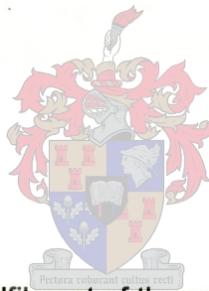


**THE PRINCIPLE OF RESPECT FOR AUTONOMY AND THE STERILIZATION OF
PEOPLE WITH INTELLECTUAL DISABILITIES**

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Assignment presented in partial fulfilment of the requirements for the degree Master
of Philosophy (Applied Ethics) at the University of Stellenbosch

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Declaration

I, the undersigned, hereby declare that the work contained in this assignment is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

ABSTRACT

The implementation of eugenic policies reached its peak during the 20th century when thousands of people with intellectual disabilities and other "undesirable qualities" were involuntarily sterilized. Although most of the eugenic policies have been removed, countries such as South Africa, still make legally provision for the involuntary sterilization of people with intellectual disabilities.

Torbjörn Tännsjö (1998) used the "argument from autonomy" to argue that involuntary sterilization practices are wrong because it involves compulsion. According to him, society should never interfere with people's reproductive choices and people should never be required to qualify for the right to have children. The aim of this assignment was to systematically assess the "argument from autonomy" as far as the policy of involuntary sterilization of people with intellectual disabilities is concerned. To this end, the concept of autonomy and the principle of respect for autonomy are discussed and applied to the intellectually disabled. It is argued that autonomy and respect for autonomy are useful concepts to apply to some people with intellectual disabilities. These individuals should not be automatically assumed to be incompetent, but their competence needs to be determined on an individual level, with reference to the complexity of the decision to be made. Special effort is needed from health care professionals to obtain (where possible) informed consent from people with intellectual disabilities. The application of the principle of respect for autonomy to matters of reproduction leads to the conclusion that people with severe to profound levels of disability, are unable to provide informed consent for sexual intercourse. Therefore some form of paternalistic protection is needed for these individuals. People with mild to moderate intellectual disabilities who are however competent to consent to sexual intercourse should never be prohibited from procreation by means of involuntary sterilization. State interference in matters of reproduction should be limited to interventions where (i) children are seriously harmed by parents and (ii) to protect those who are incompetent to consent to sexual interactions with others. Apart from these exceptions, the intellectually disabled is entitled to the same procreative rights as all other citizens.

OPSOMMING

Die implementering van eugenetiese beleid het gedurende die 20 ste eeu 'n hoogtepunt bereik met die onwillekeurige sterilisering van duisende persone met intellektuele gestremdhede en ander "ongewenste kwaliteite". Alhoewel meeste van die eugenetiese wetgewing verwyder is, maak lande soos Suid-Afrika steeds wetlik voorsiening vir die onwillekeurige sterilisasie van persone met intellektuele gestremdhede.

Torbjörn Tännsjö (1998) maak gebruik van die "outonomie argument" om te argumenteer dat onwillekeurige sterilisasie praktyke onaanvaarbaar is omdat dit dwang bevat. Hy voer aan dat die samelewing nooit in die reprodktiewe keuses van mense behoort in te meng nie en dat dit nooit vir mense nodig moet wees om vir ouerskap te kwalifiseer nie. Die doel van hierdie werkstuk was om sistematies die "outonomie argument" te analiseer ten opsigte van die beleid van die onwillekeurige sterilisasie van persone met intellektuele gestremdhede. Met hierdie doel voor oë word die konsep outonomie en die beginsel van respek vir outonomie bespreek en toegepas op die intellektueel gestremde persoon. Daar word aangevoer dat outonomie en respek vir outonomie nuttige beginsels is om in ag te neem in kwessies rakende intellektueel gestremdes. Hierdie individue moet nie outomaties as onbevoeg beskou word nie, maar hul bevoegdheid moet eerder op 'n individuele basis beoordeel word, inaggeneem die kompleksiteit van die besluit wat geneem moet word. Voorts word daar van gesondheidsorgpersoneel verwag om moeite te doen met die verkryging van oorwoë toestemming (waar moontlik) by persone met intellektuele gestremdhede. Die toepassing van die beginsel van respek vir outonomie op aspekte rakende reproduksie, lei tot die gevolgtrekking dat persone met ernstige intellektuele gestremdhede nie in staat is om toestemming tot seksuele omgang te verleen nie. Dus, is 'n vorm van paternalistiese beskerming in hierdie gevalle aangedui. Persone met intellektuele gestremdhede wat egter wel bevoeg is om toestemming tot seksuele omgang te verleen, moet nooit weerhou word van voortplanting deur middel van onwillekeurige sterilisering nie. Inmenging deur die staat in kwessies rakende reproduksie moet beperk word tot intervensies waar (i) kinders ernstige skade berokken word en (ii) die beskerming van persone wat onbevoeg is om toestemming tot seksuele interaksies met ander te verleen, benodig word. Afgesien hiervan, is die intellektueel gestremde persoon geregtig op dieselfde reprodktiewe regte as alle ander landsburgers.

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CHAPTER 1

INTRODUCTION AND PROBLEM STATEMENT

1.1 Introduction

During the 20th century the involuntary sterilization of the intellectually disabled occurred in the USA, European as well as developing and third world countries as part of eugenic policies. Since then these policies have been heavily criticized and removed. Although the eugenic policies have been removed, the involuntary sterilization of the intellectually disabled still continues worldwide as part of reproductive health programs. It remains a controversial practice, with numerous ethical and legal implications, some of which will be discussed in the present assignment. This chapter gives a brief overview of the ethical/philosophical issues underlying the practice of sterilization of the intellectually disabled as well as the focus and outline of the present assignment.

1.2 Problem statement

Ever since the first safe forms of sterilization were introduced during the late 19th/ early 20th century, sterilization as a form of contraception has been both acclaimed and criticized. Acclaimed by those who favored a safe, long-term contraceptive that will render them some social and sexual freedom. Criticized by those who view it as a form of oppression: oppression against women and those who are not able to consent to voluntary sterilization.

The availability of this new technology led to a period of increased governmental intrusion in reproductive choices (Areen, 1989:94). For example, the sterilization of people with intellectual disabilities who were unable to give consent, occurred increasingly during the 20th century as part of eugenic legislation. These eugenic practices stemmed mainly from beliefs that intellectual disabilities were hereditary and that legalised eugenic movements were needed to prevent people with an intellectual disability to "reproduce more of their own" (Denekens, Nys & Struer, 1999:25; Park & Radford, 1998:318). Countries in which eugenics was practised include Germany, Sweden, Norway, India, Africa, USA, Peru, etc. (Strauss, 1995:10-11).

Following the exposed horrors of Nazi Germany and Sweden, the human rights movements, and new scientific developments proving that few forms of intellectual disability is hereditary, a growing disapproval of mandatory sterilization for the mentally handicapped developed. In 1942 the US Supreme Court declared that reproduction is a fundamental human right and in 1971 the UN declared that people with an intellectual disability are entitled to the same human rights as all other human beings (Denekens et al, 1999:25). From these premises the conclusion can easily be drawn that procreation is a basic human right which also applies to the person with an intellectual disability.

Whereas the eugenic movements were characterized by public and state interference in matters of procreation, the human rights movements emphasize the private nature of decisions regarding procreation and reproduction. The tension between procreation as a private versus a public matter has become a contentious issue. Although most people will agree that human beings are autonomous and that their autonomy should be respected in matters of reproduction, the notion of autonomy and respect for autonomy becomes extremely problematic when applied to the person with an intellectual disability. Precisely those faculties which make informed consent and voluntary decision-making possible, are affected by the disability these people suffer from. Therefore, from a philosophical point of view, it doesn't necessarily follow that an intellectually disabled person has "personhood" and that the principle of respect for autonomy can be applied in matters stemming from reproductive rights. In fact it is often questioned whether they do not have "marginal personhood" that may exclude them from certain human rights (Boddington & Podpavec, 1991:178; Spicker, 1990:139).

A myriad reasons supporting or challenging the ethical basis of the involuntary sterilization of the intellectually disabled, emerged in recent years. Some cited reasons such as:

- the inability of the intellectually disabled person to make decisions about procreation,
- the inability of the intellectually disabled person to care for a child,
- the trauma associated with pregnancy and giving birth for the disabled person,
- the disadvantages of long-term contraception to the person's health,

- the burdens placed on the family caring for the intellectually disabled and
- managing dysmenorrhea as support to their arguments in favour of sterilization of the intellectually disabled.

The opposite position is often motivated by arguments such as:

- procreation and personal inviolability are basic human rights,
- sterilization is invasive and permanent,
- people who are intellectually disabled are not necessarily incapable of giving informed consent
- and to anticipate future “hardship” for the intellectually disabled person or his/her offspring is difficult to determine since “hardship” is such a subjective term (Draper, 1991:95-97; Canadian Law Reform Commission, 1983: 1-8).

According to Torbjörn Tännsjö (1998;1999) the compulsory sterilization practices which occurred in Sweden can be criticized according to three strands of criticisms, namely the argument from autonomy, the argument from caution and the argument from biological scepticism.

The argument from autonomy (which is also supported by Tännsjö) regards the sterilization policy as wrong because it involved compulsion. Society should never interfere with people’s reproductive choices and the legal right to have children should be absolute - not a right people have to qualify for. This argument implies that neither the possibility that someone cannot take good care of their children nor the chance that the child will be born with a serious hereditary disease should be grounds for compulsory sterilization.

The argument from biological scepticism, does not problematize the fact that sterilization is compulsorily done nor that people who are not mentally handicapped are held as such and therefore sterilized, but that the aim of the policy is to avoid the birth of people with handicap and disease. People who support this view deem sterilization wrong if it is aimed at avoiding hereditary disease to spread. According to this view, it is immaterial whether someone consents to it voluntarily or compulsorily.

The argument from caution regards Sweden's policy of compulsory sterilization as wrong, not because the policy is wrong as such but because the policy has been abused. This line of thinking presupposes that there are cases in which compulsory sterilization is in order. It should just be exercised in a responsible manner and should only be directed at people who are really not capable of taking care of their children or to prevent the birth of seriously ill or handicapped people. This position was also taken by the South African legislators in the formulation of the Sterilization Act of 1998. According to the act, people who cannot consent to sterilization can be sterilized against their will if a selected panel of experts have made such a recommendation upon a received application from a caregiver or family member.

The aim of the present assignment is to systematically assess the "argument from autonomy" with reference to the South African situation as far as the policy of involuntary sterilization for people with intellectual disability is concerned. In the process the principle of autonomy and respect for autonomy will be critically scrutinized as well as the implications of a strict and prima facie adherence to this principle.

1.3 Outline of present study

The following chapter will give a brief factual and historical overview of sterilization as a form of contraception as well as a discussion of the ethical problems associated therewith. A description of the current South African policy in this regard is also provided. The notion of "intellectual disability" will be discussed in chapter three by means of a brief historical overview as well as attempts to provide both the medical/psychological and philosophical perspectives on intellectual disability.

In the fourth and fifth chapters, the concept of autonomy and the principle of respect for autonomy will be addressed. First a conceptual analysis will be provided followed by the application thereof to reproductive choices in general. The sterilization of the mentally handicapped, specifically, will be discussed in chapter six. Concluding remarks and recommendations will be given in chapter seven.

CHAPTER 2

CONTRACEPTIVE STERILIZATION

2.1 Introduction

The quest for effective birth control¹ has been present ever since the beginning of (wo)mankind. It gained momentum during the late 19th/early 20th centuries when major advances were made regarding the development of safe and effective methods of contraceptives. One of the contraceptive methods that were developed (and which is currently the most popular among women in the United States), is female and male sterilization. Sterilization is one of the few methods that are approaching 100% effectiveness and its effectiveness is not influenced by so-called "user-error". Although this development had the potential to provide women and men with sexual freedom, it also became the ideal method to limit procreation among people who were deemed unfit for parenthood. In this chapter an overview of sterilization as a form of contraception and some of its accompanying ethical problems, are provided, after which the use of sterilization for eugenic purposes is discussed. This is followed by an outline of the present sterilization legislation and the implementation thereof in South Africa.

2.2 Contraception: current practices

The use of mechanical, animal, chemical and plant materials as contraceptives has been described in ancient documents. For example the papyri of Kahun (1850 BC) recommended a vaginal suppository, made from crocodile dung or honey, and in papyri of Ebers (1550 BC) the use of condom-like covers, made from intestines or skin, were described. During the 16th century Gabriello Fallopio developed the prototype of the condom in order to prevent the spread of venereal diseases, such as syphilis, and in the late 19th, early 20th century safe and effective forms of sterilization were developed (Noonan, 1978:204). During the 20th century various forms of contraceptives were developed and/or refined of which the following are currently known and used (Duncan, Dunstan & Wellbourn, 1977:96-97; Knight, 1998:355-365):

¹ Birth control can be defined as any method used to prevent birth, including contraceptives, contraceptives and chemical or surgical abortion after implantation, whereas contraception refers to birth control methods that have prevention of conception as their primary birth control action (Callahan, 1998:335).

- **Oral contraceptives.** “The Pill” was approved by the Food and Drug Administration of the USA in June 1960 and since then various forms of oral contraceptives, all containing different combinations of synthetic progestagens and estrogens, were developed. Their effectiveness in preventing pregnancy have been proved to be 97-99% with relatively few side effects and health risks.
- **Subdermal implants** (such as Norplant)
These implants deliver progesterone on a continuous basis, and are highly effective methods of birth control for a period of at least 5 years. Although it has been piloted in South Africa it is not considered for widespread use due to practical limitations.
- **Depo-Provera**
“The injection” contains injectable progesterone, and is a highly effective form of birth control for a period of three months. The use of Depo-Provera often (but not always) results in the cessation of menstruation, which proves to be useful in the management of menses of women who are intellectually disabled. This method of contraception has only been used since the early eighties and relatively little is known about the long-term effects of its use. Some concerns have been raised, though, that long-term use may result in cardiovascular disease and it has been associated with breast and uterus cancer in experiments with animals. Although it has been used widely outside the USA as a contraceptive, the U.S. Food and Drug Administration has not approved it as a contraceptive, but it is available for other purposes (Ackerman & Strong, 1989:65).
- **Condoms**
Male condoms are currently widely used, since it both acts as a contraceptive and prevents the transmission of sexually transmitted diseases and the HI virus. It is 97-99% effective as a form of birth control, provided that it is used properly. Female condoms have also been developed and were recently piloted in South Africa.

- **Other**

Other contraceptives available, although not commonly used, are the diaphragm, the cervical cap, the contraceptive sponge, spermicides, intrauterine devices (IUD) and postcoital contraception (known as the “morning after pill”).

- **Surgical sterilization**

Sterilization can be defined as “ any procedure, the primary purpose of which is to render a person incapable of reproduction” (Duncan et al, 1977:310; Hellman, 1978:1606). It can take a contraceptive (the intention of permanently removing reproductive capacity as a means of family planning), therapeutic (performed to prevent harm resulting from reproduction itself) or eugenic (the intention of preventing reproduction in those considered to have undesirable genes) function (Draper 1991:77).

Surgical sterilization is currently the most common form of birth control in the United States. Worldwide it is calculated that 16% of married women are protected from pregnancy by tubal ligation. Although there are numerous procedures and modifications for contraceptive sterilization, they all basically involve the bilateral cutting, tying, sealing and/or removing of a small part of the fallopian tubes (in women) and the vas deferens (in men). In order to perform a tubal ligation, electro- or thermocoagulation, mechanical rings or clips and chemical adhesives may be used. A tubal ligation (salpingectomy) prevents the ovum and sperm to reach each other at the necessary site of fertilization in the fallopian tube, whereas a vasectomy prevents sperm to pass from the epididymis (where it is stored) to the vas deferens. Tubal ligations and vasectomies are regarded as less intrusive forms of sterilization since it involves only minor surgical incisions (Duncan et al, 1977:311-312; Hellman, 1978:1607; Knight, 1998:364).

In contrast hysterectomies (the removal of the uterus), the removal of the ovaries (oophorectomies) and male castration (orchidectomies) are regarded as more intrusive sterilization procedures. Oophorectomies involve the surgical removal of the ovaries and are often referred to as female “castration”. This procedure usually results in the early onset of menopause and consequently has serious health risks. The lack of estrogen has the cessation of menstruation as a side effect with

accompanying hormonal changes and symptoms of hot flashes, depression and a decrease in bone density which can lead to the early onset of osteoporosis (Park & Radford, 1998:339).

The male version is called orchidectomy (male “castration”) and usually involves the removal of the testicles. It can serve a double purpose, since the probability of reproduction is reduced and supposed aggressive sexual behaviour is curtailed because the level of testosterone is reduced, if not eliminated by the procedure (Park & Radford, 1998:339). Until the recent past, both oophorectomies and orchidectomies were commonly performed on people with intellectual disabilities – often with the onset of puberty. For females, it was an easy solution to problems associated with menstruation management and for males, it was an easy solution to problems associated with sexual and aggressive behaviour, making these people “more controllable” within an institutional environment. According to current sterilization legislation in South Africa, these operations may only be performed if the person in question’s health is seriously jeopardized if these operations are **not** performed. Yet, parents and care givers of children with intellectual disabilities often request sterilization, thinking (and hoping) that a hysterectomy will be performed and that their problems with menstruation management will be resolved².

2.3 Ethical problems related to fertility management and sterilization

Birth control and contraception have been and still remain highly complex moral, legal, religious, political, cultural, class, racial and gender issues within our society. Areen (1997:105) distinguishes between three historic stages in fertility management – each accompanied by its own ethical and moral concerns. During the first period, limiting procreation, also among married couples, was prohibited. Both religious and secular authorities supported this view. The second stage involved the eugenics movement during which many people regarded as unsuitable for procreation, were involuntary sterilized. Thirdly, the period since the 1960’s during which the human rights movements discouraged any state interference with the individual’s right to privacy in matters of reproduction. Concerns about autonomous decision-making and informed consent became more pronounced during the latter phase.

² I am indebted to Marie Adamo, Deputy Director, Reproductive Health, Dept of Health for this information.

Throughout the three phases, the social attitudes and the position of the state toward birth control were tied to various considerations such as sexuality, politics, religion, economics and the social status of women (Callahan, 1998:336).

2.3.1 Religious and secular views

In ancient times, Jewish scriptures did not explicitly condemn contraception. Yet, various scriptures emphasize the importance of fertility and the duty of procreation, ranging from passages such as Genesis 1:27-28 in which God ordered man to “increase and multiply”, to the promise of God in Deuteronomy 7:13 that “no man or woman among you shall be childless”. Genesis 38:8-10 describes how Onan angered God because he purposefully let his seed “fall to the ground” and therewith disobeyed his father’s orders to impregnate Tamar, the wife of his deceased brother. Later Jewish thought were divided on the issue of duties to propagate race: some rabbis recognized that there are certain cases in which a woman may “legitimately use root potions as a contraceptive”. It seems therefore that Jewish thought in general disfavoured the practice of contraception although it was never explicitly forbidden in the scriptures (Noonan, 1978:205).

According to Noonan, (1978:206) a specific doctrine on sexuality evolved during early Christianity, and had the following major themes:

- the superiority of virginity
- the institutional goodness of marriage
- the sacred character of sexual intercourse
- the goodness of procreation and
- the evil of extramarital intercourse and homosexual conduct.

Early Christianity therefore viewed virginity as desirable, but marriage as good. Within marriage, husbands were expected to “use their wives moderately and only for the raising up of children” and within this context, contraception was excluded.

Augustine provided a detailed analysis in which he argued that the use of contraceptives is the enemy of the church. According to his analysis, offspring is one of the goods of marriage and in order to keep marital intercourse free from sin, the couple must have “offspring in view”. The “mere absence of procreative intent made marital intercourse venially sinful; positive prevention of procreation turns the bridal

chamber into a brothel" (as quoted in Noonan, 1978:208). Today the Catholic Church is still divided on the issue with some members of the papal commission supporting the use of contraceptives in marriage. Others support the view expressed by Pope Paul VI in *Humanae Vitae* where he re-established the position of Pius XI and XII, namely that contraceptive intent and practice is acceptable for serious personal and social reasons, but each marital act should otherwise be open to its procreative purpose (Duncan et al, 1977:94; Noonan 1978:213).

Early Protestantism echoed the views on contraception formulated by the Roman Catholic church and this was even more pronounced as these religious counterparts were in competition for numeric support.

Until 19th century Christian theology developed, both Protestantism and Catholicism were opposed to contraception - a view also supported by the secular governments. For example, in 1877 Annie Besant and Charles Bradlugh were prosecuted in Britain for distributing texts on contraception and in the United States the Comstock law was passed (in 1873) which forbade the mailing or importation of contraceptives (Noonan, 1978:210). Most American states also forbade the selling and advertising of contraceptives since contraceptives were associated with promiscuity and the moral decline of family values. Therefore, despite the scientific advancements, the use and distribution of effective and safe forms of contraception were met with strong social resistance (Callahan, 1998:336).

From the last quarter of the 19th century until the 1930's a major shift took place in terms of the moral acceptance of contraception. This was in part stimulated by the advancements in science, sociology and economy. Infant mortality rates decreased and the life expectancy of people increased as social circumstances were improved and the science of medicine became more vigorous. Concerns were increasingly voiced on the dangers of overpopulation and the effect it will have on the world's resources. Therefore, in the West, the use of contraceptives became a solution to the pressing problem of overpopulation, a substitute for abortion and an aid to personal happiness. The humanist arguments in favour of contraceptives were increasingly accepted and after the Second World War the opposition to contraception gradually disappeared. In efforts to deal with concerns of population

control, governments revoked certain laws and developed policy in which “family planning” was actively promoted. (Noonan, 1978:211).

