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Abstract

This short article argues that too frequently sexuality is construed as being inexorably tied to child-bearing and that performing sterilisation procedures will decrease sexual vulnerability or activity. It recommends that parents and professionals form a partnership and work together to sustain a commitment to ensuring the right to human dignity and decision-making for young women with disability. **Keyword: Ethics**

STERILISATION

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Reprinted, with thanks, from 'THE YOUNG PERSON WITH DOWN
SYNDROME - TRANSITION FROM ADOLESCENCE TO ADULTHOOD'

Edited by Siegfried M. Pueschel.

The issue for which parents of adolescent females with Down syndrome most frequently seek counselling is that of sterilisation, an issue that demands extreme caution. Unfortunately, however, parents and caregivers often approach this issue in a panic. Most frequently, panic occurs when a girl with Down syndrome is beginning to show an interest in boys. The fear of an unwanted child and/or the wish (based on erroneous perceptions) to decrease sexual desire prompts many toward sterilisation.

Too frequently, parents and professionals construe sexuality as being inexorably tied to childbearing; further, they may believe that performing a hysterectomy or tubal ligation will decrease sexual vulnerability or sexual activity. Sterilisation does NOT -

- (1) decrease sexual desire;
- (2) remove the possibility of vulnerability;
- (3) remove the risk of sexual abuse; or

(4) remove the risk of venereal disease.

All sterilisation accomplishes is the removal of the risk of having a baby, a risk that can be as effectively removed by means of appropriate birth control and adequate training. The intent of today's sterilisation laws is to protect both the mother and the unborn child. Legislation has been enacted that requires informed consent and guarantees to persons with Down syndrome and other forms of retardation the right to participate in the decision-making process. This legislation ensures the right of these persons to participate in the selection of the time, place, and method of sterilisation, as well as the right to refuse the procedure.

The legislation has come in response to the massive sterilisation of persons with mental retardation that has occurred in the United States for many years. In the past, young females with Down syndrome were often sterilised between the ages of 10 and 18, and frequently long before they had reached full sexual development. Most often, complete hysterectomies

were performed so that the matter of menstruation did not need to be addressed. Aside from blatantly abridging the civil rights of young women with Down syndrome, this former policy was not monitored, and little care was taken to treat these women hormonally to offset the changes that should have accompanied sexual development. These women often then failed to develop sexually from the waist up. Working closely with parents and caregivers, professionals and advocates need to help families work toward the following goals on the issue of sterilisation:

THE REMOVAL OF PARENTAL FEARS

Discuss birth control and promote adequate time for decisions on sterilisation. Take time to evaluate the person with Down syndrome and her learning possibilities, so that decisions are made at a time when she can most enter into them.

THE PROVIDING OF ADEQUATE INFORMATION ON ALTERNATIVES TO STERILISATION

Appropriate birth control methods may allow the time for an education process to occur. It is important to have the time needed to meet the legal demands of the informed consent process.

The most important element of the issue of sterilisation is ensuring that the legal requirements of the informed consent laws are met. There have been several legal cases in which a person with mental retardation has later challenged the prior decision on the informed consent issue.

A DIFFERENT PERSPECTIVE

While much of this chapter has affirmed the right of young persons with Down syndrome to marry, to have a sexual relationship, and possibly to have children, it is not the sexual side of these issues that is of prime importance. In fact, the social/sexual needs of those with Down syndrome have little to do with these more sexual issues. Of far greater significance is the basic need for approval, in short, to be liked. The wish to avoid loneliness is much more important to most people than sex; a basic need of individuals with Down syndrome is to make themselves attractive so that they can receive praise and acceptance. To have friends, to do things and go places together is also a strong need. A current hairstyle, using cosmetics, wearing jewellery and establishing an identity as a young adult is far more important than sex.

