Becoming Sexually Able: Education for Adolescents and Young Adults with Disabilities By Mitchell S. Tepper, PhD, MPH

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egislation enacted during the past 25 years has enabled people with disabilities to gain their

Rightful place as equal members of American society. The Rehabilitation Act of 1973, the 1975 Education for all Handicapped Children Act {Public Law 94-142}, and the 1990 Americans with Disabilities Act, have added opportunities for inclusion and integration for people of all abilities. Unfortunately, attitudes toward people with disabilities have not changed as fast as laws, especially in the area of sexuality and disability. Many people still deny that individuals with disabilities have sexual needs or believe that people with disabilities should live their lives without fulfilling their sexual needs (Kempton, 1988).

People with disabilities have the same feelings, needs, and desires as people without disabilities. Still, many myths revolve around their sexuality or their lack of sexuality. Denial of their sexuality — accompanied by society's general level of sexual illiteracy and negative, secretive, and sometimes shameful attitudes toward sexuality — creates a double challenge for sexuality education among people with disabilities and their families (Kempton, 1988).

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. This is essential, for without assistance in dispelling the myths around sexuality and disability and without encouragement to develop their sexual potential, people with disabilities sometimes begin to believe these myths themselves (Cole, 1988). Kohlberg (1968) points out children without disabilities learn "I am a girl" or "I am a boy" and then adopt role attributes. Children with disabilities, however, first learn that they are disabled before learning to see themselves as sexual people (Cole, 1988). Thus, sexuality educators need to affirm that people of all abilities, including people 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 where their student's disability occurred and the subsequent effect this may have had on the student's psychosocial development. The needs of a student with a congenital or developmental disability may vary tremendously from the needs of

one who acquired a disability later in life because the former often feels as if s/he was meant to be that way; different and less able (Wabrek, Wabrek, & Burchell, 1978).

The population of interest described in 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. 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.

Students with developmental disabilities may or may not have overlapping difficulties with learning. Difficulty learning may be the result of hydrocephalus, an increase in pressure on the brain from unabsorbed spinal fluid, or other insult or trauma to the brain during development. Other problems may include lack of control of leg muscles, lack of control of the bladder and bowels, lack of sensation in the skin, and/or a curvature of the spine. 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 (1983) details the possible implication of such problems on education with respect to children with spina bifida. For example, children with spina bifida may have recurrent acute problems (e.g., shunt malfunction, urinary track infections, and repeated hospitalizations and surgery), mental problems (e.g., attention disorders, learning disorders, and even mental retardation), and physical problems (e.g., lack bladder or bowel control, be less active than children without mobility impairment and thereby prone to obesity with excess weight that impedes ambulation and contributes to pressure sores) (Wolraich, 1983). The socially limiting nature of such problems combines to affect almost every aspect of the child's performance in an educational setting.

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 educator must first understand human development in children without developmental disabilities. A review is provided here 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 five categories: (1) psychosocial, (2) cognitive, (3) maturity, (4) typology, and (5) person-environment interaction (Knefeikamp, Parker, 6c Widick, 1978). Physical growth and cognitive maturation interact with external societal demands to influence an individual's psychosocial development. Psychosocial skills or cognitive abilities will depend on environmental factors that occurred during defined periods of life.

Models such as those of Erikson (1968) and Piaget (1964) focus on the developmental process of males without physical or cognitive disabilities. The unique challenges faced by females in our society and people with developmental disabilities are not represented in these models. Further, all theories include normal development of physical/motor skills or cognitive ability as part of the process.

Using normal development as a framework, we can begin to see how a disability such as spina bifida may impact this process. Impaired physical/motor skills resulting in mobility limitations, lack of privacy, limited opportunities to interact with peers, and organically based cognitive impairments are all factors that will slow or limit the psychosocial and intellectual development of people with spina bifida. While some of these 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 across crucial developmental periods and continuing throughout the lifespan.

Cole (1988) makes the 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 wishes 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.

It becomes easy to see how growing up with a disability influences development in young adulthood and creates road blocks to establishing a firm sexual identity and healthy relationships.

In addition to being overly protected by family, isolated from peers, and mobility impaired, the child with a disability 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 (Cole & Cole, 1990). Poor body image and self-concept also limit natural sexual development. Issues that may hinder the development of a healthy body image and self-concept include:

- Use of braces, crutches, wheelchairs and other assistive 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)
- Mistrust of own body's ability to give pleasure to another or to give pleasure to themselves
- Chronic pain or spasticity

By taking these factors into consideration. Cole and Cole (1990) developed a typology for purposes of a construct of disability and sexuality for people with early onset physical disabilities, suggesting important differences that may interact with the developmental process. Accordingly, people may experience a life time 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.