The development of contraceptive technology as well as social and political factors led to the second phase in fertility management identified by Areen (1997:105), namely a period of eugenics. During this phase contraception, especially sterilization, came to be an effective way of dealing with “unwanted” or undesirable elements in society and to keep them from having more of their own. The period of eugenic policies started and reached its peak in the early half of the 20th century.

2.3.2 Eugenics

During the 19th century scientific thought in general supported the belief that important social traits were inherited. Francis Galton, cousin of Charles Darwin, was the first to express these ideas in modern scientific language, although Plato and Aristotle have expressed similar ideas (Galton, 1998:266). In his scientific endeavors, Galton collected family pedigrees to show that “high achievement” ran in families and by implication so did traits of alcoholism and criminality (Reilly, 1996:1). The term “eugenics” (derived from the Greek: *eu-* good, well; *gen-* genesis, creation), was also the brainchild of Galton and in 1907 he became the Honorary President of the English Eugenics Education Society founded in the same year (Galton, 1998:263). The Society concerned itself with “questions bearing on what is termed in Greek, *eugenes*, namely good in stock, hereditarily endowed with noble qualities” (Hubbard & Henifin, 1984:76). Galton’s main proposals were: (a) Extensive family records should be kept and in competitive examinations for professional posts, extra marks should be awarded for “family merit”; (b) Women from “gifted families” should be encouraged to get married young and be given financial incentives for having many children; (c) Rules of celibacy for gifted individuals should be abolished; (d) The state should take some form of action against the procreation of the feeble-minded, the insane and some classes of habitual criminals (Galton, 1998:266; Galton & Galton, 1998:101).

This world view was implemented in various western societies from the 1920’s onwards. In the USA it was implemented politically by the eugenic sterilization laws and the Immigration Restriction Act of 1924. The Supreme Court, in the case *Buck vs Bell* (1927) supported these practices when it ruled that the Virginian law passed

in 1927, which allowed the state to sterilize individuals found to be incompetent, was constitutional. The view of the majority of the Supreme Court was expressed by the words of Judge Oliver Wendell Holmes,

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often felt to be much by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes.....three generations of imbeciles are enough (Smith & Polloway, 1993:208-209; Strauss, 1995:10).

By 1931, almost 30 states had enacted compulsory sterilization laws that were aimed at the "feeble-minded" or people with "hereditary defects" such as epileptics, drunkards, sexual perverts, the insane, rapists and habitual criminals (Duncan et al, 1977:121). Many of these laws were never enforced, yet by January 1935 some 20 000 people had already been forcibly sterilized and by the 1970's more than 60 000 individuals were sterilized involuntarily in the USA (Park & Radford, 1998:318; Smith & Polloway, 1993:209).

These sterilizations often accompanied the institutionalization of people with mental retardation. Smith and Polloway (1993) studied the data of 212 individuals who were sterilized in Virginia and found that those sterilized in institutions were mostly female, poor and young, that the majority of sterilizations were performed between the ages of 15 and 24 and that 15,8% of the discharged individuals who did not have intellectual disabilities, were also sterilized. People who were suitable for placement outside institutions, such as people with mild or borderline intellectual disabilities, were more often sterilized than those within the severe-profound range.

Park and Radford (1998) analyzed the files of the eugenics board for the province of Alberta and found that most sterilizations were seen by the board as a form of protection and not a form of punishment. In Alberta people were sexually sterilized if

they were found to be in danger to transmit mental deficiency to their children, or were regarded as incapable of intelligent parenthood. The reasons cited for sterilization included:

- mental deficiency;
- the danger of the transmission of the progeny of "mental disability" or "mental deficiency";
- the danger that the exercise of the power of procreation may involve risk or mental injury either to the patient or her progeny;
- inability to be "intelligent" parents;
- poor family history of 'mental deficiency';
- nervousness and insanity;
- epileptic hemiplegic imbecility;
- uncontrolled sexual interest and activities;
- elevated risk of pregnancy when returning home for holidays;
- offspring born with physically handicaps (Park & Radford, 1998:325).

Sterilization was often seen as a biological solution for social and behavioural problems such as behavioural difficulties (abnormal sexual behaviour, destructive and criminal tendencies), deprivation of family support, parental death, spousal abandonment, impoverished family background and a precondition to institutional release (Park & Radford, 1998:327-335).

In Germany eugenic sterilization started during 1933 and within two years almost 56,244 people were judged to be hereditary defective and were consequently sterilized without consent. Although the sterilizations were initially aimed at the "feebleminded", it was quickly extended to include homosexuals and other "undesirables". Eugenics quickly escalated from sterilization to euthanasia and eventually led to the murder of millions of Jews, gypsies and other outcasts. These excesses eventually contributed to the decline and eradication of eugenic movements (Hubbard & Henifin, 1984:78; Reilly, 1996:2).

To the surprise of many, eugenics was also practiced in the Scandinavian countries. In Denmark around 40 000 handicapped people have been sterilized since 1929 and in Sweden approximately 60 000 handicapped people were sterilized between 1935

and 1976. The main motivation behind the eugenic movements in Scandinavia was to remove undesirable people and to save money. ".....sterilization was a cheap and simple means for reducing the numbers of the socially undesirable and marginalized, while reducing welfare spending in a time of global economic depression" (Gems, 1999:202). Sterilization was also required as a condition for teenagers to be released from schools for children with learning difficulties and as a precondition in order to get an abortion or permission to marry. By 1970 over 170 000 Scandinavians were sterilized as part of these programmes. Although some have argued that sterilization was never compulsory in the Nordic countries, this argument creates a false impression. For example, many mentally ill and retarded people couldn't give or withhold consent. Therefore, as legal incompetents, decisions were taken on their behalf by relatives and state authorities (Gems, 1999:293).

After the Second World War and the Nazi eugenic movement, the role of genes and especially recessive genes were increasingly investigated and the nature/nurture debates surfaced. It became clear, scientifically, that the inheritance of "social traits" is a very complex process (Hubbard & Henifin, 1984:79).

According to Hubbard and Henifin (1984:77), the importance of the eugenics movement lies in the fact that it provided scientific justifications for people's social and economic failures or successes, or in the words of Park and Radford (1998:338): "eugenic sterilisation was a 'prophylactic measure' designed to curb the procreation of undesirables while at the same time firmly placing the blame for their disabilities on the victims or their immediate families". Objections to the 20th century eugenics movements are that they were authoritarian and based on an inadequate understanding of human genetics and that they were infringements on the individual's privacy regarding reproductive matters (Lappé, 1978: 462). Some writers suggest that the principle of doing no harm should preclude any attempt at genetic intervention that might generate unintentional harms and that socio-economic factors which are strongly associated with increased incidences of birth defects or reduced scores on IQ tests, should be addressed.

The increased genetic knowledge which makes the ability to predict the consequences of reproductive behaviour more accurate, brings two ethical traditions into conflict. The one assigns a high value to autonomy and self-determination in

decision-making, while the other imbues individuals with a sense of duty to act for the common good. Some argue that society does not have an unmitigated right to interfere and intervene in the reproductive behaviour of the individual. Others feel that the state has an obligation to educate and instruct in matters affecting reproduction, since society has the implicit obligation to future generations to at least not leave them worse off genetically (Lappé, 1978: 466).

Tännsjö (1998:238-239) provides a summary of the three main strands of criticism that were raised against the eugenic sterilization policies of Sweden. According to the argument from autonomy the sterilization policy was wrong because reproductive matters are private and should never be interfered with by society. People (including people with intellectual disabilities) should never have to qualify for the right to have children. If parents fail to take adequate responsibility for the upbringing of their children, society should act and take custody of the children or assist and support the parents.

The argument from caution regards the sterilization policies as wrong because it wasn't conducted carefully. It was based on bad science and was conducted in a rash and careless manner. This approach does not regard compulsory sterilization as intrinsically wrong, but argues that if it is undertaken, it must be aimed at people who are really not capable of taking care of their children or should only be undertaken to prevent the birth of seriously ill or handicapped people.

Thirdly, Tännsjö (1998:239) describes the argument from biological scepticism according to which the sterilization policies were wrong because they tried to avoid the birth of people with handicap and illness. The more radical version holds that handicaps should not be cured even if cures exist, since it is a good thing that society has to adapt to the needs of groups with special needs. In the less radical version, handicap and illness are regarded as problematic, and if possible, should be cured. Yet, it is not morally permissible to see to it that healthy children, rather than ill or handicapped children, are born. This implies that sterilization, in order to avoid the spread of hereditary disease, is wrong, regardless of whether it was done compulsorily or voluntarily.

Whichever of the three arguments one uses to criticize eugenic programmes, it has important implications for future policies in this regard. In South Africa, the current legislation is supportive of the “argument from caution” - it makes provision for the sterilization of the intellectually disabled, but also has stringent control mechanisms in place to safeguard against the abuse thereof.

2.3.3 Current ethical concerns

Since the Human Rights Movements and the so-called “sexual revolution” of the 1960's, contraceptives were more readily available and more widely accepted. Consequently the ethical concerns about sterilization shifted towards the role of gender, race and class issues in sterilization programs and questions about the individual's right to self-determination and autonomous decision-making.

In South Africa the so-called triple oppression in terms of race, class and gender, was especially pronounced during the “Apartheid” years, also in the way contraceptives were marketed, distributed and sometimes given without obtaining proper informed consent. Family planning and birth control technology was often used in the service of ideological motives. Contraceptives were actively promoted among black and poor women in order to limit population growth among the non-whites, while white women were given incentives (such as tax alleviation) to have more children. There were also many reports of black lower class women who have been involuntary sterilized, when they had caesarian sections (Department of Health, Policy document for reproductive health, 3rd Draft). These practices are not unique to South Africa, but is reported to happen in various developing countries such as China, India and Peru where sterilization is actively promoted among women in order to curtail population growth. In these countries women are often coerced, forced or rewarded if they undergo sterilization while the health care staff are rewarded if certain targets are met (Duncan et al, 1977:313).

In Peru, for example, it has been estimated that more than 100 000 women were sterilized between July 1995 to November 1997 as part of a sterilization campaign (supported by USA funding). Although not all of the sterilizations were involuntary, many women were enticed to accept the procedure with promises of free food or money. Peruvian health care workers were also given “credits” for meeting the sterilization targets. Human rights leaders in Peru have criticized these programs for

targeting the poor, the illiterate and the young (The Miami Herald, 11/01/1998; The Wanderer, 05/05/1998; The New York Times, 15/02/1998).

According to Draper (1991:79-80) more sterilizations are performed among the lower classes and these are usually performed at a much younger age than the upper classes. Among the upper classes, more vasectomies are performed and in general sterilizations are done at a later age. These findings were also supported by a survey conducted among American Obstetricians, finding that only 6% of the respondents favoured sterilization for private patients, while 14% favoured it for their welfare patients. Another study also found that 43% of women sterilized in federally financed family planning programs, were black (Hubbard & Henifin, 1984:80).

Some fetal protection policies in the USA also require women to provide evidence that they have been sterilized before they can be appointed in certain positions. These jobs usually involve exposure to toxins, which could endanger the healthy development of the fetus. Not surprisingly, these jobs are usually also the best-paid jobs in the industry (Callahan, 1998:349).

It seems therefore, that it is often the powerless, such as women, the poor and the disabled, who are most at risk for being coerced or forced to undergo sterilizations (Rock, 1996:123). To borrow a quote from Hubbard & Henifin (1984:74), "our society is not one in which power and knowledge are equally distributed among all segments of the population. On the contrary, physicians are more powerful than the great majority of their patients – and not because they know more about the disease, but because they usually are members of a more privileged race, class and gender....".

Although the principle of autonomy guides many health care decisions in the western world, asymmetrical power relationships between medical staff and the consumers still exist. The challenge seems to lie partly in the problem of obtaining informed consent from the poor and the poorly educated. Doctors often find it easier, quicker and more convenient to make paternalistic decisions on behalf of their patients than to go through the long and often cumbersome process of obtaining proper informed consent from people with limited knowledge and education (Draper, 1991:81-82).

But what about women who are educated, informed and able to give consent? Should they be allowed to undergo sterilizations just because they wish to have the procedure performed? Take for example the hypothetical case presented by Basson (1981:135) where Elizabeth Stanley, a healthy 26 year old intern medical student requested a tubal ligation. After having thought about it for a long time she was convinced that she would never want to have children. She has never been pregnant and is not interested in other available contraceptives. Since she is an informed, rational, adult person who can give consent, should her request be granted on the grounds of autonomous decision-making? Or should the doctor act paternalistically and refuse on the basis that her wish is not in her best interest. The sterilization will render her permanently infertile and if she should ever change her mind on the matter, she probably will not be able to reverse the effects of the tubal ligation. According to Draper (1991:83), doctors often feel these decisions should only be made after the age of 35 since they assume that every woman naturally desires children.

Various guidelines were subsequently developed in order to deal proactively with scenarios like these. In the USA the so-called 120 Rule was used as a criterion for sterilizing women. Unless a woman's age, multiplied by the number of her children equaled at least 120, she would generally not be granted a request for sterilization unless it could be justified on medical grounds (Callahan, 1998:348).

Some countries make use of a waiting period between giving consent and performing the procedure. The actual time periods vary and may reach from three days to 30 days. In Denmark a maximum waiting period of six months is stipulated so that if more than six months has lapsed, informed consent has to be obtained anew (Friedman, 1978:1617).

Some guidelines also take the number of children the woman already has, into account before the sterilization can be performed. Depending on the country the minimum number of children can vary from one to five. For women who have never given birth, a longer waiting period is often suggested (Friedman, 1978:1617). Age is another guideline often used, suggesting that minors should never be sterilized and requests for sterilization should only be considered once a woman has reached the age of 30-35 (Draper, 1991:98; Friedman, 1978:1616).

Other conditions such as proof of economic or social hardship, spousal consent, and government supervision of the procedure has also been taken into consideration. Written consent should always be obtained, preferably by both partners - which in itself becomes problematic if one of the partners should refuse (Friedman, 1978:1617). Some suggest that only people who are sexually active and whose best interests will be served must be allowed to undergo a sterilization. The implication of this is that men should never be sterilized since they are not exposed to the dangers and risks associated with pregnancy and giving birth (Draper, 1991:87).

Draper (1991:84-86) argues that someone who wants a sterilization and who can give valid consent, should not be refused a sterilization since: (a) the refusal is based on a third party's consideration that their perception of what is in the person's best interest, is actually better than the person's own; (b) if a sterilization is refused, people are actually being coerced into accepting other forms of contraception or into becoming parents; and (c) the argument that the childfree, by the lack of knowledge about what it is like to have children, are incompetent to make this particular decision themselves, is invalid.

The strict measures to discourage certain groups of women to undergo sterilizations and the strong encouragement of other groups of women to undergo the procedure, hint at the impact that gender, class, racial and also population concerns have on law and public policy governing birth control. Some governments adopt "pronatalist" policies such as disallowing contraception (including contraceptive sterilization), as well as elective abortions and precluding women from working outside the family. These may be motivated by concerns of national survival and national superiority as well as fears that birth control is harmful to the general good. Other governments adopt antinatalist policies, where families are forbidden to have more than a certain number of children. This often results in women being pressured into abortions and sterilizations accompanied by a sharp increase in the occurrence of infanticide and child abandonment (Callahan, 1998:337-338). Some governments adopt a combination of pronatalist and antinatalist policies in order to maintain the dominance of a certain group whilst eliminating the "unfit". These types of policy were especially pronounced during the eugenics movement described in 2.3.1.

Although sterilization abuse still occurs (especially in the developing countries), it is the sterilization of people with intellectual disabilities which remains a much debated and controversial topic. Some are strongly opposed to the sterilization of people with intellectual disabilities, since these individuals cannot consent to the procedure. Others feel that these individuals shouldn't be denied the opportunity to be sterilized only because they are disabled – they are entitled to the same choices of contraception available to the rest of the population. Countries such as the UK have no formal policies or legislation that allow for the sterilization of the intellectually disabled. If sterilization for someone who cannot consent to it, is sought, a formal application has to be made to the court. In countries such as Germany and South Africa legislation in this regard does exist (Strauss, 1995:11).

2.4 South African policy

2.4.1 The Abortion and Sterilization Act of 1975

The Abortion and Sterilization Act of 1975 regulated the sterilization of people who are incompetent to give permission, until it was replaced by the Sterilization Act of 1998. According to the act of 1975 the sterilization of someone who couldn't give consent was only allowed if the following criteria were met:

- Two medical doctors, of whom one must be a psychiatrist, had to certify in writing that the person involved was fertile and
 - (a) had a heritable disease which, if a child were to be born, the child would have a physical or mental disability of such a severe nature that the child would be regarded as seriously disabled or
 - (b) the person involved is not able to comprehend the implications of coitus or not able to take responsibility for the "fruit of coitus" because of the permanent mental disability s/he suffers from
- the person who can give proxy consent, has to do so in writing, and if this person is not available or cannot be found, a magistrate can do so on their behalf
- the Minister of National Health (or a medical officer appointed by the Minister) had to give written consent before the operation could be performed

According to Strauss (1995:11) an average of 140-150 sterilizations of people with mental handicap, were performed annually under this law, amounting to approximately 1817 people by the year 1989 (Nash & Navias, 1992:438). According to data from Groote Schuur Hospital for the period 1975-1989, 291 people were referred for evaluations for sterilizations. The majority of people referred, were coloured (80%), followed by 13% white and 7% black patients. Seventy-nine percent of the applications were approved. Most of the applications came from family members of whom one third were already caring for illegitimate offspring born to the intellectually disabled women (Nash & Navias, 1992:437).

Decisions about whether or not to approve the applications were often problematized by the difficulties of accurately assessing the degree of intellectual disability. These decisions often relied heavily on formal individual IQ testing with psychological tests that only had valid and reliable norms for white Afrikaans and/or English speaking people. Furthermore the Act of 1975 did not specify the age at which sterilizations were permitted. This resulted in many adolescent girls being sterilized by means of hysterectomies at the onset of puberty. By the year 1998, approximately 200 sterilizations were performed annually in the Western Cape under the 1975 legislation³.

2.4.2 The Sterilization Act of 1998

The Sterilization Act No.44 of 1998 replaced the previous legislation. The new act makes provision for sterilizations to be performed on anyone who can give consent and who is above the age of 18. It also explicitly states that no person who is capable of consenting, may be involuntarily sterilized.

The Sterilization Act of 1998 also prohibits the sterilization of people under the age of 18 unless failing to do so will seriously impair their physical health.

For people who are intellectually disabled or incapable of giving consent, the following criteria have been stipulated:

³ I am indebted to Marie Adamo, Department of Health for this information.

- The parent, spouse, guardian or curator has to apply for sterilization and has to give consent for the procedure to be performed once the application has been approved.
- A panel consisting of a psychiatrist (or Medical Officer if a psychiatrist is not available), a psychologist (or social worker) and a nurse must conclude that:
 - the person for whom the application is made, is at least 18 years old;
 - that apart from sterilization, there are no other safe and effective forms of contraception available;
 - the person is mentally disabled to the extent that
 - s/he cannot make their own decisions about contraception or sterilization
 - s/he is incapable of developing mentally to a sufficient degree to make an informed decision about contraception and/or sterilization
 - s/he is unable to fulfill the parental responsibility associated with giving birth;
 - the degree of mental disability is severe; therefore, people with mild to moderate degrees of intellectual disabilities are excluded from panel approvals;
 - the person performing the operation must ensure that the method of sterilization holds the least health risk to the person.

Although this legislation has only been implemented recently, some ethical questions have already been raised, such as, which form of birth control is regarded as the one with the least health risk: long-term use of Depo-Provera or tubal ligation? Since the Sterilization Act of 1998 came into effect, only 20 applications for the sterilization of people with intellectual disabilities have been received in the Western Cape during the first year. The reason for the relatively low rate is unclear, although it could be that people are not familiar with the new legislation or that the criteria are so stringent that very few people qualify. It is also possible that the majority of people for whom sterilization is normally requested, fall within the mild to moderate range of intellectual disability and according to this legislation can give informed consent through the normal routes. As will be discussed in chapter three, it is often these individuals who are interested in sexual relationships and who often struggle with the demands of parenthood if only limited support is available. The issues of informed consent, competence and the exercise of autonomous decision-making becomes

interesting challenges when they are applied to people with intellectual disabilities who have the desire to become parents. These issues will be dealt with in the rest of the assignment.

2.5 Conclusion

Professionals and the public, for various reasons, welcomed the development of techniques to sterilize men and women. Not only did it provide a safe and relatively effective form of contraception. Its effectiveness is also not hampered by human error, such as forgetfulness. It quickly became the "ideal" contraceptive for people regarded as unsuitable for parenthood. Although eugenic policies and population control programmes led to the sterilization of hundreds of thousands of individuals (mostly people with mental disorders and intellectual disabilities), it is also often criticized, especially for the authoritarian, coercive and careless ways in which the procedure was implemented.

Currently the South African law does make provision for the involuntary sterilization of people with moderate to severe intellectual disabilities, but this practice raises many ethical questions related to the principle of autonomy, informed consent and autonomous decision-making. The individual's right to make autonomous decisions about procreation and contraception (without state interference) is generally and widely accepted. However, when it comes to people with intellectual disabilities, there often exists a conflict between the interests of the individual and the interest of society at large (Duncan et al, 1977:312).

