

# **Sexuality and Individuals with Down Syndrome**

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## **Sexuality**

The development of a healthy sexual identity is a lifelong process, with each life phase presenting a particular task. Infants and toddlers face the tasks of developing trust and personal autonomy. Young children face the tasks of development of self, intimacy, and physical closeness and with later childhood comes the need to master the concepts of modesty and privacy (Grant 1995; Haka-Ikse and Mian 1993). For the adolescent, significant issues include masturbation, personal safety, and relationships (Grant 1995; Haka-Ikse and Mian 1993; Smith 1995).

Unfortunately, the sexuality of mentally disabled people has historically been ignored or denied (Carmody 1996). Prior to the last decade, most of this population was housed in large, sex-segregated institutions with few opportunities to socialize. Society in the past has tended to view mentally disabled people as asexual or, if they appear overly affectionate, hyper-sexual (Carmody 1996). However, personal relationships and sexuality are essential to the normal development of all adults, including those adults both with and without physical and/or mental disabilities (Smith 1995). While some mentally disabled individuals may not be able to participate in the most typical societal relationship - marriage with children - they can still participate in interpersonal relationships in meaningful ways. The healthy expression of sexuality need not require sexual intercourse, and can take a broad range of forms including close friendship, physical close-ness, and nongenital contact.

This presentation reviews the current literature on sexuality and related issues in people with Down syndrome. Specific topics covered include sex education, abuse, reproductive health issues, contraception, and marriage. Because of an almost complete lack of data, the issues of homosexuality, trans-sexuality, prostitution, and sexual dysfunction in this population will not be discussed.

## **Sex education**

An increasing body of literature and a growing dialogue exist regarding sexuality and sexual expression for individuals with mental disabilities (Ames 1991; Parker and Abramson 1995). Unfortunately, these have not been combined with an equal growth in appropriate programmes for sex education, parent education, the development of support systems, and mechanisms for guidance to help ensure appropriate opportunities and meaningful sexual and personal relationships (parker and Abramson 1995; Shepperdson 1995)

Comprehensive sex education that includes training in personal and emotional safety as well as in relationship issues should be a standard part of the educational programme for all individuals with Down syndrome (Edwards 1997). Although many such curricula already exist, they are often limited to the discussion of abstinence, contraception, and safe sex. While prevention of disease and unwanted pregnancy is important, it is also vital that such programmes address appropriate social behaviours, privacy issues, relationships, and personal values (Pueschel 1996,1997).

The current educational trend is towards open and early sex education in the classroom and in the family. Whether sexual information should be provided by the family or by the school, and which moral traditions and values should be reflected in the curriculum, are both topics of continuing debate. In any case, school-based sex education programmes should include all students with developmental disabilities. Since individuals with Down syndrome have a wide

range of cognitive levels, learning styles, living and work arrangements, and health issues, such programmes require an individualized approach (Pueschel 1996; Van Dyke et al. 1995).

One popular curriculum in this subject area is the Circles Concept curriculum (Walker-Hirsch and Champagne 1992). This method uses a set of large, brightly coloured concentric circles as a paradigm of physical and emotional distance. Each coloured circle represents a level of physical and emotional intimacy. As students stand in each circle, they learn the appropriate level of physical contact for each level of emotional intimacy.

AD eight-week course of sex education has been developed by Elkins (1997) and is outlined in Appendix 4.1. It includes the Circles Concept as well as other materials.

For those individuals with severe cognitive or sensory deficits, the 'good touch/bad touch-model' should be considered (Van Dyke et al. 1995). This concept can be used to teach self-protection skills (Haseltine and Miltenberger 1990) and is often used in elementary schools to teach children to recognize sexually abusive behaviour (Monat-Haller 1992).

### **Reproduction/pregnancy**

Approximately 70 per cent of women with Down syndrome are estimated to be fertile (Hsiang et al. 1987; Tricomi et al. 1964). Studies by Scola of basal body temperature curves suggest that ovulation occurs in approximately 89 per cent of women with Down syndrome (Scola and Pueschel 1992). Hsiang et al. demonstrated elevated luteinizing hormone (LH) and follicle-stimulating hormone (FSH) levels in a group of postpubertal females with Down syndrome, suggesting some degree of primary ovarian dysfunction (Hsiang et al. 1987). Pregnancies have been documented in this population with both Rani et al. and Bovicelli et al. reporting pregnancies in more than 30 women with Down syndrome, resulting in liveborn infants both chromosomally normal and with trisomy 21 (Bovicelli et al. 1982; Rani et al. 1990). This number probably represents only a fraction of actual conceptions.