By tracing the development of a child with a physical disability like spina bifida from early infancy through young adulthood and incorporating various developmental theories and models, we can get a better idea of their specific developmental needs. Because Erikson's psychosocial stages of development are well recognized and widely accepted, his first six stages will be used here as a framework for discussion, further dividing stage six, puberty and adolescence, into early adolescence and adolescence.

EARLY INFANCY (BIRTH TO 1 YEAR)

According to Erikson (1968), 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. The resolution of this crisis is performed primarily by maternal care. If the child receives affection and has needs promptly satisfied, s/he will develop a sense of trust and the basis of 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.

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 additional 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 the child will have a physical and possibly mental disability.

LATER INFANCY (1 TO 2 YEARS)

During later infancy or the toddler years, the unimpaired child begins to creep, then crawl, and finally walk. He or she is toilet trained and learns to talk and interact verbally with others, and play. Rapid gains in muscular maturation, locomotion, verbalization, and discrimination set the stage for the child to develop a sense of autonomy, or shame and doubt.

The child with a physical disability often has 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. 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 their ability to learn. The ability to learn language and symbols may be further hindered by damage caused to the brain as the result of hydrocephalus. The child with a disability often has less access to experiences throughout all developmental stages (Head, 1993).

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; the child may depend on others to catheterize her or him, and/or to change her or his ostomies and/or protective undergarments throughout childhood and adolescence.

Because of physical and sometimes overlapping cognitive impairments, the child with a disability has fewer opportunities to develop a sense of autonomy and will power. For some, this may result in compulsive overcompliance or impulsive defiance (Erickson, 1968). The direct impact on sexuality has not been explored but one can hypothesize that over-compliance may leave one vulnerable to sexual abuse; reliance on others for bowel and bladder care beyond what is typical for non-disabled children may contribute to low sexual self-esteem, and impulsive defiance may be a barrier to establishing close, intimate relationships.

EARLY CHILDHOOD (3 TO 5 YEARS)

Erikson (1968) sometimes refers to this as the play age. The developmental crisis faced here is initiative versus guilt; the successful outcome would leave the child with a sense of purpose. The unimpaired child at this stage is able to move about independently and vigorously and begins to develop a stronger sense of expected gender roles and the differences in the sexes. The child tries out new roles including gender role identity conveyed by parents, social roles and norms of culture. Although the child's ability to think logically is growing, the child still makes heavy use of imagination in reasoning (Calderone & Ramey, 1982).

The child with a disability is at a competitive disadvantage when it comes to options for play. This can hinder initiative and sense of purpose. The child with a disability, socialized into a disabled, asexual role, does not receive the same sexual messages as their non-disabled peers, which may slow the development of his or her sexual curiosity and imagination (Rousso, 1982).

Sexual questions at this age are factual: "Where do babies come from?" "How do they get out?" "What is a belly button for?" "How come Daddy doesn't have breasts?"

The child at four or five years of age is usually beginning more formal schooling. In these early school years, the child is responsible to more people and exposed to greater influences. The major issues surrounding going to school include the child's ability to learn and the child's ability to control his or her behavior and to get along with others.

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. S/he may also have more opportunities to interact and learn from other children. Although Freud referred to this stage as the latency period, others have demonstrated that children are highly interested in sexual matters at this age (Calderone &c Ramey, 1982) and that this interest is likely fueled by hormones excreted by the adrenal glands (McClintock & Herdt, 1996). Children learn a great deal about sex from their playmates. 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 and experiences.

Piaget (1964) pointed to the development of knowledge at this stage as apposed 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 understanding of the feelings of others. The child with a disability has fewer opportunities to gain knowledge than one without disabilities.

Erikson (1968) warns that the danger of this stage lies in the development of a sense of inadequacy. The child with a disability such as spina bifida or cerebral palsy often has difficulty learning or an impaired mental capacity. Difficulty in learning can set him or her up for developing a sense of inferiority and inadequacy. Societal influences also gain in importance. If the child learns through experience that his or her disability, rather than his or her will to learn, will determine his or her opportunities in society, he or she may begin to internalize a feeling of unworthiness or inferiority. This child is at special risk of developing "learned helplessness" where he or she believes that personal failures are caused by his or her lack of ability and cannot be remedied (Dweck &: Goetz, 1978).

Friendships become of prime importance. Egocentrism is on the decline while intimacy and a renewed sense of self are on the rise (Rubin, 1980). Some children with disabilities such as spina bifida and hydrocephalus tend to go through puberty sooner (a year or more) than their peers and therefore need to be prepared in this stage.

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. Education around puberty issues should be undertaken if it has not been done already. Early adolescents begin the process of separation from family and establishing connections with peers. There are increasing sexual attractions.