CHAPTER 3

INTELLECTUAL DISABILITIES

3.1 Introduction

The question, "who are the intellectually disabled?" can be approached from a philosophical and/or a psychological/medical perspective. According to Boddington and Podpadec (1991:177), the psychological approach is often very clear on definitions of intellectual disability but not so much concerned about "value questions". In contrast, the philosophical approach tends to focus on issues of personhood and is not so clear on definitions of intellectual disability. In this chapter both approaches will receive some attention. First, the historical trends, definitions and diagnosis of intellectual disabilities and related matters such as sexuality will be addressed after which the notions of personhood, moral rights and moral status will be briefly discussed.

3.2 A brief historic overview

The earliest written reference to intellectual disabilities can be traced to the Therapeutic Papyrus of Thebes dated 1552BC. Yet there is widespread anthropological evidence that the occurrence of intellectual disabilities predated this time. Throughout the ages, political and socioeconomic factors largely determined the understanding and treatment of the intellectually disabled. For instance in nomadic tribes where the tribe couldn't afford to be burdened by nonproductive members who used the limited resources without contributing meaningfully to the tribes' survival, nonproductive members were regarded as expendable. In a similar fashion, political authorities in the western world created either favorable circumstances for handicapped people, or encouraged discriminatory and repressive practices (Drew, Logan & Hardman, 1990:56).

Before the 18th century, intellectual disabilities were generally not regarded as a major social problem and therefore didn't receive much attention. According to Drew et al (1986:54) this could be explained by the fact that the "severely retarded" tended to die of natural causes at a young age, whilst the mildly retarded were able to contribute meaningfully to an agrarian society. Persons who were unable to cope with life because of mental defects, were mostly dealt with by the policeforce - ending up in jail or cage-like facilities (Allen & Allen 1979:25).

Until the 18th century no distinctions were made between mental illness and intellectual disability. It was only thereafter that a distinction between the "lunatics" (mentally ill person) and the "idiots" (person with intellectual disability) was gradually being made. In recent years intellectual disabilities were once again closely associated with mental illness, largely as the result of the wide acceptance of the medical model (Molteno, 1997:115).

During the 19th century a "strong awakening of interest in the humane treatment of the mentally retarded and insane" took place (Anastasi, 1982:5). A prerequisite for appropriate treatment, however, was an accurate method to distinguish between the two. One of the first attempts was made by a French physician, Esquirol, who devised a system to distinguish between various types of "mental deviates" (Lea & Foster, 1990:4). Eventually this led to the development of intelligence tests by people such as Binet, Simon and Cattell, which in turn stimulated the development of an (unrealistic) optimism at the turn of the 19th century that mental defectives could be "cured" through intensive education. One of the first schools for children with intellectual disabilities was established by the French physician, Seguin, who rejected the belief that intellectual disabilities were incurable. However, the initial enthusiasm was soon to be followed by a sense of disillusionment. Consequently the educational programmes were replaced by custodial care initiatives (Allen & Allen 1979:25; Lea & Foster, 1990:5). The movement towards custodial care followed from a set of beliefs that the intellectually disabled are sick or diseased, in need of treatment and hospitalization where the emphasis is on safety, cleanliness, comfort and medical services. Although this was motivated by humanitarian concerns, it inevitably led to the view that these people needed indefinite custodial care (Allen & Allen 1979:16).

The abovementioned historical trends illustrate the changes that took place in the conceptualization of intellectual disabilities. Initially (mid 1800's), people were concerned with the provision of adequate care and education for a group of people who have been neglected and abused, but later on (early 1900's), people with intellectual disabilities were generally viewed as morally defective and a danger to society. Cohen, quoted in Foster (1990:23), describes four significant changes in the way care was provided during the 18th and 19th centuries, namely:

- increasing involvement by the state and a bureaucratic apparatus in the business of deviancy control;
- increasing differentiation and classification of deviant groups into separate categories, each with its own body of specialized scientific knowledge and professional concern;
- increasing segregation of deviants into asylums, or "total institutions" (prisons, reformatories, homes for wayward girls, mental hospitals, special schools), that is, relatively closed and purpose-built institutions;
- decline of treatment or punishment in purely physical terms, with the mind replacing the body as the object of repression.

In the words of Lea and Foster (1990:8), "to be mentally handicapped has come to mean that the person is seen as a devalued member of society, one who is less than fully human, one who is incapable of producing, one who is dependent and incompetent, one who needs to be controlled and one whose civil rights are curtailed". These changing conceptions also had major implications for the care the intellectually disabled received.

Since the 1960's Western societies have seen what Cohen refers to as "destructuring", a new pattern regarding the control of "deviancy". This is characterized by shifts away from:

- the state, by means of deregulation and decentralisation;
- the expert, by means of deprofessionalisation, anti-psychiatry;
- the institution, by means of normalization, decarceration and community care;
- the individual, by means of a movement back to justice, human rights and a community focus.

This pattern is also apparent in the current South African situation, where people with intellectual disabilities are being deinstitutionalized and taken care of in the community according to the principles of normalization. The term "normalization" was coined by B. Nirje in 1968 and can be defined as:

.....making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular

circumstances and ways of life of their society. Second, normalization means giving society a chance to know and respect mentally retarded persons in everyday life and to diminish the fears and myths that once caused society to segregate them (Allen & Allen, 1979:67).

Normalization is therefore concerned with normalizing the environment of people with intellectual disabilities and not necessarily with normalizing the person with an intellectual disability (Allen & Allen, 1979:67; Drew et al, 1990:324). The principles of normalization and deinstitutionalization would be expensive if consistently translated into policy and also creates numerous ethical problems and dilemmas, many of which are discussed by Rose-Ackerman (1982). The normalization principle may encourage policies that place people with intellectual disabilities in life situations that are close to those chosen by normal people, with emphasis on aspects such as housing, schooling, work, friendship and family life. Yet these people are often not awarded the right to autonomous choice and self-respect. Rose-Ackerman (1982:90) cites the example of an adult with an intellectual disability who may feel oppressed when forced to normalize by settling down in a middle-class neighbourhood, doing a regular job. According to her, this kind of normalization is not consistent with the principle of autonomy. A similar argument may ensue for reproductive rights and the intellectually disabled. Whilst the principle of normalization may lead to life situations in which people with intellectual disabilities may become involved in sexual relationships and may consider having a family of their own, they are often not awarded autonomous decision-making powers in matters of reproduction.

3.3 Intellectual disabilities: the medical/psychological perspectives

The medical/psychological approach to intellectual disabilities concerns itself with issues of terminology, classification and diagnoses. These aspects as well as sexuality-related matters will be discussed in the next section.

3.3.1 Terminology

The use of terminology and labels to distinguish between categories or groups of people can become very problematic. On the one hand, the label can lead to stigmatization, devaluation and discrimination of certain groups of people: for instance, it can lead to so-called "self-fulfilling prophecies where someone is labeled as "ineducable", denied educational opportunities, and therefore the person becomes

less competent, justifying the original label. On the other hand, the label can also be beneficial in that the person's behaviour is better understood or that the person becomes eligible for certain grants, exemptions or services (Molteno, 1997:114).

Through the ages various terms and labels have been used to refer to people with intellectual disabilities. These terms include words such as "holy innocents", "special children of God" (Allen & Allen, 1979: 25), "idiot", "imbecile", "moron" and "feeble-minded". Binet and Simon preferred the term "debile" to "moron" while others used the term "mentally deficient" and later terms such as "backward" and "mentally defective" (Lea & Foster 1990:10). Some of these terms, such as "idiot" and "imbecile" are currently viewed as archaic and have disappeared in most countries, although in South Africa they are occasionally used in legal contexts. The label "mental deficiency" has been replaced by the term "mental subnormality" and later "mental handicap" in the UK and by the term "mental retardation" in the USA. The World Health Organization (WHO) has recommended the term "mental subnormality" which include two separate and distinct categories, namely, mental retardation and mental deficiency. According to the WHO, mental retardation is used for subnormal functioning secondary to identifiable underlying pathological causes, whereas mental deficiency is mostly used as a legal term, applied to persons with an I.Q. of less than 70 (Kaplan & Sadock, 1988:685). The term "feeble-mindedness" was often used in American literature and is still used in Great Britain to refer to the mild forms of mental retardation. "Oligophrenia" was commonly used in the Soviet Union, Scandinavia and other Western European countries (Kaplan, Sadock & Grebb, 1994:1025). In general, it is regarded as unacceptable to refer to anyone as "mentally handicapped". The preferred description is "a person with an intellectual disability". Currently the term used by the Western Cape Forum for the Intellectually Disabled, is "intellectual disability". This is also the term which is currently preferred in the Department of Health and Social Services and therefore also the term used in the current assignment.

3.3.2 Diagnosis

Intellectual disability is not a unitary disorder and the intellectually disabled not a homogenous group. The causes of intellectual disabilities are manifold and are to a large extend still unknown, whilst the experiences, personalities and histories of the intellectually disabled vary greatly (Kaplan & Sadock, 1988:685; Molteno, 1997:113).

In general there are two major conceptual approaches to defining intellectual disabilities, namely the biomedical and the sociocultural adaptational models. The biomedical model emphasizes the presence of basic changes in the brain as essential to the diagnosis of intellectual disability whereas the sociocultural adaptational model places emphasis on the social functioning and general ability of a person to adapt to accepted norms in society (Kaplan, Sadock & Grebb, 1994:1025).

The most commonly used definition of mental retardation/handicap/intellectual disability was developed by the American Association on Mental Deficiency (AAMD) in co-operation with scientists, practitioners, consumers and family organisations and read as follows:

Mental retardation refers to substantial limitations in the present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with limitations in two or more of the following applicable skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18.

This definition illustrates the movement towards the sociocultural adaptational model away from the pure biomedical model.

According to the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV), mental retardation can be diagnosed if the following criteria is met:

- A Significantly subaverage general intellectual functioning: an IQ of 70 or below on an individually administered IQ test (for infants, a clinical judgment of significantly subaverage intellectual functioning, since available intelligence tests do not yield numerical values).
- B Concurrent deficits or impairments in adaptive functioning (i.e., the person's effectiveness in meeting the standards expected for his or her age by his or her cultural group in areas such as social skills and

responsibility, communication, daily living skills, personal independence and self-sufficiency).

C Onset before the age of 18.

The DSM IV criteria for mental retardation is similar to the definitions provided by the AAMD. The DSM IV also describes the following four types of mental retardation (reflecting the degree of retardation): mild, moderate, severe and profound. For a more detailed description of the developmental characteristics and IQ range associated with each of these categories of mental retardation, the reader is referred to table one.

The diagnostic criteria of the DSM IV is viewed as problematic because of its heavy reliance on formally administered intelligence tests and intelligence scores. Until recently the norms for the tests used in South Africa were developed on white subjects only. No norms were available for the non white sector of society, yet they were diagnosed as intellectually disabled on the basis of their achievement in these tests. These intelligence tests are also strongly culturally biased and often assume a formal educational background. Psychosocial deprivation such as deprivation in social, linguistic and intellectual stimulation can contribute to scoring low on IQ tests. Some of the problems associated with formal assessments of intelligence in South Africa include: the use of English tests for populations that have not been exposed to English as it is used in the tests; the use of culture-bound concepts which are difficult to translate appropriately into other languages; the ecological invalidity of tests which doesn't assess the functional skills required in a particular socio-cultural, economic, linguistic and geographic environment; and the use of inappropriate norms to determine level of intellectual functioning (Venter, 1993:35-36).

IQ tests are constructed with a mean of 100 and standard deviation of 15. This means that if you score an average of 70, your "real" IQ can range anything from 55 to 85. The implication being that your score of 70 can be indicative of either a moderate intellectual disability or a "below average" level of intelligence. Needless to say, this can have serious implications - also in terms of sterilization policies - if not interpreted with caution. With an IQ of 85 a person can most probably take reasonably good care of their own children. With an IQ of 55 the person will probably

Degree of mental handicap	IQ Range	Mentally handicapped population (%)	Age 0-5: maturation and development	Age 6-20: training and education	Adult 21 and over : social and vocational adequacy
Profound	Below 20 or 25	1-2	Gross retardation; minimal capacity for functioning in sensorimotor areas; needs nursing care; constant aid and supervision required.	Some motor development present; may respond to minimal or limited training in self-help.	Some motor and speech development; may achieve very limited self-care; needs nursing care
Severe	20-25 to 35-40	3-4	Poor motor development; speech minimal; generally unable to profit from training in self-help; little or no communication skills	Can talk or learn to communicate; can be trained in elemental health habits; profits from systematic habit training unable to profit from vocational training.	May contribute partially to self-maintenance under complete supervision; can develop self-protection skills to a minimal useful level in controlled environment.
Moderate	35-40 to 35-40	10	Can talk or learn to communicate; poor social awareness; fair motor development; profits from training in self-help; can be managed with moderate supervision	Can profit from training in social and occupational skills; unlikely to progress beyond second-grade level in academic subjects; may learn to travel alone in familiar places.	May achieve self-maintenance in unskilled or semiskilled work under sheltered conditions; needs supervision and guidance when under mild social or economic stress.
Mild	50-55 to approx. 70	85	Can develop social and communication skills; minimal retardation in sensory-motor areas; often not distinguished from normal until later age	Can learn academic skills up to approximately sixth-grade level by late teens; can be guided toward social conformity	Can usually achieve social and vocational skills adequate to minimum self-support but may need guidance and assistance when under unusual social or economic stress

Table 1. IQ range and developmental characteristics of the intellectually disabled according to the DSM IV (Kaplan & Sadock, 1988, p.1026)

experience it as more challenging and will have high support needs. This illustrates that reliance on IQ testing alone is problematic and that an assessment of the person's level of adaptive functioning is imperative.

In the South African context further distinctions used to be made according to a child's level of intellectual functioning. According to Wigton, Adnams and King (1997:45) children with an IQ between 50-80 used to be classified as in need of special education (i.e. educable), with an IQ between 30-50 as trainable and with an IQ of less than 30 as being untrainable. The Department of Education was a key role-player in the lives of children with mild to moderate intellectual disabilities whereas those with severe disabilities were the responsibility of the Departments of Health and Welfare. Currently calls are being made for a more integrated approach through which the rights of the intellectually disabled are protected and a supportive atmosphere of individual considerations is created.

3.3.3 Sexuality, pregnancy and matters of reproduction

If one accepts the different categories of intellectual disabilities described in the DSM IV, it is clear from table one that the largest group (85%) falls within the mild range. This group often develops an interest in relationships, including sexual relationships and the wish to have their own children. According to Drew, Logan and Hardman (1990:335) as a group, 50% of people with intellectual disabilities remain unmarried, although marriage is highly valued. Sexual intimacy is both valued and feared. These writers also found that although success have been achieved in teaching the intellectually disabled some social/sexual skills, staff working at institutions generally believe that the intellectually disabled should not be allowed to express their sexuality freely. Despite the fact that the intellectually disabled are increasingly encouraged and educated to become involved in relationships and to express their sexuality appropriately, they may still experience pregnancy, childbirth and child-rearing as very stressful and may need intensive assistance and guidance during these periods.

According to Molteno (1997:117) the question of sexuality for people with intellectual disabilities underwent various changes. For a long time it was felt that sex should be eliminated or forbidden among people with intellectual disabilities. Molteno (1997:117) ascribed this to the public's opinion that these people were oversexed and degenerate and therefore should be punished. On the other hand, people with

intellectual disabilities are often viewed as perpetual children in whom the preservation of innocence is desired. Gradually more tolerance has been expressed, but it is still often seen as desirable that sexual relations be controlled and that sexual boundaries between the general public and people with intellectual disabilities be strictly enforced. This was relatively easy whilst people with intellectual disabilities were institutionalized, but with an increase in deinstitutionalization, and the implementation of normalization principles, the expression of sexuality and the management thereof became more challenging. With these developments, sex and relationship education for people with intellectual disabilities became paramount. However, in South Africa the attitude regarding sexuality and the intellectually disabled has not changed much, and it is still viewed as something that should be eliminated or at the very least, be tolerated.

A further confounding factor is the conflict between the law and the free expression of sexuality by the intellectually disabled person. For example, the Mental Health Act of 1973 states that any person who has carnal intercourse with a female who is detained in an institution shall be guilty of an offence. Similarly, the Sexual Offences Act of 1957, section 15, states that a person who has, or attempts to have, sexual intercourse with a male or female "idiot" or "imbecile", which is not rape, shall be guilty of an offence. According to Davis and Foster (1990:239) the mentally handicapped person cannot enter a valid marriage contract. "A person who is incapable of understanding the nature of the marriage contract or the duties or responsibilities which it creates due to his or her mental disease or defect, cannot contract a valid marriage nor can such a person's legal capacity be agreed by a curator" (Hahlo, cited in Davis & Foster, 1990:239). Although these acts are intended to protect people who are vulnerable for sexual abuse or exploitation, it doesn't make provision for those individuals with intellectual disabilities who wish to express their sexuality in meaningful ways within the confines of for example a marriage. These discrepancies between the law and departmental policies illustrate the need to investigate questions of autonomous decision-making and informed consent for sexual intercourse as well as a need to initiate a process of education regarding sexuality and socially acceptable practices (Molteno 1997:118). Roelofse and Kleintjes (1996) conducted a small study on informed consent and the intellectually disabled and some of their results are summarized in tables two and three.

Aspects of informed consent	Profound	Severe lower	Severe upper	Moderate lower	Moderate upper to Mild
Sexual knowledge (knows important facts)	No	No	Poor	Poor	Poor-fair
Consequences (Know risks and benefits)	No	No	No	Poor	Poor-fair
Expressive comprehension (of knowledge and consequences)	No	No	Very limited	Very limited to limited	Limited-fair
Ability to follow through on knowledge/value systems	No	No	Very limited	Limited	Limited-fair
Choice: ability to say yes/no to non-coercive sexual opportunities	No	No	Limited	Limited	No-Fair
Coercion: ability to withstand force (physical, emotional, power in sexual advances)	No	No	No	No	Extremely limited and inconsistent

Table 2. Ability to give informed consent in persons with profound to mild mental retardation (Roelofse & Kleintjes, 1995).

Level of functioning	IQ range	Developmental age	Sexuality
Profound-Severe lower	Under 27	Under 4 years	<ol style="list-style-type: none"> 1. Enjoys physical stimulation including stimulation of sexual organs. 2. Cannot contextualise sexual contact or activity within social norms. 3. Cannot discriminate between "acceptable" and "unacceptable". 4. Cannot recognize potential or actual abuse (sexual) or danger. 5. Cannot grasp the implications of AIDS/HIV and STD's. 6. May occupy self with self-stimulation (including sexual) in situations where alternative constructive stimulation is not provided/available. 7. Most probably will not become sexually active with a person, unless exposed to and/or encouraged to become sexually active by another person. 8. Cannot say no. 9. Cannot give informed consent.
Sever upper-Moderate lower	28-42	4-6 years	<ol style="list-style-type: none"> 1. Severely limited ability to place sexual activity into context of social norms and taboos. 2. Will become involved in "imitative relationships" but do not understand full meaning of scope/limits of intimate association i.e. limited grasp hence of terms such as "girlfriend" and "boyfriend". 3. Open to abuse by family members as not capable of fully understanding these relationships and sexual limits within family setting. 4. Also may be sexually active for reward. 5. Multiple partners if opportunity, despite professing knowledge of single partner policy. 6. Explore definition of sex as tends to label all intimate touching as sex, eg. Hand holding, kissing, genital touching. Unlikely to become orogenitally active unless introduced to it by someone else. 7. Informed consent: severely limited ability in all individuals 8. No understanding of AIDS/STD's, contraceptives 9. Can be taught concept of privacy, safe/hygieneic sexual techniques, cannot follow through consistently. Reminder need to be built into daily programme.

Level of functioning	IQ range	Developmental age	Sexuality
Moderate Upper - Mild	43-70	6-10½ years	<ol style="list-style-type: none"> 1. Most able to understand basic relationships 2. In terms of expectations of different relationships but still have difficulty defining terms 3. Can be taught to recognize danger and abuse, but under pressure still not able to follow through safely. 4. May engage in full range of sexual activity but some remains sexually inactive or only involved in self-stimulation. 5. Can understand concept of privacy and practice this but remains open to abuse under pressure. 6. Small percentage may engage in multi-partner relationships, but many will follow through on consistently taught one partner policy. 7. Responds to educational input in small groups on couple or individual basis - environmental structuring and reminders needed. 8. May not always follow through consistently.

Table 3. Expectancies for sexual knowledge and practice in persons with severe to mild mental handicap (Roelofse and Kleintjes, 1995).

From these results it is clear that informed consent with reference to sexual relationships and the intellectually disabled remain difficult to implement on a practical level. These individuals often constitute borderline cases in terms of decision-making abilities. The tension between respecting the person's autonomous decision-making in matters of sexuality and procreation and acting paternalistically to protect the person from exploitation and suffering, remains a dilemma that will be further investigated in the remainder of this assignment.