Only when it seems that no other vehicle is available for establishing social relationships will sex become overly important to the person with Down syndrome. To experience the feeling of "togetherness" is one of the deepest, indeed most "normal", of human needs. Most of our social/sexual needs can be met outside a physical relationship and yet it, too, is one component of human relationships. Out of sexual togetherness a warm feeling of solidarity can grow and become the foundation of the finest, mutually rewarding relationship that mankind experiences.

Some persons with Down syndrome will normally grow and desire this kind of solidarity. Others will meet each other and become lifelong friends without any sexual element. But either kind of relationship can bring freedom from loneliness,

which is a real need of all people. Liberation from loneliness gives new meaning to life. Young people with Down syndrome want what non-handicapped young people want -

- A friend - someone to talk to, with whom they can share "important things":
- Some warmth, someone to touch, someone who will put their hand on their shoulder in a way that says, "I like you":
- Approval - some message from others that tells them, "You're okay":
- Affection - love, and the feeling that they are loved. This is not necessarily sex:
- Dignity - some communication from others that they are of worth:
- Social outlets - to avoid loneliness:
- Sexual satisfaction - the purely biological need for sexual contact and stimulation. This need is small in comparison to the other needs listed here, but it is very genuine, nonetheless.

While there is a wide range of intellectual function in persons with Down syndrome, and although a great many other variables need to be taken into account when dealing with the issues of sexuality, marriage and parenting, it is essential that these issues be addressed.

SUMMARY

This chapter has proposed that a discussion of sexuality,

relationships and marriage is incomplete if it is separated from the consideration of social skills training and competence building. Therefore, social skills developed through a community-based, "real-life", situational-programming training programme reinforced by parents and caregivers are fundamental to the fulfilment of the sexual needs of the person with Down syndrome.

In spite of the recognised importance of the ability of persons with Down syndrome to learn to function with others, it is only recently that concerted efforts have been directed toward relationship and sexuality training within the social skills context. The inclusion of identity formation, self-acceptance, awareness of others, problem-solving, decision-making, communication and assertiveness form the backbone of such training. Learning social amenities - such as how to meet and greet people, how to show others we care, proper eating and language seem to be suitable skills for initial community contacts. These capacities have been researched and have proven to be dependent on opportunities for recurrent, diversified, and satisfying interactions with other people.

Young adults with Down syndrome are frequently shut off from such interaction, however. Although "the enlightened" may deny that first impressions actually do impress, the fact remains that physical appearance is a crucial component of interpersonal contacts for persons with Down syndrome.

Several aspects of appearance can affect the acceptance of the young person with Down syndrome, including: minimising the visibility of physical differences, culturally

appropriate clothing and hairstyles, and proper body weight. Young people with Down syndrome who do not fit into the prevailing criteria for physical attractiveness because of facial or body expression and form, gait, and/or speech become the victims of their labels - "retarded", "childlike" - and therefore are assigned lowered expectations. Intervention procedures to normalise these persons' appearance help to break down some of the barriers to their social integration.

Sexual activity and marriage are probably the most controversial and feared aspects of social skills training. Likewise, the denying of these rights and behaviours cancels out the humanness of sex. Sex, sexuality, and sexual activities are important facets of social skills training. To bypass the teaching of appropriate social/sexual facts is to deny persons with Down syndrome a large share of their personal rights. The expression of sexual needs and the self-control important in sexual expression can be taught, and is critical to the development of the self-concept and self-esteem of

persons with Down syndrome (Frank & Edwards, 1986).

Young persons with Down syndrome need social/sexual skills training even more than "normal" persons do, both because the former do not have the opportunity to otherwise acquire this awareness through the usual channels of socialisation in society and because they do not learn well incidentally. The scope of this skills training must include teaching, social amenities, decision-making, interpersonal satisfaction, relationships, marriage, anti-fertility methods, parenthood, and the meaning of sexual relations. Numerous state-of-the-art curricular materials are available that utilise proven methods of training for persons with Down syndrome. But success of training seems to be dependent on parents and professionals forming a partnership, affording normalising experiences with heightened expectations, and sustaining a commitment to ensuring the right to human dignity and decision-making.