The early adolescent begins to ponder what is logically possible with his or her life. The early adolescent begins to think about himself or herself and develops an erroneous "belief that others are preoccupied with his or her] appearance and behavior" (Elkind, 1967). This adolescent egocentrism results in self-consciousness and a need for greater privacy and independence. Egocentrism leads to the compelling question of, "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 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 at this age may include: "Why do some girls have their period at 10 and others do not have them until 13 or 14?" "What is a wet dream?," "Is it okay if I don't have one?," What does 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)

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 (1968), 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.

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 to serious risk of being excluded.

The adolescent is also developing formal reasoning (Piaget's sense) and moral development (Kohlberg, 1968). The middle adolescent (13 to 16 years of age in girls or 14 to 17 years of age in boys) 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 in girls or 17-plus years of age in boys) 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 them, is driving.

Sexual topics of interest include dating, relationships, sexual activity, contraception, abortion, and safer sex. Questions will 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 they do?" "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 (1968), 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." 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. Many of the young person's peers may be stuck in the prior stage and are unable to have an intimate relationship with someone who has a disability because they are not secure in their own identity.

Possible questions regarding sexuality will include: "How do we move a relationship from friendship to romance?" "How do I tell someone about my ostomy without having them reject me?" "How do I protect myself against HIV and STIs 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" (Knefelkamp et al., 1978). 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 a disability 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. In a specific study on sexuality and spina bifida, Wabrek et al. (1978) conducted structured interviews to assess the sexual questions, concerns, and adjustments of 26 males and 26 females with spina bifida ranging in age from 12 to 31.

They found that self-image was poor in four out of five individuals. They also found that many did not feel accepted by their parents either because they were put up for adoption (or put in foster homes) or because their parents tried to hide them. Many did not feel accepted by boys and girls of their own age because of teasing in regard to the issue of incontinence or collection devices. Many had trouble accepting themselves because of deformed body parts. Poor body image often hindered the development of interpersonal skills and relationships. They were also confused by pressure—implicit and explicit—to date other individuals with disabilities or to try to date normals. Wabrek et al. (1978) also reported on the status of sexual functioning among males. Of the 26 male subjects, 76 percent were able to have erections; 61 percent had ejaculated; 46 percent had masturbated; and 38 percent had experienced nocturnal emissions. It is worth noting that among males in the younger age range three out of four who were 12 years of age did not get erections and none of the four had ejaculated by any means.

For the 26 females, subjects were separated into two age groups to study sexual involvement. Of the 16 girls in the 12- to 18 year-old group, one had masturbated with arousal while none of the remaining girls had ever had any experience with masturbation. In fact, six had never heard of it and the other nine who had heard of it had a negative connotation. Six of these girls had boyfriends but none of them had participated in petting or intercourse. All of the boyfriends had disabilities. Of the 10 females in the 18- to 30- year-old group, two had masturbated with arousal. The remaining either did not know about masturbation or were not comfortable with the behavior. Seven of the 10 females reported they had a boyfriend. In all cases in the older age group, the boyfriends did not have disabilities. One of the women had had intercourse.

ROLE OF PARENTS

As mentioned earlier, the child with a disability is often protected more 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 (1990) 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.

Cole (1988) suggests 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 or adolescent with a disability may need is unavoidable, 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 are not immune to them. Cole (1988) recommends 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 that 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.

LESSON PLANS

Considering what we know about some of the medical aspects of disability, the psychosocial developmental issues, the social and environmental issues, and the issues of parents, I will layout a blueprint for lesson plans that are developmentally appropriate for young people with disabilities. Lesson plans designed to help individuals with developmental disabilities should target three interrelated goals:

- 1) Knowledge: Early adolescents, adolescents, and young adults with disabilities will increase their knowledge of human sexuality.
- 2) Attitude: Early adolescents, adolescents, and young adults with disabilities will affirm their identity as sexual people.
- 3) Behavior: Early adolescents, adolescents, and young adults with disabilities will increase their social and interpersonal competence. Lesson plans should incorporate 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.

As noted in this article, developmental disabilities often create need for extra care, often from parents, and young adults face limited opportunities for private learning and exploration of their non-disabled peers. They also face architectural and structural barriers, and transportation barriers, limiting access to social situations and events that are needed to develop social and relationship skills. Even with access to events and inclusion, there can exist the experience of emotional isolation based on being the only one who is different, being too short in a wheelchair to participate equally in conversations, or inability to maneuver in a crowded situation. As time and resources allow, facilitated "field trips" and role-playing should be included in a more comprehensive curriculum to give experience and social relationship skills. The curriculum should promote skills to critically examine the sexual messages sent from the media, the medical profession, and sometimes teachers and families, in order to help them evaluate which of these are realistic and which are unrealistic, whether you are disabled or non-disabled. They should be exposed to positive sexual role models with disabilities in film and in real life.

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