.family.org/cforum/fnif/news/a0015268.html).)

Yet, the same article has raised questions on more issues than just parental notification. Focus on the Family staffer Amy Stephens asked, "[should] we not de-fund some of Title X and give that money to abstinence organizations?"

Secretary Thompson's positions will become clearer as he transitions into his new role. With less than two months at the helm, there are more questions than answers.

## INSTRUCTIONS FOR AUTHORS

### Submitting Articles and Book and Audiovisual Reviews for Publication in the *SIECUS Report*

**E**ach issue of the *SIECUS Report* features groundbreaking articles and commentary by leaders and front-line professionals in the field of sexuality and education, along with news, special bibliographies on varied topics, book and audiovisual reviews, recommended resources, and advocacy updates. All of this comes to members and other subscribers six times each year.

Manuscripts are read with the understanding that they are not under consideration elsewhere and have not been published previously. Manuscripts not accepted for publication will not be returned. Upon acceptance, all manuscripts will be edited for grammar, conciseness, organization, and clarity.

To expedite production, submissions should adhere to the following guidelines:

#### PREPARATION OF MANUSCRIPTS

Feature articles are usually 2,000–4,000 words. Book and audiovisual reviews are typically 200–600 words.

Manuscripts should be submitted on 8½ x 11 inch paper, double-spaced, with paragraphs indented. Authors should also send a computer disk containing their submission.

All disks should be clearly labeled with the title of submission, author's name, type of computer or word processor used, and type of software used.

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