Another related matter that is often a concern for parents of intellectually disabled daughters, is the management of menstruation. Parents and care-givers of these women often hold views and attitudes that menstruation is inconvenient, embarrassing and that many would avoid it as far as possible - very similar to the societal taboos on menstruation. This resulted in many intellectually disabled women not being adequately prepared for menarche and not being seen as capable of learning menstrual management. In general the suppression or elimination of menstruation among these women is widely accepted by the people who assist and care for them (Griffin, Carlson, Taylor & Wilson 1994:106, 112). Until the recent past, these attitudes have often led to routine administration of hysterectomies at the onset of puberty.

In a study conducted by Taylor and Carlson (1993) it was found that requests for hysterectomies were mostly motivated in terms of menstruation management. It was argued for instance, that for women with intellectual disabilities, menstruation is:

- unnecessary and unhealthy;
- the removal of the uterus have no long-term health effects on the woman;
- menstruation is inevitably painful;
- the intellectually disabled woman will react negatively to menstruation and
- teaching menstrual skills is stressful and impractical.

Taylor and Carlson (1993:142) found no evidence in the research literature that support these views and also note that very few alternatives to hysterectomies were investigated in these cases. Their suggestion is that "a proactive, supportive approach to assisting young women and their families prior to menarche would be preferable to a reactive and potentially confrontational approach when decisions to

seek menstrual and fertility elimination have been made on the basis of possible limited information" (p.151).⁴

To conclude, parents, caregivers and members of society often feel that people with intellectual disabilities should not be encouraged to become involved in relationships, including sexual relationships and should not be considered to have children of their own (Edgerton, 1999:1). Although many express concerns for the well-being of children born to the intellectually disabled, many are also concerned for the disabled person's own physical and emotional well-being, should they be sexually active or become parents. Many of these opinions stem from beliefs that the intellectually disabled should not be awarded the same rights and moral status as other members of society because the intellectually disabled do not have the mental faculties to make decisions on these matters - they should rather be cared for and protected by others. Underlying many of these beliefs is the notion that the intellectually disabled do not have personhood (or at best, only marginal personhood), are of lesser value and therefore normal human and moral rights (and the right to procreate) are not applicable to them. In contrast to this view the Symposium on Normalization and Integration of 1977 states: "there is a need for age-appropriate sex education, including birth control techniques and parenthood information. With regard to voluntary sterilization and abortion, the same rights apply to a mentally retarded person as to any other citizen" (Allen & Allen, 1979:83). There seems to be two opposing points of view: on the one hand people with intellectual disabilities are seen as persons entitled to the same treatment in matters of procreation as all other members of society. On the other hand people with intellectual disabilities are regarded as subhuman or less than human and consequently not entitled to equal moral status than other human beings.

⁴ Currently it is relatively common practice to prescribe contraceptives, such as Depo Provera, to these women since it has the cessation of menstruation as an additional effect. Although relatively effective, it also leads to weight gains and there is still uncertainty as to the long-term effects it might have on the woman's health. The receiving of three-monthly injections is often also reported as a source of stress for many intellectually disabled persons.

3.4 Intellectual disabilities: the philosophical perspectives

The philosophical perspectives on intellectual disabilities often focus on value questions, such as the moral status of the intellectually disabled person, issues of personhood and the ascription of rights (including reproductive rights) to them. In the final section of this chapter these aspects will be briefly discussed.

3.4.1 Moral status and personhood

"When does a human life start to matter morally?" is the question mostly posed in the abortion debates. With regard to debates about intellectual disabilities, the question can be rephrased to, "what gives a human life moral status or significance?" The answer to this question led theorists to search for universal criteria of moral status. The following have been most commonly proposed in the abortion debates: life, sentience, genetic humanity and personhood (Warren, 1993:307).

In terms of the "ethic of reverence of life", echoing Albert Schweitzer's sentiments, all organisms have a will to live and generally will strive for survival of itself and often also the species. Implicit to this argument, is the notion that all living organisms warrant respect and have some sort of moral value or moral status. Based on these assumptions, all things being equal, the killing of any form of life without good reason is wrong (Warren, 1993:309). People with intellectual disabilities, normal persons, animals and other organisms all should be respected because any form of life has intrinsic value and therefore warrants respect. Yet, people do not generally regard the moral status of simple organisms and animals as being equal to that of human beings. Humans kill animals and other life forms for their own survival, therefore from necessity. An adult human being and a fetus are not usually treated as if they have equal moral status. For instance, in emergency situations where a pregnant woman's life is in danger, the focus of intervention will normally be to save the woman's life, even if it will lead to the loss of the fetus. Thus, although it is generally agreed that all life has worth and is intrinsically valuable, this criterion is not helpful in determining sufficiently the moral status of various life forms. It is not helpful in determining whether people with intellectual disabilities have equal moral standing to other human beings or not, even though people may agree that they deserve some form of respect since they do constitute a form of life.

Common genetic humanity has also been suggested as a requirement for equal moral status. According to this position, all life forms that are genetically related to human beings, have equal moral status (Warren 1993:308). These include fetuses, infants, people with disabilities, comatose individuals, etc. People with intellectual disabilities, according to this argument should be regarded as having equal moral standing to all other human beings, because they are genetically related to the human species. From this it follows that all humans deserve respect no matter what their level of intelligence may be. Kopelman (1982:72) argues that there are four types of respect, namely, esteem, regard for agency, regard for class membership and attention to or acceptance of limitations. She argues that all people with intellectual disabilities (even the profoundly disabled) are deserved of respect due to their class membership and common genetic humanity.

As a third possible prerequisite for moral status, sentience has also been suggested. The sentience criterion regards moral status as dependant on the capacity to have experiences, especially those of pleasure and pain. In general it can be said that sentient beings have a basic interest in the experience of pleasure and the avoidance of pain and that sentience requires a functioning central nervous system (Warren, 1993:308). According to this criterion, all things being equal, if a person with an intellectual disability is sentient and can experience pleasure and/or pain, they at least have equal moral status to other sentient beings such as animals (Spicker, 1990:142).

Some theorists, such as Locke, have classified people with intellectual disabilities as falling within a category somewhere between human and animal, such as "subhuman". This view was also supported by Downie and Telfer who write: "On the lowest level are the animals, who are regarded as having a presumptive right not to suffer....Next we have what we may call 'sub-normal' humans, who are not accorded full respect but are not treated like animals either...Finally we have the normal humans who are accorded full respect (quoted in Spicker, 1990:143). According to these writers, sentience alone is not a sufficient criterion to distinguish between the moral status of animals, normal human beings and the intellectually disabled. Instead, they suggest that personhood (or lack thereof) be used in discussions about the equal moral status of human beings. People with intellectual disabilities are thus

often considered as cases of marginal personhood, of less than fully human beings, yet distinctively different from other sentient beings.

There seems to be no general agreement about the concept of a person, yet most philosophers agree that personhood refers to an entity which has moral rights, including the right to life, and therefore should be treated as a full member of the moral community (Pryzyluska-Fischer, 1997:168). In discussions of what constitutes personhood the following criteria have been suggested:

- Any being capable of valuing its own existence. This becomes apparent in the use of language and other indications of self-consciousness and self-awareness (Harris, 1985:18).
- The ability to be conscious of oneself as existing over time - as having a past and a future, as well as a present (Buchanan & Brock, 1989:160).
- The ability to appreciate reasons for or against acting; being (sometimes) able to inhibit impulses or inclinations when one judges that it would be better not to act on them (Buchanan & Brock, 1989:160).
- The ability to engage in purposive sequences of actions (Buchanan & Brock, 1989:160).
- Dennett (quoted in Boddington and Podpadec, 1991:185) identified the following conditions for personhood: (1) A person is a rational being. (2) Persons are beings to which states of consciousness are attributed or psychological or mental or intentional predicates are ascribed. (3) Whether something counts as a person depends in some way on an attitude towards it. (4) The object to which this personal stance is taken must be capable of reciprocating in some way. (5) Persons must be capable of verbal communication. (6) Persons are self-conscious.
- Each individual is an original center of being and action, with distance between what they are and what they do. Persons are knowing subjects with a certain degree of freedom (Van Melsen, 1978:1207).
- Being a person is a dynamic process, meaning that a person has the possibility of becoming more and more of a person and this is the result of a dynamic process between the individual and sociocultural aspects (Van Melsen, 1978:1207).

- A person is an *individua substantia rationalis naturae* (an individual substance of rational nature). There are therefore two necessary conditions, which are jointly sufficient for personhood, namely individuality and rationality (Mori, 1996:158).

The abovementioned criteria or requirements for personhood are not very useful in debates such as whether people with intellectual disabilities can claim equal moral status or moral standing to other "normal" human beings. First of all, there is no agreement as to which of these criteria should be used to determine personhood and secondly it is unclear how one on an empirical level can determine whether someone has for instance sufficient self-consciousness to award them personhood. The intellectually disabled as a class cannot be classified as having personhood or not, since the degree of disability within the group vary so much. This type of classification will have to take place on an individual level.

Furthermore the concept of a person need not be restricted to human beings. As suggested by Prsyluska-Fiszer (1997:168) it is quite possible to hold that some persons, such as God, angels, devils, higher animals such as chimpanzees, are not members of *Homo Sapiens*. Prsyluska-Fiszer (1997:168) also argues that the concept of a person as with the term "human", is used both in a normative (moral/legal) sense and a descriptive (commonsense) sense. The requirements for personhood as listed above are used in a descriptive sense to make claims about a human being in the moral or normative sense. Yet, it can be argued convincingly that normative moral principles, rights and obligations cannot be derived from what is essential to the concept of a person. To determine whether a person with intellectual disabilities can be regarded as a person is a moral decision for which one require moral reasons. Although people with intellectual disabilities may lack some faculty or set of faculties that other persons possess, it doesn't necessarily follow that they do not have personhood. Unless one can argue that there are some faculties that are essential to being a person, this cannot be a sufficient basis on which to deny their humanity.

From the arguments presented above, it seems that although personhood as an inclusion criteria of moral equality, is important, it does not serve sufficiently as an exclusion criterion. Equal moral status to all persons should be acknowledged, but people cannot be excluded from moral equality because it is suggested that certain

human beings such as the intellectually disabled and infants are lacking certain faculties that are regarded essential to personhood.

Furthermore, history proves that it is all too easy for dominant groups to rationalize oppression by claiming that oppressed persons are not really persons at all, because of some alleged mental or moral deficiency. This has been especially true of the intellectually disabled who are generally devalued in society and consequently often denied moral rights and moral status and even treated inhumanely because they are categorized as non persons or less than persons.

The proposed solution is to seek a middle path between the "ethics of reverence for life" which is too inclusive as a criterion for moral equality, and personhood, which seems to be too exclusive. A plausible middle path is to use a combination of the criterion of common genetic humanity and sentience. Therefore, any being who are genetically related to *Homo Sapiens* and who can be classified as sentient should be awarded equal moral status and equal moral rights. Most, if not all, people with intellectual disabilities do have sentience and share genetic material with other human beings and thus warrants equal moral status.

3.4.2 Moral rights

Liberal individualism, especially in the form of rights theory, has emphasized the importance of creating a space in democratic societies, within which the individual is protected as well as allowed to follow and pursue personal projects and initiatives. Rights can be defined as "a justified claim or entitlement, validated by moral principles and rules". Rights are often classified in two ways, namely legal rights and natural human rights (which are usually divided into life, liberty and the pursuit of happiness). Although classified in this way the two types do not exclude each other and actually serve to reinforce each other (Ulrich, 1976:351). The first rights of a citizen are his rights as a person, his human rights. Constitutions and legal rights were developed to guarantee these fundamental human rights.

Legal rights can be further divided into two kinds: (1) legal rights which protect one from undue interference by the state and from harmful acts of others; and (2) legal rights that permit persons to make choices which have significant long-term consequences, choices that seem to require mature capacities (Hafen, quoted in

Schoeman, 1980:7). When applied to the intellectually disabled, it could be argued that the latter group of rights is not appropriately ascribed to some people with intellectual disabilities and that the right to be protected from their own immaturity or impairments should also be safeguarded.

In 1971 the United National General Assembly produced a Declaration of General and Special Rights of 'the Mentally Handicapped' (see Appendix A) in which it was clearly stated that people with intellectual disabilities should be awarded the same human rights as all other citizens as far as it is feasible. The constitution of the Republic of South Africa, 1996 does not explicitly mention rights of the intellectually disabled, but acknowledges the following rights of relevance to people with disabilities:

- the right to equality and freedom from discrimination;
- the right to dignity;
- the right to family care, parental care or alternative care, basic nutrition, shelter, basic health care and social services;
- the right to be protected from maltreatment, neglect, abuse or degradation;
- the right to a basic and further education (Wigton et al, 1997:46).

Among theorists, the ascription of rights to the intellectually disabled by the United Nations, is a contentious issue. Some feel that there are serious reasons why handicapped people need to have rights: rights protect them from limitations and abuses, and it offers them scope for further personal development. The intellectually disabled need the right to have rights (Spicker, 1990:149).

Others claim that natural rights cannot be generalized to the intellectually disabled, because in order to have a right, a being must be able to understand what it is like to have a right and to have it respected or violated. For the intellectually disabled, to possess human rights, some degree of competence is a prerequisite. A person can only make claims about rights if that person has a right to choose, therefore the person must have the capacity to choose. It is claimed that people with intellectual disabilities do not have these abilities and therefore do not meet the requirements of personhood and the claim to rights. This argument is refuted by the fact that many incompetent people such as comatose individuals and infants, are still regarded as having rights even though at that point in time, they cannot comprehend all the

implications of having that right (Woozley, 1982:48). A rights-holder does not necessarily have to assert those rights in order to have them. This has an important implication for children, the comatose and the intellectually disabled, since it means that they still have rights even though they may not be able to claim those rights. Rights claims can be made on their behalf by authorized others (Beauchamp & Childress, 1994:71-72).

Murphy (1984:11) argues that the intellectually disabled will never be in a position where it could be claimed that their destinies ought to be determined by their own choices and decisions. Based on social contract grounds he argues that they do have rights, but these will for the most part be rights to a certain kind of paternalistic protection. Mechanisms are needed through which the interests of people with intellectual disabilities are protected, but there is also the serious risk that the ascription of "incompetence" to the intellectually disabled may ultimately diminish rights rather than protect it (Spicker, 1990:147).

A mid-way between the two positions, is suggested by the declaration of the United Nations of 1971 when it states, "some mentally retarded persons may be unable, due to the severity of their handicap to exercise for themselves all of these rights in a meaningful way". Thus, it may be necessary that the modification of some or all of the rights is appropriate for some people with intellectual disabilities and/or that their rights will have to be claimed on their behalf. Margolis (1982:22-23) suggests that the procedure used for the modification must contain proper legal safeguards against every form of abuse, must be based on an evaluation of the social capability of the intellectually disabled person by qualified experts and must be subject to periodic reviews and to the right of appeal to higher authorities. The intention behind this is to allow a gradation regarding competence among the intellectually disabled to determine which rights could justifiably be restricted to specific individuals.

Clearly there exist a tension between the individual with an intellectual disability and the intellectually disabled as a class. Rights are usually ascribed to a person based on class membership. In the same way as an animal has rights as a member of the class of sentient beings, the intellectually disabled may be seen as in possession of rights, some as a human being with certain capacities, others as human beings with certain incapacities. As argued earlier, the intellectually disabled is regarded as on

equal moral standing with other human beings and therefore they are also entitled to the same rights. However, they may be limited in their abilities to exercise those rights themselves, and some modifications to the content and process of rights ascription may be needed. These modifications however, need to be made on an individualized basis since people with intellectual disabilities vary so widely in terms of the degree of disability. One of the areas, in which the modification of rights for the intellectually disabled has been suggested, is the right to reproduce.

The right to conceive and bear offspring is seemingly implied in the right to life, liberty and the pursuit of happiness. It can be interpreted as a claim to natural human rights, specified by Cartwright (1994:75) as a liberty right and not a claim right. The right to reproduce can be regarded as a negative right that is a right to be free from interference by others in choices regarding reproduction. This right is not regarded as absolute, since for example marriages of close kinship is prohibited in most countries and in some countries (i.e. China) couples are restricted to the number of children they may have. Furthermore, reproduction does not only occur by means of sexual intercourse, and the question can be asked whether reproduction by means of in vitro fertilization is also included in reproductive rights' claims.

The right to reproduce, as a liberty right, implies that reproduction occurs with a willing partner and that it is not restricted to the right to beget or bear children, but also the right to rear children. Two possible constraints identified by Cartwright (1994:75-76) in exercising these rights, are (1) an understanding of what one is doing and (2) the person who is reproducing have certain obligations to fulfill to its offspring. Thus, although people with intellectual disabilities may physically be able to perform sexual intercourse and conceive offspring, they may lack an understanding of what they are doing. Therefore they are not able to do so out of choice and thus lacks the right to have children. According to this argument a certain minimal level of conceptual competence is required before the right to have children can be exercised. Exactly what this level of competence is, however, is not clear.

The second possible constraint, suggested by Cartwright (1994:80-81), is that those who choose to reproduce have the obligation to do what is minimally required to equip their children to lead independent adult lives. This obligation may be interpreted as a constraint to the right to reproduce: those who are unable or

unwilling to comply with this obligation will lack the right to reproduce. This, however, is a problematic argument, since there is no consensus as to what constitutes adequate care for children. Although children may have disadvantaged lives, it doesn't mean that their lives are not worthwhile. However, rights and obligations have a "firm but untidy correlativity" (Beauchamp & Childress, 1994:74) and therefore the right to reproduce obligates parents to care for their children. If they fail to provide "minimal required care" the parents may forfeit the right to their children. The right to have children, however should generally be safeguarded by society, although the right to one's children is not regarded as absolute.

Writers such as Tännsjö (1999:238) argue that, based on the principle of autonomy, society should never interfere with people's rights to conceive, bear and raise children. This standpoint also includes the intellectually disabled person. If people have demonstrated their inability to care adequately for their children, then and only then, could society interfere with matters of procreation. According to writers such as Tännsjö and Cartwright (1994), the practice according to which people have to qualify in order to exercise their right to procreate, based on only one criterion such as their perceived ability to care for children, is discriminatory. In general then, the right to procreate is regarded as a universal and natural human right which can be exercised freely, unless due to some unique and serious consideration (such as the risk for genetic illnesses due to procreation by close family members), society deems it necessary to interfere. These arguments, as it pertain to the intellectually disabled, will be further discussed in chapter six.

3.5 Conclusion

The intellectually disabled do not constitute a homogenous group - their personalities, experiences and levels of functioning may vary greatly (Boddington & Podpadec, 1992:361). Consequently the way they experience and express their own sexuality may also show a large variation. Some may show an interest in intimate, sexual relationships while others may not. Some may express the wish to have children of their own, whilst others do not. Yet, until relatively recently, society in general has not been supportive of their free expression of sexuality - often out of concern for the well-being of children born to them as well as concern for their own physical and mental well-being. As discussed in the present chapter, these sentiments follow from beliefs about the inferior moral status of the intellectually

disabled. They are often seen as not morally equal to other human beings, and therefore not entitled to the same moral and human rights as other citizens. In this chapter it was argued that the intellectually disabled has equal moral standing to other human beings because (1) they are sentient and (2) they share a common genetic humanity. It was also argued that they are in principle entitled to the same rights as other citizens, although the content and process through which these rights are exercised may have to be revised to accommodate their limitations. In terms of the right to procreate, some authors are of the opinion that, based on the principle of autonomy, no one should be prohibited from conceiving children. Others feel that the right to procreate cannot extend to people who do not possess a certain minimal level of conceptual competence and who therefore cannot be granted autonomous decision-making power. Autonomy, the principle of autonomy and how it can be applied to the intellectually disabled will be discussed in the next chapter.

CHAPTER 4

AUTONOMY: A THEORETICAL ACCOUNT

4.1 Introduction

The emphasis on autonomy and respect for autonomy as guiding ethical principles, is often regarded as the distinguishing feature of 20th century Western medical ethics. Some alleges that autonomy and the principle of respect for autonomy has largely replaced the principles of benevolence and non-maleficence - principles that dominated Western medicine since the adoption of the Hippocratic oath. Attempts at definitions and conceptualizations of autonomy, respect for autonomy and the application of this principle to medical ethics are manifold and haven't reached any finality yet. Therefore, the present chapter will aim to provide a brief overview of the historical as well as contemporary ideas concerning the concept of autonomy. More specifically, the work of Kant and Mill will be discussed as well as the ideas of contemporary writers, such as Feinberg and Dworkin. This chapter will conclude with a discussion of feminist and communitarian critiques of autonomy.

4.2 Autonomy

The word autonomy is etymologically derived from the Greek words *autos* (self) and *nomos* (rule or law) and therefore literally means self-determination or self-rule (Holm, 1998:267). Although the concept autonomy can be traced back to the early Greek political philosophy, it was almost always used to refer to city-states and not to individual persons. It is only since the Enlightenment that the concept autonomy has been associated with the individual - both in philosophy and society at large (Holm 1998:268). Two philosophers that have contributed to the notion of autonomy in ethics, although in completely different ways, are Immanuel Kant and John Stuart Mill.

4.2.1 Autonomy in Kant's Ethics

Immanuel Kant's formulation of ethics, focussed on three interrelated aspects, namely the preservation of human freedom, the dignity of man and the idea that moral obligation follows from reason (O'Neill, 1993:175). Kant argues that freedom entails more than only freedom from external constraint (such as proposed by Hume). He distinguishes between negative and positive freedom where negative freedom can be understood as freedom from "foreign causes". However, he states

that a free will must be positively free and its "causality must be a capacity for autonomy". Freedom is presupposed to belong to all rational agents, who are free to apply their practical reason to direct the choice of moral principles. In the words of Secker (1999:46), "if we have a rational will, or practical reason, then we are free in a positive sense, and capable of autonomy and thus bound by morality".