Pregnancy may put a woman with Down syndrome at high medical risk. Smaller maternal size, potential medical issues common in this population such as cardiac malformation, thyroid dysfunction and seizures, and potential problems understanding and adhering to prenatal care regimens all represent risks for both mother and foetus. Pregnant women with Down syndrome should be referred to a high-risk obstetric facility with teams of professionals experienced in caring for developmentally disabled women and their pregnancies.

### **Birth control**

In the United States, an estimated one million pregnancies occur per year in young females between the ages of 15 and 19 years; about half of these are brought to term (Spitz et al. 1993). It has been estimated that nearly half of all female high school students are sexually active (Gold 1995). The level of sexual activity of females with Down syndrome is unknown, but is thought to be low. In a study by Goldstein (1988) of 15 female adolescents with Down syndrome and 33 age and sex-matched controls, 13 of the girls with Down syndrome had not had sexual intercourse while no information was available on the remaining 2. Nine of the 33 controls (27%) were sexually active.

No forms of contraception are totally contraindicated for women with Down syndrome (Elkins 1997; Schwab 1992). Methods of contraception available to women include abstinence, surgical sterilization, hormonal therapy including Depo-Provera, Norplant, and oral contraceptives, the intrauterine device (Dalkon shield), cervical cap, diaphragm, spermicidal foams and gels, and female condoms (Doty 1995; Elkins 1990; Laros 1993; Lawson and Elkins 1997). The most frequently selected methods include abstinence and, because of their relative ease, the hormonal methods (Lawson and Elkins 1997; Van Dyke et al. 1995). The major contraindications to hormonal therapy in this population are the same for women with Down syndrome as for women

in the general population: dysfunctional uterine bleeding, history of breast cancer, liver disease, and ongoing or history of thromboembolic disease (Heaton 1995). Relative contraindications particular to women with Down syndrome include abnormal thyroid function; chronic treatment with anticonvulsants, systemic antibiotics, or antifungal medications; and cardiac abnormalities, in particular congenital heart disease (Heaton 1995; Van Dyke et al. 1995).

Surgical contraceptive procedures include laparoscopic tubal ligation, total abdominal hysterectomy, and endometrial ablation (Laros 1993; Lawson and Elkins 1997; Van Dyke et al. 1995). Surgical sterilization of mentally disabled women remains a controversial subject (American College of Obstetrics and Gynecology 1988; Heaton 1995; Patterson-Keels et al. 1994, Villanueva 1994). Major parental reasons for considering surgical sterilization are fear of pregnancy from sexual abuse, sexual activity, and contraceptive failure (Patterson-Keels et al. 1994). Such procedures require informed consent and the involvement of patient, parents or legal guardians, guardian ad litem and other legal advocates. Consent in most cases requires review by a human subjects review committee or hospital ethics review board. The process for some parents may be emotionally burdensome and financially draining. Useful resources include the American College of Obstetrics and Gynecologists Committee on Ethics publications or an attorney with experience with disability advocacy issues.

### **Sexual abuse**

As individuals with Down syndrome become more independent and visible members of the community, they become more vulnerable to emotional and sexual abuse (Carmody 1996; Pueschel 1996). The child abuse literature has documented that individuals with mental disabilities are clearly at increased risk for physical, sexual, and emotional abuse (Furey 1994; Schor 1987; Schwab 1992).

Some study groups of mentally retarded individuals have shown incidences of sexual abuse as high as 50 per cent (Elvik et al. 1990; Schor 1987). Sexual abuse is more common in females, and with those with borderline to mild mental retardation. The incidence of abuse decreases as the level of retardation becomes more severe (Elvik et al. 1990; Purey 1994; Schor 1987). Of even greater concern is that many people with mental retardation may be victims of recurrent episodes of sexual abuse (Ammerman et al. 1989; Schor 1987;).

Multiple factors predispose this population to abuse. Social isolation, communication and cognitive problems, and a small peer group all combine to put individuals with mental retardation at increased risk for sexual exploitation and abuse (Schor 1987). The living environment, which can be communal and involve multiple and transient caretakers, compounds the risk (Schor 1987). People with mental disabilities may be quite lonely and grateful for any form of attention; their often strong desire to be 'normal' and anxiety to please may predispose them to tolerate sexual maltreatment (Heaton 1995).