From this it follows that a moral agent's actions can only be judged morally when the moral agent chooses his/her actions freely on the basis of moral principles that were also chosen freely. Moral agents thus have to be autonomous in that they can choose their moral laws for themselves (Holm, 1998:268). However, these moral laws cannot follow from any principle, the principles have to be universalizable - must be able to serve all. Kant was committed to the identification of fundamental principles of action that ought to be universally adopted, and for this, he relied on rational procedures. He formulated the "Categorical Imperative" as the supreme principle of morality. In its best known form, the Categorical Imperative states: "Act only on the maxim through which you can at the same time will that it be a universal law". Moral autonomy, according to Kant, is linked to conformity with this principle and gives the moral agent freedom to act on objective, universally valid rules of conduct derived by reason alone. Actions that are based on moral principles that were not self-chosen (i.e. not legislated by reason) are heteronomous (Blackburn, 1996:31).

To act from duty is another distinguishing element of Kants' ethics. Each person has the duty to try and perfect him/herself in order to attain moral autonomy, as well as a duty to respect the moral autonomy of others (Holm, 1998:268). This second duty follows from Kant's "Formula of the End in Itself" which states: "So act as to treat humanity, whether in your own person or in that of any other, never solely as a means but always also as an end" (quoted by Norman, 1983:102). This second order principle demands respect for persons - more specifically to respect (and leave intact) other persons' capacities to act. Moral failure results when (1) others are used as things or tools and not as agents and (2) by doing something to which others cannot consent to. Kant does not appeal to consent as a criterion of legitimate action, but rather appeals to the universalizable moral principles that were identified by rational beings (O'Neill, 1993:177-178). According to Kant a limited beneficence is required and when others or oneself is treated as ends, it is regarded as a failure of

imperfect duties. The moral implication of Kant's idea of respect for persons involves both respect for the other party's liberty as well as their autonomy. It involves "respect for the other person's own pursuit of his or her own ends through his or her own free action, and I am to help in the promotion of those ends only in ways which are compatible with that basic respect". Following from this, Kant also laid great emphasis on the notion of human rights (Norman, 1983:121-122).

To conclude, according to Kant, the "autonomy of the will is that property (of the rational will) by which it is a law to itself independently of any property or object of volition". Having autonomy according to Kant, is to consider principles from a point of view that requires temporary detachment from the specific desires and aversions a person may have. Autonomy is an *ideal* feature of a person as moral legislator (Hill, 1991:45). Kant conceptualizes autonomy as *moral autonomy* where the focus is on the individual and her decisions about what she wants for her life, instead it addresses the moral question, "is this what one ought to do?" (Secker, 1999:48).

4.2.2 Autonomy in Kantian Ethics

Kantian ethics refers to a wide range of so-called "quasi-Kantian positions in ethics" which may range from rights theories to action-based forms of thinking in which the focus is on universal principles, respect for humans and human rights (O'Neill, 1993:183). One of the best-known forms of Kantian ethics can be found in John Rawls' work on justice. His work contains a strong rejection of utilitarian thinking as well as the centering of morality around a self-governing individual. According to Rawls the issues and problems of justice are too complex for individuals to solve independently. Instead, he argues for a social-contract basis for morality where members of society should cooperate in equalizing the inequalities that result from historical and biological factors. He uses a hypothetical social contract in which valid principles are those to which we would all agree to if we could freely consider the situation from the "original position". The original position refers to a standpoint from where individuals are equally ignorant of particular individual characteristics, desires, interests and objectives. This position is aligned with Kant's conceptualization of autonomy, since individuals give themselves moral laws from the perspective of autonomy alone. Persons are regarded as autonomous in the original position because they choose the moral law out of their nature as rational, independent and

"mutually disinterested" persons (Beauchamp & Childress, 1994:59-60; Schneewind, 1994:147).

In terms of the concept of autonomy, the Kantian position in biomedical ethics, usually focuses on individual autonomy. As such, an autonomous person is regarded as a free, independent, self-governing individual who bases decisions on rational reasons after effective deliberation. This person is free from physical or psychological constraints and does not act or decide for emotional reasons (Secker, 1999:48). This conceptualization of autonomy is usually referred to in texts on patient autonomy and respect for autonomy and will be elaborated on in chapter five.

4.2.3 The influence of J.S. Mill on conceptualizations of autonomy

Mill never used the term "autonomy" explicitly, but he did write extensively on freedom and liberty. In his work "On Liberty" the extent of and limitations to the individual's liberty is discussed especially as it pertains to the role of the state in regulating the individual's actions.

Mill was in favour of freedom for all and regarded the individual as someone who has absolute independence over himself - his own body and mind. He writes, "each person is the proper guardian of his own health, whether bodily, or mental and spiritual" (Mill, 1996:16). This is however, only applicable to human beings that have the necessary mental capabilities and therefore does not apply to children, those under-aged according to the law, those who need to be taken care of by others and "those backward states of society in which the race itself may be considered as in its nonage" (1996:13). The only limitation to this freedom would come when the individual may cause harm to someone else, and in these situations society would be justified to interfere with the individual's liberty. Mill explicitly states that this limitation does not apply to situations where the interference of society may prevent harm to the individual. Mill therefore contributed to the idea of autonomy as freedom from external constraint.

As a utilitarian, Mill was concerned about the promotion of ends and therefore regarded the right action as the one that produced the greatest happiness for the greatest number in a way that will promote quality of life. His work shows a shift towards a qualitative notion of pleasure, as is clear in his famous claim: "It is better to

be a human being dissatisfied than a pig satisfied; better to be Socrates dissatisfied than a fool satisfied. And if the fool, or the pig, is of a different opinion, it is because they only know their side of the question. The other party to the comparison knows both sides" (1996:vii). Mill regards the development of individuality as an essential element of well being. He argues that respect for the liberty of others is valuable since people prefer to be the authors of their own lives, they have a special interest in and special expertise regarding their own lives. According to Mill utility is produced as a by-product when people are allowed to develop their own lives. The conclusion can be drawn that Mill did not view autonomy as valuable in itself, but rather that the value of autonomy is situated in the utility, happiness and quality of life it directly and indirectly produces (Holm, 1998:268).

4.2.4 Contemporary ideas regarding autonomy

Both Gerald Dworkin (1988:6) and Joel Feinberg (1989:28) discarded the idea that autonomy has a single coherent meaning.

Feinberg (1989:28) describes the related notions that formulate the general conception of what he refers to as "personal autonomy". The four meanings used to describe autonomy are: (1) the capacity to govern oneself, (2) the actual condition of self-government, (3) an ideal of character derived from that conception and (4) the sovereign authority to govern oneself.

The right to self-governing is usually determined by the capacity to govern oneself, which in turn is associated with the ability to make rational choices (infants, insane persons, the comatose, the intellectually disabled, etc. are usually excluded). Feinberg adopts the threshold conception of natural competence described by Daniel Wikler. In contrast to the legal-like conceptions of competence, this account describes a certain threshold above which people are regarded as competent. Those who fall beneath the threshold are regarded as incompetent. Those above the threshold may possess various natural abilities, in various degrees, one of which is intelligence. Although this may enhance their decision-making abilities, it does not render them more or less incompetent. In other words, the person whose relevant capabilities are just above the threshold of competence may be regarded as qualified for self-government, even though the person may rule herself badly, unwisely or partially. Someone who falls beneath the threshold and therefore are genuinely

incompetent, is incapable of making his/her own decisions - even "stupid ones" (Feinberg, 1989:30).

According to Feinberg autonomy as condition requires aspects such as:

- **Self-possession:** The person is his/her own person, has a distinct self-identity and does not belong to anyone else.
- **Authenticity:** The person has his/her own tastes, opinions, values, ideals and preferences, and does not merely function as a mouthpiece for other people's ideas. However, the person is not totally indifferent to the reactions of others, and will subject his/her opinions and beliefs to rational scrutiny, and if necessary alter these opinions for his/her own reasons.
- **Self-creation (self-determination):** The autonomous person is a "self-made" man, in other words, has the habit of critical self-revision, instilled by significant others and that results in a process of self re-creation. In other words, an autonomous person continually integrates new experiences and old policies in a rational manner to make "greater coherence and flexibility" (Feinberg, 1989:34).
- **Self-legislation:** In the work of Immanuel Kant, it is stated that man is only bound by moral law if the law was legislated by his own free rational will. This idea was further developed by Rawls' conception of autonomy as rational will. According to Rawls the correct moral principles are those that we would consent to as free and equal rational beings.
- **Moral authenticity:** The autonomous person's moral convictions and principles are his/her own, derived from a committed process of continually reconstructing the value system which s/he inherited. The autonomous person will only change his/her principles and convictions after debate, argument and reflection and not by means of coercion.
- **Moral independence:** An autonomous person should not be thought of as someone who is maximally independent of the demands of others, a totally uncommitted person. If autonomy is thought of as a condition that is an ideal condition, there should not be conflict between moral autonomy as an ideal and moral commitment.
- **Integrity (self-fidelity):** The autonomous person is faithful to his/her own principles and therefore integrity presupposes moral authenticity. Yet, complete

moral authenticity does not guarantee an unfailing integrity, because other character traits may have a greater motivating power than moral principles.

- **Self-control (self-discipline):** An autonomous person governing him/herself is not being governed by someone else ("from the outside"), but is in control of him/herself, therefore governed from the "inside".
- **Self-reliance:** A person who is self-reliant does not rely on the commitments from others to him and in other words are able to rely on himself when others fail. This person has inner resources such as strength, courage, resilience, etc.
- **Initiative (self-generation):** The autonomous person has his/her own projects and strategies and has his/her own "undertakings" and/or initiatives. The autonomous person is not someone whose activities are solely determined by others' proposals or initiatives.
- **Responsibility for self:** "De facto autonomy" is a conceptually presupposed condition of most judgements of responsibility. If an autonomous person makes a voluntary choice, that person also takes the responsibility for all the foreseeable consequences that may follow his/her choice.

Feinberg (1989:43) defines autonomy as condition in a relatively vague fashion in order to allow for flexibility. Yet, as an ideal, he is of the opinion that it needs to be narrowed down in order to make it attractive, even though it will always be at best only a partial ideal. Autonomy needs to be defined in ways that, with all other things being equal, will regard 'to be autonomous' as the preferred state. He acknowledges the role that communities and interactions between the individual and communities play in limiting personal autonomy. Based on this given, Feinberg (1989:45) defined the ideal of the autonomous person as "an authentic individual whose self-determination is as complete as is consistent with the requirement that he is, of course, a member of a community".

Dworkin (1988:10), attempts to analyze what an autonomous person is and largely views (similar to Feinberg) autonomy as a moral, social and political ideal. He further defines autonomy as "a second-order capacity of persons to reflect critically upon their first-order preferences, desires, wishes, and so forth and the capacity to accept or attempt to change these in light of higher-order preferences and values. By exercising such a capacity, persons define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are" (1988:20).

Therefore, an autonomous person can rationally accept, identify with or repudiate a lower-order desire or preference in a manner that is independent of the manipulation of desires (Beauchamp & Childress, 1994:122). Dworkin strongly argues that autonomy is more than only the promotion or hindrance of first-order desires. Human beings have the unique ability to reflect upon and adopt attitudes towards their first-order desires and by leaving this out of an account of autonomy, according to him, is to fail to capture an important aspect of human agency (1988:19).

Dworkin's theory of autonomy has received criticism for:

- the focus on second-order desires as an unnecessary complication of the theory, since some second-order desires cannot be clearly distinguished from first-order desires;
- the act of identification with a desire requires an independent act of identification on a higher level. This may result in an infinite regress without ever reaching autonomy;
- the theory lacks a way of allowing ordinary persons to qualify as deserving of respect for their autonomy when they have not reflected on their preferences at a higher level (Beauchamp & Childress, 1994:122).

4.3 Respect for autonomy

The principle of respect for autonomy forms a central part of the so-called "principle approach" to ethics. It supports the notion that it is not sufficient to regard people as autonomous beings, but they should also be respected as such. Among other things, respect for autonomy includes the acknowledgement of the person's right to have his/her own opinions and views, to make choices and to act on personal values and beliefs. People are not to interfere with others' personal affairs and also have the obligation to maintain capacities for autonomous choice and to enhance people's capacity for autonomy. Aspects such as informed consent, (in)competence, decision-making and surrogate-decision-making are usually associated with this principle and will receive more detailed attention in the following chapter.

4.4 Criticisms against an emphasis on autonomy

Traditional ethics consists of ethical systems that aim to discover, articulate and interpret the ultimate moral principles that should govern someone's actions.

Uneasiness with the emphasis placed on autonomy as a prerequisite for moral standing or of respect for autonomy in these theories has been expressed by three main groups, namely the feminists, the communitarians and non-American ethicists.

Both feminine and feminist ethics criticize the emphasis placed on autonomy in moral theories. From the feminine ethics' point of view, moral theory has been developed mainly by men with the result that the moral experiences and intuitions of women are absent in the ethical theories. Only the male virtues, such as reason and rational thought, are treated as being of philosophical interest or genuine moral worth (Sherwin, 1992:47). It is especially the work of Carol Gilligan that contributed to the notion that men and women have different "moral voices". According to her research, when women are faced with moral decisions, they tend to focus on the particular, expressing concern over special relationships and feelings, whereas men are more concerned about the abstract duties and rules considered from an impersonal perspective. The feminine ethicists argue that most women do not find ethical models based on the image of an ahistorical, self-sufficient, atom-like individual credible (Sherwin, 1992:47).

The feminist ethical perspective is in agreement with the feminine perspective that personal feelings such as empathy, loyalty or guilt can play significant roles in moral deliberations. However, feminist ethics have a very explicit political perspective in which the oppression of women is regarded as morally and politically unacceptable (Sherwin, 1992:52). The principles sought after by the "traditional ethics" are regarded as universal and impartial, governing everyone irrespective of race, class and gender and the persons they govern are supposedly autonomous (endowed with enough knowledge and power to be able to decide for themselves what is right and wrong) (Tong, 1993:11). Yet, in reality this is seldom the case. Gender, race and class contribute to asymmetrical power relationships where people are not equal, impartial, independent and autonomous. People often have varying degrees of education and knowledge which is determined by asymmetrical power relations informed by race, gender and class. A lack of education and knowledge, together with relative powerless positions, make it problematic for many people to act autonomously.

Feminist ethics also rejects traditional ethical theory's emphasis on purely abstract reasoning and the view of moral subjects as autonomous, rational, independent and virtually indistinguishable from each other. People have historic roots and develop special relationships within specific human contexts and therefore never function as isolated individuals who can be totally self-legislating. This objection to the primacy of autonomy shows a strong resemblance with the communitarian critique against autonomy.

Communitarianism first emerged as a critique of liberalism. From this perspective, liberalism is criticized for its focus on an "impoverished view of human nature and freedom". It is argued that the primacy of individual rights in the libertarian tradition is self-defeating, since liberalism neglects the social and cultural conditions necessary for the emergence of strong individuals. More specifically, the communitarians attack the liberal view for its reliance on an "atomistic conception of the self" ("unencumbered by essential attachments to others") and the commitment to universality (Moon, 1998:553).

The communitarians find the focus on autonomy problematic because autonomy presupposes an atomistic individualism where moral agents are seen as totally separate from each other, able to function totally independently. According to the communitarian point of view, people are social and historical creatures whose values, capacities and identities result from being born and raised in particular communities. People are therefore strictly speaking, not capable of independently choosing their own moral principles and own conceptions of the good. A person's fundamental aims and purposes are part of his identity that is socially constituted.

The other main criticism offered by the communitarian perspective against liberalism is the focus on universality. Communitarians argue that it is not possible to identify a set of universally valid principles, which are normatively binding at all times, places and to all persons. People are historical and social beings whose moral lives are constituted by the system of beliefs, concepts and values which make up a "community's shared understandings". The focus of moral inquiry should be on these shared understandings and not on identifying universal principles (Moon, 1998:555).

A third strand of criticism comes from non-American countries who view the emphasis on autonomy, and especially respect for autonomy as a reflection of American society and its values. Since the principle of respect for autonomy forms part of the principle-based approach to ethics (which is in turn informed by the common morality), it is criticized for reflecting dominant principles in American society, and not the principles that are valued in other regions or countries. The emphasis on autonomy in the American health care system is practiced at the expense of principles such as beneficence and justice which are valued in other societies (Holm, 1998:272). Dickens (1999:249) for example shows that Southern Europe tend to follow a deontological code where patients have the positive duty to maximize their own health and to follow doctor's orders. The physician is constrained by professional norms, rather than by an emphasis on patient rights. In the social welfarist models of the Nordic countries, the focus is on positive rights, and entitlements to universalist healthcare provision. In the USA and some Western European countries, liberal rights-based models are used where patients retain the negative right to override medical opinion, even if his/her capacity is in doubt.

4.5 Autonomy and the intellectually disabled

All the accounts of autonomy described in this chapter view autonomy as an idealistic principle, described in terms of complex cognitive capacities such as language and self-consciousness, memory, logical relations, empirical reasoning about beliefs and their validity and the capacity to use normative principles (Richards, 1981:6). These required capacities necessarily exclude large numbers of people from reaching a continuous state of full autonomy. Not only do people with the capacity to make autonomous decisions sometimes fail to make autonomous decisions, but also people who are generally regarded as not autonomous, can at times make autonomous choices. This is especially true for the person with an intellectual disability.

Depending on the degree of disability, some may not have any of the required cognitive abilities to reflect, make decisions, or self-legislate whereas others may have capacities to do so. The severely intellectually disabled may be able to indicate a wish or preference of his/her own (first-order desires), but will not be able to reflect rationally or critically on these desires. People with mild intellectual disabilities may however be able to reflect to some extent on their first-order desires. Even despite

the fact that people with intellectual disabilities cover such a wide range of capabilities and decision-making abilities, they are often as a group regarded as incompetent (falling below the threshold level of competence) and incapable of autonomous agency and actions. This approach is supported by the following remark from Beauchamp and Childress (1994:127), "the principle (of autonomy) is not so broad that it covers nonautonomous persons. The principle should not be used for persons who cannot act in a sufficiently autonomous manner (and cannot be rendered autonomous) because they are immature, incapacitated, ignorant, coerced, or exploited. Infants, irrationally suicidal individuals and drug-dependent patients are typical examples". The *individual* (with an intellectual disability) and his/her abilities to act as an autonomous agent who can make autonomous decisions, is often not considered at all. Therefore the one approach to the question of autonomy and the intellectually disabled, is to deny all people with intellectual disabilities autonomy, by defining very stringent requirements for autonomous agency and decision-making. However, these ideal notions of autonomy and autonomous decision-making, will lead to the exclusion of many, since very few "normal" people will meet the stringent requirements for autonomous agency. For example, in matters of procreation and reproduction, many otherwise "autonomous" people will not base decisions about having children on self-legislated principles, reached through a process of deliberation and reflection. Rather, it could happen (and often does) through pure biological and instinctual desires, without any rational thought entering the process. Yet, people with intellectual disabilities are expected to adhere to these prerequisites for autonomous decision-making. As mentioned by Beauchamp and Childress (1994:123), any theory of autonomy that presents an ideal beyond the reach of normal choosers is not acceptable and therefore not very helpful.

The opposite position is represented by the "evidentiary point of view", cited by Ronald Dworkin (1993:223). According to this view autonomy should be respected because each person knows what is in his own best interests better than anyone else. It is therefore better in the long run to recognize a general right to autonomy which is always respected than by reserving the right to interfere with other people's lives whenever it is thought that they have made a mistake. This view is also supported by Tännsjö (1999), in his argument that autonomy should be respected in all matters of procreation. Procreative decisions belong to the private realm and should be respected as such. Therefore no-one should ever have to qualify in order

to have children, and no-one (including the intellectually disabled) should ever be involuntary sterilized because they are deemed unfit for parenthood. This perspective rests on the assumption that autonomy should be respected, because it protects the person's welfare. However, people often make unwise or foolish decisions which are not in their best interest and not protecting their own welfare.

In contrast to the evidentiary view of autonomy, Dworkin adopts the integrity view of autonomy (which is also the point of departure for the present study). According to this viewpoint, autonomy protects the capacity to express one's own character. It makes self-creation possible because it acknowledges a person's right to a life structured by his/her own values. However, this argument requires that a person must have the capacity that autonomy is supposed to protect. One of the implications is that someone, who lacks this capacity, is still entitled to the right of beneficence and that his preferences be considered, but he doesn't have the right to make decisions contrary to his interests. In the words of Ronald Dworkin (1993:226), "That may sound harsh, but it is no kindness to allow a person to take decisions against his/her own best interests in order to protect a capacity he does not and cannot have". The question to be answered then is, to what extent do people with intellectual disabilities have a right to make autonomous decisions about procreation?

4.6 Conclusion

The prominence of autonomy as a guiding ethical principle has received support in the writings of people such as Immanuel Kant, John Rawls, Gerald Dworkin and Joel Feinberg. It has also been criticized for being too American-centered, too masculine-centered, too individualistic and not sensitive enough to the social and community aspects of personhood. Many of the conceptualizations of autonomy also lean towards the ideal notion of an autonomous agent as someone who is free from outside influences, who is self-legislative, who reflects and deliberates on his/her own moral principles and values and who is his/her own person. This ideal notion seems to have limited usefulness in practice since it serves to exclude so many. People with intellectual disabilities are usually assumed to be incapable of autonomous decision-making and therefore not deserving of respect for autonomy. It was argued that some people with intellectual disabilities might in fact be capable of autonomous decision-making and therefore deserve to receive respect for their autonomy. How

this should be applied to matters of procreation, remain to be discussed in the following two chapters.

CHAPTER 5

THE PRINCIPLE OF RESPECT FOR AUTONOMY

5.1 Introduction

"Just as bioethics has tended to concentrate primarily on the rights of the competent patient, so philosophical work has centered on the rights of competent persons and the grounding of these rights in utility or in autonomy, rather than on decisions for those who are incompetent. Although Mill said one can justifiably interfere with the liberty of the incompetent, for their own good and to keep them from harming themselves, it doesn't say which guidelines to use or which principles should be used in those decisions."

This quote of Buchanan and Brock (1989:3) is not only applicable to those who are clearly incompetent to make autonomous decisions, but also to those who may be competent at times (but not otherwise) or competent to make certain decisions (but not others) for themselves.

The purpose of the present chapter is to explore the principle of respect for autonomy and whether it can be applied to the intellectually disabled. Related aspects such as paternalism and surrogate decision-making are also discussed.

5.2 Respect for autonomy: some initial considerations

Beauchamp and Childress (1994:123) describe autonomous agents as, "normal choosers who act intentionally, with understanding and without controlling influences that determine their action". To respect someone as autonomous therefore entails the acknowledgement that decisions are up to the individual person and that other parties should refrain from efforts to control those decisions (Hill, 1991: 47). Respect for autonomy goes beyond a description of someone as autonomous (mature/reflective/independent) towards the granting of a right to control certain matters for him/herself without interference in the form of controlling threats and bribes, manipulations and the willful distortion of relevant information (Hill, 1991:48). Yet, respect for autonomy does not entail unlimited freedom - if your autonomous actions interfere with someone else's autonomy, or if your action is in conflict with other moral principles, a limit may be placed on the extent to which your autonomy

could be respected. Respect for autonomy is therefore a *prima facie* principle that can be overridden by other competing principles, such as beneficence and nonmaleficence.

Although certain limits may be imposed, respect for someone's autonomy generally allows them to make their own decisions, even though these may be foolish, unwise or irrational. In the words of T.E. Hill, "the right of autonomy allows people to make their own choices, it does not dictate what those choices should be" (1991:49). However, if someone makes a choice or a decision that seems to be clearly self-destructive, the health care professional is often faced with the dilemma of reconciling respect for people's autonomous decisions with a real and deep concern for their welfare. In these situations some will argue that paternalism is justified and appropriate because either (1) the expressed preference is not a real preference or (2) the person is not fully autonomous (or competent) and therefore it is not really what the person wants (Harris, 1985:195).

According to Harris (1985:196) there are four ways in which an individual's autonomy can be undermined and diminished:

A Defects in control of own choices

- Where the preferences expressed are not necessarily the genuine preferences of the individual due to e.g. mental illness.
- Where the person's behaviour is controlled by desires which the person does not wish to have: e.g. drug addiction where there is a tension between the first order desire to have the drug and second-order desires not to. Addiction itself is generally not regarded as destructive to autonomy, only so when the agent wishes not to be addicted.

B Defects in reasoning

- Prejudice, beliefs and an uncritical conformity to traditional values can affect reasoning. People should therefore be encouraged to establish their own views and to discover their truth or validity for themselves.
- If a person bases choices on his/her own reasons for them, these reasons should not reflect blind prejudice. In instances where the choices are based on factual claims, there should be a proportionate relationship between the

strength of the evidence for those facts and the strength of the beliefs they support. Where the choice is based on an inference from facts or propositions, that inference should be valid and logical.

- Defects in reasoning will only damage autonomy where the defects undermine or tend to undermine the agent's capacity to make choices.

C Defects in information

- This can occur when beliefs or choices are based on false or incomplete information, where the agent's own information gathering is at fault or where the agent fails to understand the information or the significance thereof.

D Defects in stability

- People change over time and therefore their opinions and decisions may also change. This is not sufficient grounds, though, to act paternalistically.

If the principle of respect for autonomy is mainly concerned with obligations on the part of health care professionals to enhance someone's capacity for autonomous choice in ways that will respect autonomy and not interfere with the individual's affairs (Christman 1989: 4), then these potential limitations to autonomy should be actively addressed. One way to circumvent these potential limitations, is through the practice of informed consent. Although informed consent has been designed to protect autonomy and to enable autonomous choice, it also functions as a way of protecting people from harm and to encourage professionals to act responsibly in their interactions with patients (Beauchamp & Childress, 1994:142).

5.3 Informed consent

According to Buchanan and Brock (1989:26), informed consent in medicine requires the free and informed consent of a competent patient to medical procedures that are to be performed. This entails the ideal of shared decision-making where patients decide in collaboration with the health care professional about health care in ways that will satisfy the patient's aims and needs. Informed consent is a temporal process, where consent is given over time and can be withdrawn over time (Beauchamp & Childress, 1994:143).

In its general form, informed consent obligates professionals to: disclose information to patients, ensure that the disclosed information is understood adequately and to minimize any form of coercion so that the person can make a voluntary decision. Beauchamp and Childress (1994:143) distinguish between (1) informed consent in terms of the rules of consent in institutions and (2) informed consent of an autonomy-based model. In the first instance, institutions have to obtain legally valid consent before procedures can be performed. Therefore the physician who performs procedures based on institutionally obtained consent, may not necessarily adhere to the stringent standards of informed consent that stems from an autonomy-based model.

The autonomy-based model represents a high standard of informed consent that can only be obtained if a person, with substantial understanding and in a substantial absence of control by others, intentionally authorizes a professional to do something (Beauchamp & Childress, 1994:143). This distinction has significant implications for the intellectually disabled. In the past, the intellectually disabled were usually institutionalized and consent for the institutionalization was given by the legal guardian or parent. As a result, this consent authorizes the institution to treat that person in ways they see fit. In the past involuntary sterilization occurred mostly in institutions, based on this form of informed consent. For the purpose of this assignment, however informed consent in terms of the autonomy-based model will be the main focus.

Beauchamp and Childress (1994:145-146) provide the following useful summary of the elements of informed consent.

I Threshold Elements (Preconditions)

1. Competence (to understand and decide)
2. Voluntariness (in deciding)

II Information Elements

3. Disclosure (of material information)
4. Recommendation (of a plan)
5. Understanding (of 3 and 4)

III Consent Elements

6. Decision (in favour of a plan)
7. Authorization (of the chosen plan)

5.3.1 Competence

Although competence is cited as an element of informed consent, it usually acts as a prerequisite element since it determines whether people are capable of adequate decision-making or not. If not, a guardian or surrogate decision-maker can be appointed to look after the person's interests.

Competence is a concept that refers to a person's ability for autonomous decision-making. Competence is often described as an all-or-nothing concept - you are either competent or incompetent. However, competence is also regarded as decision-specific, in other words, a person can be competent to make a particular decision on a specific time under specified circumstances and be incompetent under different circumstances or conditions. Buchanan and Brock (1989:18) define competence determination as "the determination of a particular person's capacity to perform a particular decision-making task at a particular time and under specified conditions". Competence therefore depends on the objective demands of the task including the level and specific form of abilities to understand, reason and decide about the options. A person's ability may fluctuate, due to e.g. dementia or an intellectual disability or may be influenced by environmental factors (such as side-effects of medications or stress) and the behaviour of others.

From a legal perspective, adults are usually presumed to be competent in making decisions about health-care for themselves. In other words, the law assigns to adults a global status of competence unless and until there has been a legal finding of incompetence. In a similar fashion, people may also be legally declared as globally incompetent. But, as cautioned by Buchanan and Brock, (1989:21), in borderline cases, the assignment of competence and incompetence should always be regarded as decision-specific. Thus, although people may be regarded as intellectually disabled, and by law as globally incompetent, they may still be competent to make decisions about certain aspects of their lives, themselves.

The following capacities have been identified as requirements for competence (and shows remarkable overlap with the descriptions of autonomy). However, competence, unlike autonomy is not a matter of degree since you are either classified as competent or incompetent (Buchanan & Brock, 1989:136).

- **Understanding and communication:** This refers to the various capacities that allow someone to be involved in the process of becoming informed and expressing a preference. It includes linguistic, cognitive and conceptual abilities that will enable the person to receive and comprehend the information relevant to the decision (Buchanan & Brock, 1989:23). It also involves an appreciation of different alternatives and future states pertaining to the decision, such as to be able to imagine what it would feel like and be like to be sterilized and not have children or alternatively to not be sterilized and perhaps bear and raise children. This requirement may be especially difficult for the intellectually disabled and young children, who have had limited life experiences and cognitive abilities. The information provided by the physician also needs to be understood and the person's own preferences clearly communicated. In general, understanding requires the capacities to receive, process and make available for use the information relevant to particular decisions. The level of understanding will also depend on the ability of the health care professional to explain abstract, complicated and technical aspects clearly.
- **Capacities for reasoning and deliberating.** Not only is it necessary for information to be understood, but sufficient short-term memory is needed to retain information, especially since informed consent is a temporal process.
- **A set of values or a conception of what is good that is at least minimally consistent, stable and affirmed as the person's own.**
- **The capacity to intend a certain outcome.**
- **The capacity to freely communicate his/her wish to caregivers (Beauchamp & Childress, 1994: 135).**

Buchanan and Brock (1989:26) defends a threshold conception of competence, according to which someone is regarded as either competent or incompetent to make a specific decision. Competence is not regarded as a matter of degree, although the underlying capacities needed to make the decision may be present in various degrees. This requires, however, a standard of competence that can serve as a

baseline against which to decide on someone's (in)competence to make a decision. Yet, no standard for competence or defined set of procedures to determine competence will guarantee that all and only the incompetent will be judged to be incompetent.

The criteria for particular competencies vary according to the context, because the criteria are relative to specific tasks. Therefore the level of competence required to make a certain decision is relative to the complexity of the decision to be made. A person can be viewed as competent to make decisions on certain things, whereas incompetent to make others. Competence in one person can also vary over time (Beauchamp & Childress, 1994:134).

In biomedical contexts a person is generally regarded as competent if s/he is able to understand a procedure, to deliberate regarding the major risks and benefits and to make a decision based on this deliberation. Yet, some people (such as someone with a reduced IQ) can perform all of these functions and still be regarded as incompetent (Beauchamp and Childress, 1994:36)

Other standards of competence have been suggested such as the ability to state a preference (regarded as a weak standard of competence), the ability to understand information and to appreciate one's situation, and the ability to reason through a "consequential life decision" (Beauchamp & Childress, 1994:137). The sliding-scale strategy as a standard of competence, advocated by Buchanan and Brock (1989) proposes that the level of competence required must shift according to the risk attached to the decision. The rationale behind this strategy is that competence determination is a way to protect people against decisions they make that are not in their best interests. So, if a medical intervention has increased risk for patients, more stringent levels of competence to elect or refuse the intervention should apply. If the consequences for well being are not so compromised, the level of capacity required for competence should be lowered. Thus the same person can be judged competent and incompetent, depending on the risk involved in the decision.

All methods of setting standards of incompetence experience difficulties of whether to emphasize the person's autonomy or to emphasize prevention from harm. Beauchamp and Childress (1994:141) argue that competence is determined primarily

by whether a person has the capacity to decide autonomously, and not by whether a person's best interests are protected. They argue convincingly that the sliding-scale strategy, although attractive, seems to be incoherent and tend to conflate riskiness and complexity. The level of competence should increase with the complexity of the decision to be made, not with the level of risk involved. Decisions with a high level of risk do not necessarily require more ability than decisions with low risk.

Furthermore, decisions to override another person's choices should be distinguished from questions of whether the person is competent or not. People seem to assume competence whilst the decisions are in accordance with the health care professional's recommendations. Yet, when the person's decision is in opposition to the recommendations made, paternalism is often justified on the basis that the person in question is actually incompetent. Paternalism is sometimes indicated, even for the competent, but in these instances it should not be implemented and defended on the basis of incompetence (Beauchamp & Childress, 1994:141).

5.3.2 Voluntariness

The concept of voluntariness as an element of informed consent, refers to a person's independence from manipulative and coercive influences. Therefore if someone consented to or refused a procedure where that decision is based on threats, manipulation or misrepresentation of information, the consent or refusal is regarded as invalid. Feinberg (cited in Ameson, 1979:483), for instance, has a very strict account of voluntariness and states, " one assumes a risk in a fully voluntary way when one shoulders it while fully informed of all relevant facts and contingencies, with one's eyes wide open, so to speak, in the absence of all coercive pressure of compulsion. There must be calmness and deliberateness, no distracting or unsettling emotions, no neurotic compulsion, no misunderstanding. To whatever extent there is compulsion, misinformation, excitement or impetuosity, clouded judgment (as e.g. from alcohol), or immature or defective faculties of reasoning, to that extent the choice falls short of perfect voluntariness". He further argues that agents can only take full responsibility for their actions when it adheres to these requirements.

The voluntariness with which someone makes decisions can therefore be diminished by people, conditions such as a debilitating diseases, psychiatric disorders or drug addictions (Beauchamp & Childress, 1994:166). Different forms of influence have been identified and it is important to note that not all forms of influence are controlling or unwelcome. For example acts of loyalty, threats, education, lies, manipulative suggestions and emotional appeals, vary in their impact on a person's decision.

Forms of influence that are usually not compatible with respect for autonomy, include the following:

- Coercion occurs only if one person intentionally uses a credible and severe threat of harm or force to control another. Both parties must believe that the person making the threat can follow through on it, or the person making the threat must successfully convince the other person that it can be done. No room for autonomous decision-making is allowed.
- Persuasion occurs if a person is convinced to believe in something through the merit of reasons put forward by another person. Non-rational and forceful "persuasion" are forms of manipulation and not persuasion.
- Manipulation involves the swaying of someone to do what the manipulator wants them to do by means other than coercion or persuasion. Especially informational manipulation is often used such as lying, withholding information, providing misleading information and exaggeration of information. All of these are incompatible with autonomous decision-making (Beauchamp & Childress, 1994:164-165).

Some influences are however compatible with autonomous decision-making and sometimes coercion and manipulation can be justified. For example when a person welcomes reasoned arguments in favour of certain alternatives because it provides information central to understanding. A distinction between influencing by appealing to emotion and influence by means of reason is needed, but difficult to determine.

Voluntariness becomes especially problematic in total institutions, especially where people are admitted voluntarily. In institutions where people are admitted involuntary, the threat of exploitation is often very real. To quote Beauchamp and Childress (1994:168):

The liberty of competent residents to live their lives in accord with their preferences and life plans must often be balanced against protecting their health, protecting the interests of others, promoting safety and efficiency in the facility and allocating limited financial and other resources. Although respect for autonomy suggests individualized care in the ways we expect outside such institutions such care can rarely be individualized in the same way.

The same will be true (maybe even to a larger extent) of people with intellectual disabilities living in institutions. Although many of the intellectually disabled are clearly incompetent with no clear life plans, unable to express preferences, and are dependent on others to make all decisions for them, many may have preferences and life plans, which have to be submitted to the welfare of others and the institution. In the past the involuntary sterilization of women were often based on arguments such as these.

Voluntariness as a prerequisite may be especially problematic with the intellectually disabled person. Not only are they known for being easily persuaded or influenced by people (especially caregivers) but they are also eager to please and not to anger anyone. Due to their disability, they find themselves as relatively powerless in asymmetrical power relationships, and therefore the level of voluntariness is often compromised. To ensure voluntariness in decision-making may take time and effort on the part of the health-care professional. Health-care professionals are often confronted with family members who exert pressure on them as well as the disabled person to consent to specific forms of treatment or prevention, such as sterilization. These are often motivated in terms of real concerns for the person and are part of attempts to take good care of them. However, it limits the possibility of informed consent and autonomous decision-making.

5.3.3 Disclosure

The disclosure of relevant information by the professional to the patient is often regarded by professionals as the only requirement for obtaining informed consent. Although this is clearly not sufficient, it does occupy a central position in the process of informed consent since the professional person's perspective, knowledge and recommendations are often essential for rational decision-making (Beauchamp &

Childress, 1994:147). On a basic level, consent depends on disclosure of all the relevant facts as well as other factors related to the treatment that may influence the person's decision (Harris, 1985:206). Patients have the right to information and according to Veatch (cited in Strong, 1979:290), whatever information a patient wants should be divulged - no limits should be placed on information a person can obtain. Normally the professional has to disclose information about:

- those facts or descriptions that people would usually consider material in deciding whether to refuse or consent to the proposed intervention or procedure;
- information the professional believes to be material;
- the professional's recommendation;
- the purpose of seeking consent;
- the nature and limits of consent as an act of authorization.

How much information has to be shared, remains a controversial issue - especially where information and knowledge may lead to an exacerbation of symptoms or risks. It is also possible that the physician may decide to withhold some information as a means to influence someone to consent to a certain procedure. Various standards of disclosure of information have been suggested, including the professional practice standard, the reasonable person standard and the subjective standard.

The professional practice standard views adequate disclosure as determined by a professional community's customary practices. The doctor has to act in the patient's best interest and has to divulge information accordingly. The reasonable person standard uses the guideline of a hypothetical reasonable person. The authority is therefore shifted towards the patient. Supporters of this standard believe that obligations to respect autonomy outweigh obligations of beneficence and on balance, the reasonable person standard better serves the autonomy of patients than the professional practice standard. From the subjective standard of disclosure, the adequacy of information is judged by reference to the specific informational needs of the individual person, rather than the hypothesized reasonable person.

None of these standards of disclosure will be without significant problems, many of which are discussed by Beauchamp and Childress (1994:147-150). They suggest that disclosure should be achieved by means of active participation by patient and

physician through the mutual exchange of information to facilitate the decision-making process. In terms of sterilization, the information provided should include information on the permanence of the operation, the risks and benefits thereof as well as alternative forms of contraception.

5.3.4 Understanding of information and giving consent

Even after a thorough assessment of competence, creating a non-coercive environment and divulging the required and requested information to the individual, it is still possible that the person, although competent, may fail to understand all the relevant information. It is generally assumed that the person shows understanding if the person has acquired the significant information and demonstrates justified relevant beliefs about the possible consequences of his/her actions. A complete understanding is not necessary, but what is required is a basic understanding of the diagnoses, the prognoses, the nature and purpose of interventions, different alternatives and the risks and benefits attached to these as well as the physician's recommendations (Beauchamp & Childress, 1994:157). The patients have to communicate their understanding of what they are consenting to, so that their level of understanding can be assessed.

There may be various reasons why people do not demonstrate a proper understanding, even though they are regarded as competent. As stated by Beauchamp and Childress (1994:158), some people have a "very limited knowledge basis", which makes it difficult for them to explain complex constructs and ideas. In South Africa with its high levels of illiteracy and vast numbers of people with limited formal educational backgrounds, this is especially true. The problem is further exacerbated by language differences, where the majority of physician-patient communication is conducted by means of a second or third language. Furthermore the large power differential between the medical professionals and patients may cause patients to be anxious and unsure of their abilities to explain their understandings of material presented. These potential stumbling blocks highlight the importance of clear and understandable communication between the professional and the patient. In terms of the intellectually disabled, communication may be experienced as very difficult and challenging, especially if the health care professional has limited experience in this field.

Another potential limitation is inadequate information processing. Where people are faced with information overload, selective perception and processing of information takes place with the effect of information being distorted, selectively remembered or unattended to. According to Beauchamp and Childress (1994:159) this occurs especially where information about risks are involved. In terms of sterilization, if the health care professional inform the person that the procedure renders a person permanently sterile, although in some cases, it has been successfully reversed, a person can easily process the information selectively and only remember that it can be reversed.

Problems of non-acceptance and false belief are a further complication in people's understanding of information. Therefore, even if someone understands or comprehends the information provided, the person may still not accept the information as true. For example people diagnosed as HIV+ sometimes refuse to believe the test result, even though they understand what the result means and how it was obtained. The physician is then confronted with the problem of whether the person's autonomy should be respected or not. Some would argue that the person's wish for no further information should be respected, whereas others feel more information can be justifiably imposed.

5.4 Paternalism

The principle of respect for autonomy strongly suggests that society should never tolerate people who are adult and capable of making their own autonomous decisions, to be coerced into accepting any kind of care. Yet, sometimes people make decisions that are clearly not in their best interests or that may even be harmful. This may leave the physician with the dilemma of choosing between respecting the person's autonomy, or acting paternalistically in efforts to adhere to the principle of beneficence.

In its broadest terms, paternalism refers to "government as by a benign parent". Traditionally the parent has the right and duty to overrule their child's preferences in the name of their real or true best interests - interests the child may not be mature enough to perceive (Blackburn, 1996:279). According to the definition of the Oxford English Dictionary, paternalism is, "intentional nonacquiescence in another person's preferences, desires, or actions with the intention of either avoiding harm to or

benefiting the person". This definition allows for paternalism to include both the overriding of intentions, preferences or actions for substantially autonomous decisions as well as overriding those decisions which do not stem from autonomous decision-making (Beauchamp & Childress, 1994:274). Not all authors agree with this conceptualization: some argue that paternalism is only justified for people incapable of reaching autonomous decisions (Tännsjö, 1999:24) and not for instances where the paternalist can show no defect in the other person's autonomy (Harris, 1985:201). Furthermore, according to Harris, paternalism is only justified when a defect in the decision-making process is relevant to the particular decision to be made, and then paternalism can only be justified for so long as it takes to apprise the agent of the defects in his decision (1985:201).