### **Masturbation**

Masturbation is a normal part of self-discovery (Etem and Leventhal 1995; Haka-Ikse and Mian 1993; Monat-Haller 1992;). It may provide gratification in itself or be a prelude to intercourse. In some individuals with mental disability, it may represent self-stimulatory or self-injurious behaviour. Reports of masturbation in males (40%) and females (52%) with Down syndrome demonstrate that this behaviour is not more common in persons with Down syndrome than in the general population (Goldstein 1988; Myers and Pueschell 1991; Rogers and Coleman 1992). Masturbation by the adolescent with Down syndrome may signal an emerging interest in sexuality. This behaviour may be disturbing and uncomfortable for caretakers, parents, and others in the community. If done in public, it may provoke embarrassment and discomfort in others.

Sex education should not focus on stopping masturbation, but on directing the activity towards appropriate times and private places (Edwards 1997). Most individuals with Down syndrome can be taught which times and places are appropriate for this activity. Relieving the discomfort of parents and caregivers may be more difficult, particularly if they view individuals with developmental disabilities as asexual (Edwards 1997).

### **Female Health Issues in Down Syndrome**

Routine gynecological care is not typically provided to women with Down syndrome. In a study by Goldstein (1988) only 7 per cent of females with Down syndrome had ever undergone gynaecological examination, in contrast to 64 per cent of controls (Goldstein 1988). Elkins et al. (1987) report markedly lower usage of reproductive health services by women with Down syndrome.

The timing of menarche in females with Down syndrome is similar to that in the general population (13.6 vs. 13.5 years) (Goldstein 1988). The age of menarche in the United States by 1990 was 12.5 years (Howard 1989). A later study by Scola and Pueschel found a mean menarchal age of 12 years 6 months in this population with a control menarchal age of 12 years 1 month (Scola and Pueschel 1992). Neither precocious nor delayed puberty is a normal finding in women with Down syndrome; both require appropriate evaluation with special attention to thyroid and cardiac status. Goldstein found that the mean duration of both menstrual bleeding and cycle are close to that of women in the general population (Goldstein 1988). Protracted bleeding and other menstrual cycle abnormalities are not normal findings and need evaluation. With appropriate guidance, many women with Down syndrome can manage their own menstrual hygiene (Kaur et al. 1997a; Scola and Pueschel 1992). In general if a woman toilets independently, then she may reasonably be expected to perform her own menstrual cares (Kaur et al. 1997b). Educational programmes successful in teaching this form of personal hygiene are concrete and repetitive (Kaur et al. 1997b).

### **Gynaecological problems**

There is little information on rates of breast cancer, reproductive tract cancer, menorrhagia, or leiomyoma in women with Down syndrome (Heaton 1995). McNeeley and Elkins reported in 1989 that 37 of 300 (12%) of women with mental retardation, including many with Down syndrome, required hysterectomy or other uterine surgery. About half of these surgeries were indicated for menorrhagia or symptomatic leiomyoma. Of the 300 cases, only three had malignancies . one uterine and two ovarian cancers (McNeely and Elkins 1989)

Only a few studies document menstrual cycle abnormalities in women with Down syndrome (Heaton 1995). Some data suggests that prolonged flow, a shortened cycle, and irregular bleeding may be more common in women with Down syndrome Jones and Douglas 1989; Mishe111987). Menstrual cycle problems in this population should prompt the same evaluations indicated in all women, with particular attention paid to evaluating thyroid function. Dysmenorrhea and premenstrual syndrome are at least as common as in the general population (Heaton 1995; Scola and Pueschel1992). Since weight gains a major concern in the older female with Down syndrome, a low-fat meal plan and regular exercise should be an integral part of health care (Sustrova and Pueschel1997).

### **Routine gynaecological health maintenance**

Routine gynaecological health maintenance for women with Down syndrome is ideally similar to that of all women. Goals of reproductive health care for women in this population are the same

as for any woman: screening for breast and reproductive tract disease, treatment of menstrual cycle abnormalities, and, if desired, contraceptive treatment.

AD annual mammogram is recommended for all women over 50 years of age (Heaton 1995). In this population, the first mammogram should be approached like the first pelvic examination: slowly and patiently, with much teaching and modelling. A significant family member or caregiver should be present or nearby for support.

A pelvic examination and Pap smear should be performed every one to three years beginning with the first episode of intercourse or the woman's eighteenth year of life, whichever comes first (Brown and Hmard 1996; Heaton 1995). After the baseline exam, women who are not sexually active need the exam repeated every three to five years or as medically indicated.

Women with a history of sexual activity continue to need an annual exam. Because of anxiety about the procedure, some women may benefit from sedation (Brown et al. 1992). Ketamine and midazolam have both been reported as appropriate sedatives for the outpatient setting. Examination under general anaesthesia is also an option, but has the drawbacks of anaesthetic-related risks and high cost (Brown et al. 1992).

For women who for whatever reason are unable to tolerate the procedure with adequate sedation, transabdominal pelvic ultrasound is an acceptable, if more expensive, alternative. Because women with Down syndrome have low rates of cervical cancer but higher rates of ovarian and uterine cancer, transabdominal examinations may actually be of greater utility in this population (Heaton 1995). If the incidence of sexual intercourse rises among women with Down syndrome, the ultrasound may not substitute for a thorough internal examination.

### **Pelvic examination**

Preparation, time, and patience are the keys to a successful pelvic examination. Well in advance of the actual examination, caregivers should discuss the procedure in concrete terms using visual aids; diagrams, fullsize pictures, dolls, and videotapes have all been used as educational tools for this concept (Heaton 1995). The pelvic examination should be done separately from other medical visits; so that the procedure is unhurried, it should be scheduled for as much time as possible (Heaton 1995). The presence of a parent or other caregiver should be encouraged. In those women who cannot tolerate speculum examination, a Pap smear can be obtained by locating the cervix with a finger and sliding a long Q-tip over the finger to obtain the sample (Elkins 1990).

### **Male Health Issues in Down Syndrome**

Puberty in males with Down syndrome is similar to that of control males in terms of timing of onset and sequence of development (Pueschel et al. 1985). While some authors find no difference in genital size, other authors have reported a relatively small testicular volume (Arnell et al. 1996; Pueschel et al. 1985).

An increased incidence of genital abnormalities, including cryptorchidism and coronal hypospadias, has been reported in males with Down syndrome (Lang et al. 1986; Smith and Berg 1976). These findings should prompt referral for paediatric urologic evaluation.

### **Reproductive health issues**

Most males with Down syndrome are sterile, with only one documented case of biological fatherhood by a man with Down Syndrome (Rogers and Coleman 1992; Sheridan et al. 1989). The aetiology of male sterility is unknown with many aetiologies proposed, among them abnormalities in sperm structure, count, and motility (Van Dyke et al. 1996).

Condoms are the only contraceptive method available to men; they may not be a practical method for some men with Down syndrome because of cognitive and fine motor problems. The question of vasectomy in this population is usually moot as most of these men are presumed sterile (Heaton 1995).

### **Routine reproductive health maintenance**

Examination of the male genitalia should be part of every routine physical examination (Heaton 1995). Genital abnormalities, and precocious or delayed puberty are indications for appropriate evaluation. Some men with Down syndrome, depending on individual cognitive status and level of personal support, may be able to learn testicular self-examination.

### **Dating and Marriage**

No major articles in the medical or psychology literature discuss dating or marriage by people with Down syndrome. Two young men with Down syndrome, however, did speak eloquently of these issues in their book *Count Us In: Growing Up with Down Syndrome*. Co-authors Jason Levitz and Mitchell Kingsley discuss with keen interest such subjects as 'having a date together, missing girlfriends, sexual stuff, and being in love with a girl' (Kingsley and Levitz 1994, pp. 74-82.). At one point, Levitz recalls when a school counsellor helped him to understand appropriate physical boundaries with female students. As this incident illustrates, the social and interpersonal skills needed for dating can be taught. Such instruction should occur as part of a life-skills-based school curriculum, preferably well in advance of any actual dating experience (Fegan et al. 1993).

Little is known about people with Down syndrome who marry. In 1988, Edwards published the results of a survey on marriage in this population. Of 38 married subjects with Down syndrome, all but three were women. None of their spouses had Down syndrome, although many had other developmental disabilities. The author found that most of the couples lived in highly supportive environments, including having family and other advocates nearby (Edwards 1988). A developmentally disabled person's right to marry is a controversial issue. In a few instances, this right has been contested in the courts by family members who wished to block or nullify such unions (Davis 1996).

Some individuals with Down syndrome have keen interest in marriage and family. The two young authors of *Count Us In* discuss these ideas of commitment and marriage in great detail. When asked what makes a good husband, one young man replies, '... you need to be able to understand how important and how you are going to support yourself and your wife... Part of my future plans is to marry and have a wife, but I need more skills' (Kingsley and Levitz 1994, pp. 101-2).

The issue of marriage in this population often frightens families (Edwards 1997). A series of studies by Shepperdson indicates that while caregivers verbally support the right of developmentally disabled people to have sex and to marry, they generally do not support it for their own children (Shepperdson 1995). While a somewhat more permissive caregiver attitude has emerged in the last two decades, it has not yet been always matched by the educational and counselling services necessary to support stable relationships potentially resulting in marriage (Shepperdson 1995).

### **Parenting and People with Mental Disabilities**

Parenting by people with Down syndrome has not yet been discussed in the literature. This information gap is consistent with a similar lack of data on the social experiences that predate child rearing, such as dating and marriage. As Shepperdson stated in his review, few individuals with Down syndrome have been given the education or freedom that are necessary to support sexual relationships leading to procreation (Shepperdson 1995).