Whether paternalism is ever justified for those who are substantially autonomous seems to be a debatable issue. Feinberg addressed this by drawing a distinction between strong and weak paternalism. Weak paternalism occurs when a physician intervenes on the grounds of beneficence or nonmaleficence only to prevent "substantially nonvoluntary conduct". In other words to protect people against their own non-autonomous actions (such as may be the case for people with intellectual disabilities) and therefore takes competence and ability into account. Strong paternalism refers to interventions by the physician which are intended to benefit a person where the person's choices and actions are informed and autonomous, albeit risky and harmful.

Weak paternalism usually does not require strong evidence to be convincing. It is generally agreed that people need to be protected from harm that may result to that person from conditions that are beyond his/her self-control. In cases where someone's autonomy is questioned, paternalism cannot threaten respect for their autonomy, since no substantial autonomy exists. However, in terms of strong paternalism, the autonomy of individuals are not respected and according to some writers, it violates individual rights and restricts people's free choice. Most writers reject strong paternalism, although some will justify it by means of appeals to beneficence and/or consent. For instance, Dworkin argues that paternalistic restrictions is justified when the person being coerced would have consented to the restriction if he were rational (Arneson, 1979:470). He further argues that paternalism may heighten a person's ability to lead a "rationally ordered life" and

does not necessarily compromise or diminish someone's autonomy. It is therefore possible that paternalism can "preserve a wider range of freedom to the individual" (Husak, 1980:29). Feinberg argued that in terms of legal paternalism, the state has a right to prevent self-regarding harmful conduct, only when it is substantially nonvoluntary or when temporary intervention is necessary to establish whether it is involuntary or not (Arneson, 1979:470).

As argued by Beauchamp and Childress (1994:282), acts of strong paternalism are sometimes needed and justified if one adheres to the principle of beneficence. Although these writers do not advocate paternalism as a state/institutional policy, they stipulate that the following conditions need to be satisfied if strong paternalistic acts are to be committed:

- a person is at risk of a significant, preventable harm;
- the paternalistic action will probably prevent the harm;
- the projected benefits to the person of the paternalistic action outweigh its risks to the person;
- the least autonomy-restrictive alternative that will secure the benefits and reduce the risks is adopted;

In his book entitled, *Coercive Care* (1998:6), Törbjörn Tännsjö argues that coercive care can err in two ways: (1) by allowing freely coercive care where it should be prohibited and (2) being too restrictive in allowing coercive care where it ought to take place. This is especially true for the intellectually disabled. On the one hand we want to respect autonomous decision-making (and refrain from acting paternalistically) for those individuals with intellectual disabilities, who are competent and can exercise autonomous decision-making in certain situations about certain aspects. On the other hand, one needs to be careful not to focus so exclusively on the principle of respect for autonomy that people who are not substantially autonomous are harmed by a lack of (weak) paternalistic intervention.

To conclude, in general, autonomous people should not be coerced into accepting any medical interventions they do not want, even if it is in their own best interest or in the best interest of others. This extends to people, capable of autonomous decision-making who did not want to exercise autonomous decision-making or did not bother

to do so (Tännsjö, 1998:9). However, since it is possible, that some people are incapable of reaching autonomous decisions, the decision-making responsibility can and should be transferred onto someone else to act as surrogate.

5.5 Surrogate decision-making

Surrogate decision-makers reach decisions for people who are nonautonomous or for those individuals whose autonomy is doubtful. Buchanan and Brock (1989:87-88) developed a theory of surrogate decision-making with the underlying values of respect for individual self-determination, concern for the individual's well-being and distributive justice. The three possible "guidance principles" suggested are, the advance directive, the substituted judgment standard and the best interest standard.

The advance directive standard applies where someone who has been autonomous and competent before, made his/her wishes regarding treatment known (whilst being fully autonomous) or appointed someone specifically to act as a surrogate to make these decisions on his/her behalf. For people with intellectual disabilities, decisions about future medical treatments, such as life-sustaining treatment, are such complex decisions to make, that most of them will not be regarded as competent or autonomous to make that kind of decision. Therefore it is highly unlikely that they will be able to formulate advance directives of any sort.

The substituted judgment standard instructs a surrogate to choose as the person would choose if the person was competent, informed of all the medical information and options and knew that he/she is incompetent. Similar to the advance directive standard, it attempts to preserve and acknowledge autonomous decision-making. The substituted judgment standard is however problematic, since it is very difficult for anyone to imagine or decide what the person with a moderate to severe intellectual disability would have wanted if they were competent, since they have never been competent to indicate their wishes and preferences in any substantial way. Although it may be technically possible for the mildly disabled to be competent to make certain decisions, and therefore a surrogate should be able to make a substituted judgment decision, it opens up possibilities for considerable abuse. In agreement with Beauchamp and Childress (1994:173) it is suggested that substituted judgment should not be used for people who have never been competent, and even for those

who have been competent, it should preferably be substituted for the "pure autonomy standard" or the best interest standard.

The best interest standard states that a surrogate must choose whichever will best serve the person's interests or will maximally promote the person's good.

The term "best" implies (1) that some interests are more important than others since they make a larger contribution to the persons "good" and (2) a particular decision can advance some of the person's interests while it frustrates others (Buchanan & Brock, 1989:94). This standard requires the surrogate to determine the net benefit for the person of each option, "assigning different weights to the options to reflect the relative importance of the various interests they further or thwart, then subtracting costs or 'disbenefits' from the benefits for each option". The alternative to implement then, is the one with the greatest net benefit to the person (Buchanan & Brock, 1989:123). From this calculation it follows that the mere fact that an alternative may benefit the person, is not sufficient in deciding in favour of that alternative. The *net* benefits for each alternative have to be calculated. The best interest standard therefore relies heavily on the notion of quality of life. Quality of life decisions are not about what the person would have wanted, or the person's social worth, but about the value of life for the individual who must live it, not the value his/her life has for others (Beauchamp & Childress, 1994:180; Buchanan & Brock, 1989:123). According to Buchanan and Brock (1989:123-124), "for those with severely reduced capacities, life may be worth living if there is a balance of simple pleasures or contentment over pain and discomfort".

Problems associated with the best interest standard mainly centre around the idea that values may enter the decision-making process which are not relevant to the person's benefits or burdens. It is suggested by Buchanan and Brock (1989:180) that judgments about benefits and burdens should focus on "tangible factors" such as physical suffering and medical diagnosis, and should be extended into other domains only with hesitation and great caution. This seems to be especially the case with predicting future emotional or psychological harm and/or suffering that may result.

Another potential problem is the extent to which the interest of others should be considered in determining the person's best interests. For example, when women with intellectual disabilities are given Depo Provera routinely from the onset of

menstruation in order to cease menstruation (even though menstruating does not seem to be a problem for the woman herself) because caregivers find it stressful, difficult or inconvenient to manage the menstruation. Some may argue that it is in the woman's best interest, because the less the strain on the caregivers, the better the care she will receive. Similar arguments can be made to justify certain treatments for people in institutional care. Although one may be sympathetic towards the caregivers and the stresses they experience, when the best interest standard is applied by the surrogate, the interests of the individual is the central concern, not the interests of others.

The decision as to who should act as the surrogate decision-maker seems to vary according to the type of decision to be made. Generally speaking, the surrogate should be competent to make reasoned judgments and decisions, should possess the necessary knowledge and information, has to be emotional stable and must show a commitment to the incompetent person's interests that is free of conflicts of interest and of controlling influence by those who may not act in the person in question's, best interests (Beauchamp & Childress, 1994:244).

Usually the closest family member is regarded as the first choice of surrogate. Family members are assumed to have a special interest in their relatives, have intimate knowledge of that person and are usually committed to furthering the person's welfare. However, instances may exist where this is not the case, and therefore the family as surrogate is not a given - especially where the family may have a conflict of interest in the decision to be made. As far as the intellectually disabled is concerned, the closest family member, legal guardian or primary caregiver (where close family members are not available) usually take responsibility for decision-making about all health-related and financial matters. However, in decisions about preventive measures, such as sterilization, it raises questions about the role their own interests may play in having the person sterilized and whether they alone should be able to authorize this type of procedure. As was mentioned in chapter three, the parents of intellectually disabled girls strongly favoured sterilization (preferably by means of hysterectomies), in order to manage menstruation more effectively and consequently lessen the burden of care-taking.

Health care professionals can also play a significant role in helping families with decision-making whilst protecting the patient's well-being and best interests. They are valuable in terms of their expertise on medical matters such as the involved risks and benefits and are usually motivated by the principles of beneficence and nonmaleficence. However, few physicians in South Africa have adequate experience in working with the intellectually disabled and have little experience in communicating with them. The anxiety attached to this may cause the professional to focus on the caretaker's position, rather than the position of the person in question or that decisions regarding competence are made prematurely. Furthermore, in the past (and even more recently), sterilization abuse was often initiated and carried out by health care professionals.

In situations where health professionals and surrogates disagree as to the course of action, institutional ethics committees and courts of law can have a valuable role to play. These committees can facilitate decision-making among professionals and surrogates and may also serve the function of monitoring professionals' conduct. However, sometimes significant disagreements arise within these committees, responsibility is often diffused and some powerful groups may "hijack" the process for the furthering of their own agendas. These committees usually have limited or no legal power to settle matters and therefore are limited in what they can do. In terms of judicial processes, courts can be helpful to reach final decisions in controversial matters or can provide additional safeguards where people have no relatives and are institutionalized (Beauchamp & Childress, 1994:147-149). However in South Africa, it is expensive, time-consuming and often only within the reach of a privileged few.

Decisions about sterilization of the intellectually disabled should preferably not reside with one person or authority only. Decision-making in this regard (if ever indicated) should include the health care professional as well as a mental health professional, the family member or caretaker, representatives of the institutional ethics committee and possibly representatives of consumer advocacy groups.

5.6 Respect for autonomy and the intellectually disabled

The worldwide policies of deinstitutionalization, normalization and integration encourage the intellectually disabled to become fully-fledged members of society. Yet, as argued in chapter three, they are usually not awarded respect and

acknowledgment of autonomous decision-making powers concomitant with community living. In the past, it was automatically assumed that anyone with an intellectual disability, by means of class membership, are non-autonomous and therefore globally incompetent to make autonomous decisions. Consequently respect for autonomous decision-making was viewed as an inappropriate principle in considerations of ethical matters pertaining to the intellectually disabled. Instead, the principles of beneficence and nonmaleficence were strongly favoured with the accompanying practices of paternalism and surrogate decision-making. Whilst acknowledging that many people with intellectual disabilities (especially the severely disabled) are incompetent and need to be cared for in ways that will serve their best interests, this does not automatically apply to all intellectually disabled individuals.

In the past these assumptions about the global status of incompetence (of the intellectually disabled), often led to practices that denied all of them, all forms of autonomous decision-making, even about relatively simple and uncomplicated matters. In chapter four it was argued that some individuals with intellectual disabilities could at times make autonomous decisions about some aspects concerning their lives and that the requirements for autonomous action should be applied equally to all - it should not be made more stringent for the intellectually disabled. The principle of respect for autonomy (also for the intellectually disabled), obligates the physician or health care professional to actively enhance people's capacity for autonomous choice in ways that will respect autonomy and not interfere with their affairs (Christman, 1989:4). The principle of respect for autonomy, as described in the foregoing section, can be applied to all who are regarded as autonomous, even some people who are intellectually disabled.

At first glance, respect for autonomy seems to be a relatively simple and straightforward process: the health care professional simply has to apply the same guidelines stipulated in the first part of this chapter, (and used for "normal" people) to the intellectually disabled. Although the same guidelines do (and should) apply, the application thereof is not such a simple process at all. For instance, most people of normal intelligence are presumed to be competent and capable of autonomous decision-making, until proven otherwise. The intellectually disabled, suspected or known to have a lower IQ, is presumed to be incompetent, until convincingly proven otherwise. The burden of proof in terms of competence seems to be shifted away

from the professional to the individual. The onus lies with the individual to show "beyond a reasonable doubt" to the physician that s/he is competent to make a certain decision. This constitutes a discriminatory practice towards the intellectually disabled - especially if it is accepted that they have equal moral status to other human beings and are equally deserved of respect (as argued in chapter three). If the principle of respect for autonomy is to be applied to the intellectually disabled, this is the first significant shift that has to take place in the approach taken by the health care professional.

The second important aspect to keep in mind, is that obtaining informed consent is a process in time, not a once-off conversation. The focus on the process-nature of informed consent is especially important with the intellectually disabled. They are often scared and shy in front of strangers, especially people in authority positions. Time is needed to build a trusting relationship, where information can be adequately and repeatedly shared and comprehended. Due to shyness or frightfulness, the impression can easily be created that they do not understand the information given to them or that they cannot deliberate rationally. Especially where the procedure to be performed is not a medical emergency (such as sterilization), adequate time should be set aside for multiple consultations on the matter. Contraceptive sterilization is not a medical emergency.

One of the major limitations, especially in South Africa, is that few health care professionals have had adequate experience in working with the intellectually disabled. In the U.K. for example, psychologists can only register with the British Psychological Society, once they have completed an approved 6-month practical during which they work exclusively with the intellectually disabled. Similar requirements do not exist in South Africa. Many psychologists and medical doctors have never had any personal contact, communications with or adequate knowledge of intellectual disabilities, yet, they are the ones expected to make crucial decisions about these people's level of competence. Therefore, the third important aspect in this regard is that people involved in making decisions about the intellectually disabled, need to have experience in working with them, or at least be working under close supervision. Experience in communicating with them, determining their preferences and wishes and being able to explain complicated terminology in understandable ways, are important skills to be developed and practiced. First-hand

contact and experience often also serve the function of removing and/or lessening the stigma and biases professionals may have against the disabled.

Although the ideal of autonomous decision-making for the mildly intellectually disabled, may seem like a worthwhile idea, it doesn't amount to much if the attitudes towards their upbringing and education do not reflect similar values. Similar to children of normal intelligence, the intellectually disabled also need to be given progressively more autonomous decision-making opportunities, whilst taking the responsibility for the consequences of the decisions they make. Lafollette (1999:139), distinguishes between normative and descriptive autonomy. He suggests that young children should be granted circumscribed normative autonomy although they do not meet all the requirements for descriptive autonomy. In other words they should be trained to become autonomous and this requires parents and caregivers to treat them in some respects as if they were already descriptively autonomous. He suggests three different stages of circumscribed normative autonomy:

1. Administrative autonomy, where the child has a sense of making some choices and take responsibility in small matters. The parents or care-takers are always ready to step in if necessary.
2. Monitored autonomy, where the child is given greater choices and greater responsibilities, and to some degree the child has to cope with the consequences. However, the parents are still there to intervene if necessary.
3. Minimally constrained autonomy, where the child makes more choices with much less interference from parents.

Although Lafollette developed this model for children of normal intelligence, it seems to be useful in fostering autonomy in those with intellectual disabilities as well. Granted, people with severe intellectual disabilities, will seldom be able to move beyond the level of administrative autonomy, but at least their "autonomous" preferences will be acknowledged. It is not expected of people with normal intelligence to develop autonomous decision-making abilities instantaneously, why should it be any different for the intellectually disabled? This process of acquiring and promoting autonomy should ideally be applied in educational settings, institutions and homes of the intellectually disabled. It requires a significant shift in attitude and

values of the caretakers who often resist the emphasis on autonomy. Caring for the intellectually disabled (as with children), is often easier if the caretaker can take all decisions on behalf of that person. Limited resources to support autonomy and community living, is also cited as reasons why autonomy should not be encouraged. However, if deinstitutionalization, integration and normalization is taken seriously, the promotion of autonomy for those for whom it is appropriate (e.g. the mildly disabled), is important.

Finally, what is argued for, is not a strict adherence to the principle of respect for autonomy, but a *prima facie* adherence. Just as it is not acceptable to view all intellectually disabled persons as incompetent and nonautonomous by means of class membership, it is unacceptable to regard all of them as autonomous and competent to make all of their own decisions. Respect for autonomy protects the individual's self-determination ability, which in turn presupposes the development of the capacities necessary for reflective choice. But, if a person does not have these capacities and the ability to determine their own life-course is compromised, the principle of respect for autonomy becomes redundant. The value of choosing for oneself and acting autonomously diminishes proportionately with the ability to do so (Buchanan & Brock, 1989:39). Therefore, for the severe/profound intellectually disabled, it will be appropriate to appoint a surrogate to make most health care decisions for them, especially since their capacities for communication, understanding and deliberation are so limited. Yet, their competence still needs to be determined on an individual basis before a surrogate can be considered to make a specific decision.

5.7 Conclusion

Adherence to the principle of respect for autonomy can be a valuable point of departure in discussions about decision-making and the intellectually disabled. Not only does it draw attention to the fact that many individuals who are mildly to moderately intellectually disabled, can make autonomous decisions at certain times regarding specific aspects of their lives, but it also compensate for the imbalances of the past, caused by global assignments of competence and incompetence. In the past, respect for autonomy and the intellectually disabled have been treated as totally irreconcilable concepts. Yet on closer analysis, respect for autonomy, especially through means of informed consent, is an attainable goal for people with mild and

even moderate intellectual disabilities, though it may be time-consuming, cumbersome and an inconvenient process for the professionals involved.

Important though, is that the principle of respect for autonomy has only prima facie standing - what is argued for is not a strict adherence to this principle, but a prima facie one. Some people with intellectual disabilities do not have any of the abilities required to exercise any form of autonomous decision-making. To ignore these limitations and allow them to suffer because of decisions they made (which they were not actually competent to make), can not be justified. In these instances weak paternalism should be allowed and surrogate decision-makers appointed to look after their best interests and well-being. The remaining question to be addressed then is, how can the principle of respect for autonomy be applied to decisions about procreation and specifically to the sterilization of the intellectually disabled?

CHAPTER 6

RESPECT FOR AUTONOMY, STERILIZATION AND THE INTELLECTUALLY DISABLED

6.1 Introduction

Liberal individualism, especially in the form of rights theory, attaches importance to the individual's pursuit of personal projects and initiatives, with no or very little interference by the state or other authorities. Procreative rights as a liberty right, usually regard matters of reproduction as private. The individual's autonomy is respected in decisions as to whether s/he wants to have children and how those children should be raised and cared for. Interference in autonomous decision-making regarding parenting is usually only permitted once the child is abused or severely neglected by the parents. However, through policies of involuntary sterilization, the state owns itself the right to interfere in matters of procreation where the intellectually disabled is concerned.

The current chapter gives an overview of procreative rights and attempts to analyze the reasons usually offered for state interference in procreative matters of the intellectually disabled, with special reference to involuntary sterilization. This will be done from the perspective offered by the principle of respect for autonomy. It is argued that adherence to the principle of respect for autonomy precludes the involuntary sterilization of any person, including the intellectually disabled.

6.2 Procreative rights

According to Mercer (1999:328) an essential assumption of liberalism is that the good life stems from freedom granted to the individual to choose his/her own way of life. A liberal society is mainly concerned with respect for persons and respect for their autonomous choices, even if these may be terribly wrong, silly or foolish. One area of life, in which the individual's autonomous decisions are usually respected, is that of procreation. Procreative rights are regarded as inviolable: the right to have children is seen as belonging to the private realm, hidden and protected from public interference. Normally no one has to "qualify" to become parents, and only once it has been proven that a person is incapable of parenting, can children be removed from their care. Even in these circumstances, the removal is often only temporary and the children returned to their biological parents once the parents have been

"rehabilitated". Torbjörn Tännsjö (1999:71) argues that a general right to procreate should be safeguarded by society, but not a general right to one's children.

Exceptions to the rule that people need not "qualify" to become parents usually include people applying for adoption and people applying for fertility treatment. In these instances prospective parents are assessed and evaluated to determine their competence and suitability to become parents - a practice inconsistent with the procreative freedom granted to natural parents. This discrepancy between procreative rights of natural parents and people applying for adoption is usually explained and justified in terms of the fact that with adoptive parents a wide range of suitable parents are available to a child already in existence. Therefore it is possible to harm the child (or at least not benefit him) when attempts are not made to choose the most suitable parent among those available. In contrast, a child not born yet cannot benefit nor be harmed from life being conferred upon him by his/her biological parents (Cartwright, 1994:82; Harris, 1983:222).

Justification for the right to a private and autonomous relationship between parents and children, according to Schoeman (1980:6), stems from the importance of intimate relationships in general. The family is entitled to the right of privacy and parents are entitled to exclude others from "scrutinizing obtrusions" into family occurrences. He further argues that the right to autonomy entitles the adults in the family to make decisions about the kinds of influences they want their children to experience and further entitles them wide latitude in remedying what they regard as faults in their children's behaviour. Yet, neither the right to privacy, nor the right to autonomy associated with the family, is absolute. According to Wald, cited in Schoeman (1980:10), coercive state intervention in family life is only allowed when, (1) serious physical or emotional harm to the child is imminent, and (2) the intervention is likely to be less detrimental than the status quo. The relatively narrow margins within which state intervention is justified, follows from practical aspects such as:

- Typically good alternatives to unfortunate family circumstances are not available (many instances of child sexual abuse occur in foster homes).
- It is difficult to predict which circumstances will have harmful long-range effects.