Of all the issues related to sexuality in Down syndrome, the topic of parenting by members of this population is probably the most controversial. The child abuse literature clearly reflects the attitude that parenting is too demanding for individuals with cognitive disabilities (Tymchuk 1992) and that children raised by such parents are at high risk of abuse and neglect. Others view mentally retarded parents more optimistically; these writers reason that parents in this population are aware of their need to seek help and so are potentially more capable than parents with normal intelligence but low socioeconomic or educational status (Nigro 1975).

As previously mentioned, women with Down syndrome are often fertile; their infants have a high incidence of Down syndrome. Many chromosomally normal infants of mothers with Down syndrome have also been reported; these infants may have a higher incidence of major organ malformations. Thus, children born to women with Down syndrome are likely to have special needs, which can exacerbate the normal stresses of parenting. Cognitively normal children without Down syndrome born to such parents with Down syndrome may possibly face the complex family dynamics, as is commonly seen in couples with dwarfism and congenital deafness who produce unaffected children. These couples often fear not that they will have a child like themselves, but they will have a child who is not like them.

### **Support systems**

Physicians, parents, and educators need to provide the individual with Down syndrome with opportunities for learning, for new experiences, for success, and for failures (Smith 1995). These normal developmental needs may sometimes be neglected in the protected environment of home and school. Individuals need to learn daily living skills, appropriate socialization, and group behaviour (Smith 1995). Those individuals in work environments outside of the sheltered workshop need special guidance and support. For those few entering marriage, a supportive network of family and other advocates is important to maintaining the relationship (Edwards 1988).

### **Working vocational issues**

Work is not only a source of income but also of self-esteem, particularly in American society (Smith 1995). Employment options need not be limited to sheltered workshop settings, and successful placement is possible in a variety of work environments (Smith 1995). For example, several American companies such as McDonald's and Pizza Hut have made the employment of people with developmental disabilities a corporate priority. Learning how to deal with sexual harassment, emotional intimidation, or other similar problems in the work place needs to be part of socialization and vocational preparation during middle and secondary education. Social skills training including sex education, vocational rehabilitation training and work experience all need to be part of the curriculum for students with Down syndrome.

### **Emotional issues in adults**

Placement in a job, however, is only the first step in successful employment; the worker with Down syndrome may need extensive support on the job. A team which includes, at minimum, the individual's employer and a job coach must provide ongoing training, performance monitoring and appropriate supervision. Since individuals with Down syndrome may be at risk for depression and adjustment reactions, the team should strive for a calm, supportive atmosphere in which the employee's emotional status can be monitored (Chicoine et al. 1994; Smith 1995).

Psychiatric disorders are reported in fewer than 25 per cent of children and adolescents with Down syndrome (Myers and Pueschell 1991). Studies show a lower incidence of conduct

disorders, neuroses, paranoia, and schizophrenia in people with Down syndrome when compared to control groups with mental retardation of other aetiologies (Collacott et al. 1992; Myers and Pueschell 1991).

Individuals with Down syndrome are, however, at some risk for depression and adjustment reactions sometimes associated with relationships (Chicoine et al. 1994; Myers and Pueschel 1991). Many of these individuals are women in their late twenties and early thirties (Prasher and Hall 1996). Early identification and treatment of these problems are important. Supportive services fostering community integration, social skills, and self-esteem are important preventive measures for depression (Sloper and Turner 1996; Smith 1995).

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## **Appendix 4.1 Sex Education for Individuals with Developmental Disabilities**

(An eight-week programme of instruction)

### **Week #1**

Presentation of the positive aspects of who we are as sexual beings. Bisexuality of society, gender and society.

Similarities and differences of males and females.

Pride in differences.

Gender role differences.

Introduction to female and male anatomy.



**Week #2**

Private vs. public body parts.

**Week #3**

Private vs. public behaviours with regard to place, time, and language.  
Group vs. single appropriate behaviour.

**Week #4, Week #5**

Circle drills.

**Week #6**

Preventing sexual abuse. Situations using Circle Concerto

**Week #7**

Test on situations.

**Week #8**

Discussion on marriage, sex, and contraception.

(From: Elkins, personal communication 1997)

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Down syndrome or Down's syndrome, also known as trisomy 21, is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. It is usually associated with physical growth delays, mild to moderate intellectual disability, and characteristic facial features. The average IQ of a young adult with Down syndrome is 50, equivalent to the mental ability of an 8- or 9-year-old child, but this can vary widely.