- There is a lack of consensus about proper methods of child-rearing and the ideal end product of child rearing.
- Our social commitment to diversity of life-styles requires a great deal of tolerance in what should be permitted.

The libertarian ideas about privacy, autonomy and self-determination in procreative matters may be regarded as praiseworthy. However, most of the arguments in favour of these policies of non-interference seem to be quickly dismissed in considerations about the intellectually disabled prospective parent. Involuntary sterilization provides us with one example where the intellectually disabled is automatically excluded from procreative rights, despite the fact that the person in question may be interested in becoming a parent and may be competent to make that decision. The "practical aspects" such as whether good alternative care is available, whether it is possible to predict future well being of children raised in these circumstances and tolerance for variety of life styles seem to disappear when intellectual disability appears. Many of the "interferences" in the lives of the intellectually disabled are well meant and motivated by a real concern for their welfare as well as that of children to be born to them. However, more recently some authors have argued that the principle of respect for autonomy precludes the involuntary sterilization of anyone. State interference is only permissible if it can be clearly and convincingly shown that the parent is unable to care adequately for the child. In these instances, interference is limited to the removal of the children from the parent's care and does not include the involuntary prevention of pregnancies (Tänssjö, 1998;1999).

6.3 Sex, autonomy and the intellectually disabled

Since the realization of parenthood usually presupposes the occurrence of sexual intercourse, it is necessary to address the issue of autonomy and sexual relations where the intellectually disabled is concerned. Section 3.3.3 dealt with some of the issues pertaining to sexuality, and therefore this section will attempt to elaborate on it further by adding the perspective from autonomy.

The libertarian position views sex as morally permissible if and only if it is consummated with mutual and voluntary informed consent. According to Belliotti (1993:319) "the test of morally permissible sex is: have the parties, possessing the

basic capacities necessary for autonomous choice, voluntarily agreed to a particular sexual interaction without force, fraud, and explicit duress?" Consequently, where one or more parties lack the capacities for informed consent or where the consent is not given voluntarily, sex is regarded as impermissible (Bellioti, 1993:320). Sexual intercourse therefore presupposes that it takes place between two willing and consenting people.

Providing informed consent for sexual intercourse is dependent on the general requirements for informed consent (as described in chapter five), such as competence, voluntariness, the disclosure of material information which has to be adequately understood, the making of a decision and the authorizing of the chosen course of action. The level of competence required to provide consent is determined by the complexity of the decision to be made and require among other things the capacities for understanding, reasoning, deliberating and the capacity to communicate decisions. The provision of informed consent for sexual relationships probably does not require the high level of competence needed for consenting to surgical procedures or entering legal contracts, but also does not constitute a decision as simple as stating a preference.

The results of the study by Roelofse and Kleintjes (1995) on informed consent (see tables 1 and 2 on pp. 31-34), clearly show that the moderate lower to profoundly disabled will probably not be able to meet the level of competence required for providing informed consent for sexual intercourse. Although competence always has to be determined on an individual level, it is highly unlikely that people with these levels of disability will be found competent to decide on participation in sexual intercourse. This raises the question whether people who are disabled to the extent that they cannot give informed consent for sexual intercourse, should be allowed to engage in sexual practices that involve other people. Especially since sexual intercourse poses serious risks such as HIV infection, sexually transmitted infections and pregnancy - risks which people with severe intellectual disabilities probably will not understand nor be able to apply appropriately in providing or withholding consent. Another interesting finding reported in table 3 (p.35) is that people falling within the range of severe upper to moderate lower disabilities, are unlikely to become "orogenitally active" unless they are introduced to it by someone else. This finding demonstrates (1) their extreme vulnerability to be sexually coerced and exploited by

others, and (2) that if they need to be protected (paternalistically) from becoming involved in sexual intercourse, it most probably will seldom be necessary. Furthermore, this restriction on sexual intercourse does not limit them from expressing their sexuality in other ways, such as self-stimulation. The position taken here is in contrast with the idea that the intellectually disabled should be allowed to express their sexuality freely. Protecting and restricting them from sexual intercourse (and sexual practices which involve other people), for which they are not competent to provide consent, acknowledges the right of the intellectually disabled to be protected from exploitation and abuse. Weak paternalistic intervention in the form of prohibiting engagement in sexual intercourse is necessary for some people with severe to profound intellectual disabilities in order to serve their best interests. Competence (and not incompetence), in these instances should always be assumed until convincingly proven otherwise and always has to be determined on an individual level - it should never be based on class membership.

Furthermore, those intellectually disabled individuals who do meet the required level of competency, and who are interested in forming sexual relationships, should be assisted in establishing sexual relations that are beneficial to them and are not exploitive or abusive. People with mild to moderate degrees of disability, constitute the largest percentage among the intellectually disabled and tend to be the group most interested in sexual relationships and parenthood. Appropriate sex education, including information about the risks and benefits, birth control techniques as well as parenthood information need to be provided to them. Education and training about being able to assert yourself when unwelcome sexual advances are made, is also crucial.

In conclusion, although people with intellectual disabilities are regarded as having equal moral status to other persons and entitled to the same rights as other people, a form of paternalistic protection is necessary for the more severely intellectually disabled where the expression of sexuality by means of sexual intercourse is concerned. This paternalistic interference should be limited to sexual expression involving other parties and should only be reserved for those who are found to be clearly incompetent to provide informed consent for sex.

6.4 The intellectually disabled parent

The principle of respect for autonomy expects health care professionals to facilitate and respect decisions made by a competent, informed person where these decisions are made voluntarily and with understanding. In terms of reproductive issues, the implication of this principle is that the state and other authorities have to respect people's decisions regarding contraceptive use and parenting. For instance, the state cannot limit the number of children a person may have, nor can parents be prescribed as to exactly how their children should be raised. The only prerequisite for procreative autonomy is that decisions on these matters have to be made by a competent, autonomous person on a voluntary basis. Therefore, if a mildly intellectually disabled woman is regarded as autonomous and competent to consent to a sexual relationship and wants to have a child, the state and other authorities, have to respect her autonomous decision and refrain from interfering - even though her decision may be viewed as foolish or unwise.

As stated before, the principle of respect for autonomy only has prima facie standing. It could be argued that if a person is regarded as incompetent to make decisions about procreative matters, weak paternalism in order to adhere to the principle of beneficence could be justified. People who support the involuntary sterilization of the intellectually disabled often defend their position by appealing to the principle of beneficence as justification for paternalistic interference. According to these arguments, the intellectually disabled, their caregivers and society in general benefit from their being sterilized and consequently prevented from conceiving children. Adherence to the principle of respect for autonomy however, will refute most of these arguments.

6.4.1 Benefits for the intellectually disabled person

Since the policies of normalization and integration have been implemented worldwide, calls have been made for more opportunities for the intellectually disabled to express their sexuality meaningfully. Consequently, sterilization is regarded as a means to increased sexual freedom since it will allow the intellectually disabled to become more fully integrated members of communities without the unnecessary "side-effects" of pregnancy. This argument is in agreement with the idea that the development and availability of the contraceptive pill symbolizes the emancipation of

women - women are now regarded as free to express their sexuality without constraints such as the risk of pregnancy. However, sexual freedom is not granted by means of contraceptives alone. Although it provides women with freedom to express their sexuality with less risk, sexual freedom for the intellectually disabled woman, will only become a reality with more liberal-minded attitudes of carers, more opportunities for relationships that are not exploitive as well as appropriate education and knowledge regarding sexual matters (Draper, 1991:95). Furthermore, contraceptives for women (except for the female condom) does not protect them from HIV and other sexually transmitted infections, neither from sexual exploitation and abuse to which they are so vulnerable. Sexual freedom presupposes a basic understanding of what sexual intercourse entails, awareness of risks and benefits such as pregnancy, sexually transmitted diseases and HIV-infection, and the ability to consent to or refuse sexual intercourse voluntarily. Contraceptives per se, (including sterilization) does not guarantee this. Sexual freedom can thus only be claimed by someone who is competent to consent to sexual intercourse with an equally competent and willing partner. Although it is possible that many people participate in sexual intercourse with little consideration of the potential risks and benefits attached to it, there is a substantial difference between acting from ignorance (whilst being competent to make autonomous decisions) and acting from a lack of competence. Sexual relationships which are potentially exploitive or dangerous (for instance with the risk of HIV infection), to which a person cannot consent to due to a lack of competence, can not be regarded as beneficial to that person, even though it may represent "sexual freedom".

Related to the argument regarding sexual freedom, is the argument that involuntary sterilization benefit the intellectually disabled psychologically because it will save them the trauma of pregnancy and birth - experiences that they will not be able to understand. Underlying this argument are various assumptions such as that pregnancy and birth are inevitably painful and traumatic, that trauma and pain should be avoided, that trauma and pain are necessarily psychologically damaging, that people with intellectual disabilities will not be able to deal with these experiences and that there are no alternative forms of contraceptives available.

Pregnancy and birth can be a traumatic experience for many women - not only for the intellectually disabled. At the same token, pregnancy and birth are not

necessarily traumatic experiences for everyone (Draper, 1991:86). Birth experiences can be made less dramatic and less traumatic by means of adequate pain control, caesarian section (under full anesthesia) and the provision of information and education as forms of preparation. However, most people will appreciate that advance knowledge of what will happen to your body during medical interventions, does not necessarily lessen the trauma or the pain it is experiencing. If the prevention of trauma as a result of pregnancy and birth is the main reason provided to sterilize someone, many more women (especially those who may struggle to understand these experiences, such as teenagers) will have to be sterilized. Contraceptives other than sterilization, which are less invasive and not permanent can serve the same purpose and are also available to women with intellectual disabilities. Furthermore, if a woman decides to become pregnant, one assumes that she is informed of the possibility of pain and trauma that accompanies the experience of birth.

Another problem with this argument is that it is extremely difficult to predict future psychological harm or future psychological benefits especially where an experience such as pregnancy and birth is concerned. Buchanan and Brock (1989:180) warn that in determining someone's best interests, tangible factors such as medical diagnosis or physical suffering, should be taken into account and not future emotional or psychological harm/suffering which is difficult to determine and predict. If we want to override someone's autonomous decisions by appealing to the principle of beneficence, we should not claim future psychological states as the prime consideration in claiming someone's best interest. Therefore to sterilize someone involuntary in order to prevent some possible future psychological harm, is not sufficient justification from the perspective of respect for autonomy.

One of the strongest arguments in favour of sterilization as the safest contraceptive for intellectually disabled women, is that it may be harmful to use other forms of contraception for extended periods of time. The harmful effects of the long-term use of contraceptives, especially Depo Provera are often minimized when weighed against the potential benefits it may have. In South Africa Depo Provera has been used and promoted since the eighties, even though it wasn't approved for contraceptive purposes in the USA, due to the potentially harmful effects of its long-term use. In the South African context, it was found to be especially useful in

governmental reproductive health programmes, since it needs to be taken only on a 3-monthly basis (especially convenient in rural areas) and human error is minimized (in contrast with the contraceptive pill), ensuring effective population control. It is often favoured for women with intellectual disabilities, not because of its contraceptive qualities, but because it usually results in the cessation of menstruation. Granted, it may provide welcome relief of pain and discomfort associated with menstruation, but it also result in these women using Depo Provera for much longer periods of time than women in the general population. Consequently alternative forms of contraception are not explored, neither are alternative ways of managing problems associated with menstruation such as the teaching of menstruation management skills, better preparation for menarche, alternatives to Depo Provera for the management of menstruation pain and discomfort, etc. What is argued for is not that the use of Depo Provera be totally discontinued, but that it should be given with discernment and only if other alternatives have been explored and were found to be inadequate. The life-long use of Depo Provera among the intellectually disabled should be discouraged and the fertility life of the intellectually disabled person managed very carefully. Although some may argue that managing menstruation hygiene is problematic for the severely-profoundly disabled the same will be true for hygiene related to general excretion functions. This emphasizes the need for adequate care and continuous supervision since involuntary sterilization still does not solve the problem of menstruation management. Tubal ligation does not result in the cessation of menses - only a hysterectomy does. Most authorities are in agreement that hysterectomies should not be considered as a form of involuntary sterilization, mostly because it constitutes a risky, invasive procedure with serious reproductive implications. Finally, the harmful consequences associated with the long-term use of Depo Provera still does not justify the involuntary sterilization of women with intellectual disabilities - one wrong does not justify another.

Those who are incompetent to give consent and are sexually active, will probably constitute a small minority, and as argued in the previous section, will mostly be in need of paternalistic protection from sexual intercourse. For the incompetent, an appointed surrogate can make decisions on issues such as the use of Depo Provera (for menstruation management), whilst considering the person in question's best interests. Sterilization as a form of contraception will serve no function for this group of individuals and therefore becomes redundant. More often than not, the person

who will be at risk for pregnancy, and who may require contraceptives will be the person with mild to moderate intellectual disabilities. These individuals will more often than not be able to give consent. The intellectually disabled person who is regarded as competent to consent to the use of contraceptives, should be given the various options and alternatives, and be allowed to make an informed decision.

This relates to a further argument in favour of sterilizing intellectually disabled women, stating that they (similar to other women) should also be able to enjoy the benefits sterilization offer as a contraceptive. This option should not be excluded from them, simply because they are disabled. Ideally all women should be given the same opportunities and options for contraceptive use - also the option of sterilization. However, sterilization is regarded as a permanent procedure that involves significant bodily invasion. Therefore informed consent is required before this procedure can be performed. General practice regards informed consent for this procedure as in need of a high level of competence because of the complexity of the decision to be made and because sterilization serves a preventative rather than a curative or therapeutic function. As discussed in chapter two, many countries adopted very strict requirements for the approval of applications for sterilization, since the end result is of such a permanent nature. It is highly questionable that people with severe to profound disabilities will meet the requirements for competence to consent to sterilization, although some people with mild/moderate disabilities, may be competent to give consent. In these cases sterilization should be given as an option and similar procedures used for other women, should apply to the disabled person. The argument that sterilization of intellectually disabled women is justified because it respects their right to equal treatment and indirectly respect their autonomy is not an accurate reflection of what respect for autonomy entails. The main prerequisite for informed consent, namely competence, need to be met before autonomous decisions can be made and be respected as such.

From the arguments presented above, it can be concluded that there are no clear and convincing benefits for the intellectually disabled person to be involuntarily sterilized.

6.4.2 Benefits for the caregivers

The benefit of sterilization is often described not only in terms of the direct benefits to the intellectually disabled person, but also the benefit it has for the care-taker and therefore indirectly for the person herself. In general it is argued that sterilization will relieve the burden of care takers since they do not have additional worries about contraceptives, pregnancy and caring for children born to the disabled. If their caring responsibilities are eased, it is argued, it may result in better care for the person concerned (Draper, 1991:94).

Caring for the intellectually disabled, can be a demanding and challenging task, especially if the person cared for is unable to perform even basic self-care tasks and is in need of constant care and supervision. The stress and demands on caregivers will probably be less if they do not have to concern themselves with contraception, pregnancy and support for children born to the intellectually disabled and it is possible that it can contribute to better care. However, it is unlikely that the gain in good care will be so significant as to justify an invasive involuntary procedure such as sterilization. Paternalistic actions which serve to override a person's autonomy can only be justified when these actions are for the person's own benefit - not to the benefit of someone else, such as caregivers. Although caregivers are also granted autonomy and their autonomy should also be respected, when they act in the capacity of surrogates for the intellectually disabled, their main consideration should be what is in the disabled person's best interest, not their own.

In South Africa the principles of normalization and integration, as applied to the intellectually disabled, unfortunately did not follow so much from a concern about the needs and wants of the disabled, but from concerns about financial and economic matters. Since funding for state institutions have been drastically reduced over the past few years, alternative options had to be explored, one of which is community living - either with family members or alternative housing such as group homes. Yet very little funding has been made available to support and develop these alternatives, with the result that many families feel burdened by their care-taking responsibilities. There seems to be a lack of group homes, day care facilities as well as respite care facilities which can lessen the burden on family members. Caregivers usually have limited accessible support and this often leads to frustration, poor care, and

eventually neglect and abuse of the intellectually disabled. The answer to problems about quality of care, doesn't seem to lie so much in procedures such as sterilization, but in the availability of more resources and appropriate support for the caregivers. Sterilization can never become a substitute for a lack of adequate care and support for the caregivers.

6.4.3 Benefits for the child to be born

Apart from the alleged benefits sterilization may have for the intellectually disabled, many arguments in its favour center on the avoidance of harm to the child to be born. The intellectually disabled are regarded as incompetent to raise children since they are not able to provide the minimal required care and stimulation that children need. These limitations, it is argued, will result in neglect and abuse of the child and since this will be harmful for the child, it is better for the child not to have been conceived in the first place.

The competence of the intellectually disabled to become parents and to raise children is a contentious issue. Although studies in general haven't found a convincing correlation between IQ and parenting capacity, it has been suggested that when intelligence falls below the mild range, parenting competency is seriously questioned (Glaun & Brown, 1999:96). Relatively little research has been conducted in terms of the intellectually disabled person's ability to parent. In a study by Glaun and Brown (1999:95) the reasons for child protection interventions among the intellectually disabled were analyzed and it was found that intellectually disabled mothers tend to neglect, rather than abuse their children. A lack of parenting skills in combination with a lack of necessary support may be crucial factors in determining the adequacy with which these mothers care for their children. (Glaun & Brown, 1999:103-104). Most of these women were granted care under a supervision order, also emphasizing the need for specific parenting support for mothers with intellectual limitations to promote the development of their children (Keltner, Wise & Taylor, 1999:45).

According to Feldman and Case (1999:27) families with intellectually disabled parents often possess many of the variables associated with child maltreatment such as low educational achievement, poverty, living in substandard housing, lack of social supports, having a history of maltreatment, depression, poor self-esteem and having

a child with developmental delays and/or behaviour problems. However, many other people from disadvantaged backgrounds share these variables - these are not unique to the intellectually disabled. Feldman and Case (1999:27) also found that parents with intellectual disabilities show a significant improvement in their parenting skills, if they are given the opportunity to participate in parenting programmes. These programmes can be successfully done with low cost, low tech and self-instructional materials.

Apart from the fact that many people with intellectually disabilities can be taught parenting skills, the variables associated with child maltreatment does not distinguish clearly between parents with intellectual disabilities and parents from disadvantaged backgrounds. Another related difficulty is the assessment of parenting competence - especially because the level of minimal required care is so difficult to define and determine (Glaun & Brown, 1999:96) and that to predict parenting competence in persons who haven't been exposed to the demands and challenges of parenthood is at best highly speculative. In an attempt to identify assessment criteria of parental competence, Macklin (cited in Denekens, Nys & Stuer, 1999:238) proposed the following:

- lack of verbal skills
- obtrusive deformation of reality
- persistent malice towards children
- inconsistent value system
- inability to transmit essential survival information or a model for life
- failure to establish and maintain interpersonal relationships

Although these criteria may be helpful in assessing parenting competence in contexts where a family is already in existence, it will be difficult to use these criteria as predictive of parental competence. For example, lack of verbal skills, will exclude people with hearing impairments or similar disabilities from parenthood, even though many hearing impaired persons have raised children rather successfully. Many people may behave rather antagonistically towards children which are not their own, and still be loving and caring parents towards their own children. Macklin's criteria, if

consistently applied, may easily serve to exclude many other prospective parents from parenthood - people who often turn out to be adequate parents.

Current practice, in accordance with the libertarian position on procreative rights, does not require people to qualify for parenthood in terms of their parenting competence. If, for instance, a woman is alcohol dependent and refuses rehabilitation, and wants to have a child, she is permitted to do so. Even though the child may be at serious risk to develop fetal alcohol syndrome and will probably be submitted to neglect and abuse, state intervention in the form of involuntary sterilization is not allowed nor is the potential mother submitted to assessments regarding parenting competence. Once the child is born and it can be shown that the child is maltreated, then and only then is state interference justified. If we hesitate to intervene in the general population, why should it be any different for the intellectually disabled only because it may seem more feasible?

It seems to be a discriminatory practice to decide a priori that a person with an intellectual disability will not be able to care for and raise children. People with intellectual disabilities are often capable of "good enough parenting", although they may require more support and training opportunities than other citizens to assist them in this process. Although some of them may struggle with the demands of parenthood, it does not justify involuntary sterilization. If harm to the child is to be prevented by means of sterilization, it could be argued that many people in disadvantaged circumstances or backgrounds would have to be sterilized to prevent harm from occurring to the child. Furthermore, it does not follow logically that it is better for a child not to be born at all, than to be born and subjected to disadvantaged circumstances. Life has to be worth living for the person who must live it and can not be judged from an objective, detached point of view. Unfortunate and disadvantaged circumstances may be harmful and may be difficult for the person subjected to it, but it does not logically follow that the person is better off without life being conferred upon him/her.

6.5 Conclusion

Procreative rights protect the privacy and intimacy of family life. Not only does it regard matters of reproduction as belonging to the private realm, but it also limits state interference to interventions where children are clearly abused or maltreated.

In the past, intellectually disabled people were excluded from these rights, but in recent years, normalization and integration policies have attempted to rectify these discriminatory practices. However, it was argued that people with severe to profound intellectual disabilities are usually incompetent to consent to sexual practices that involve others. Therefore those people regarded as incompetent to give consent need to be protected from sexual intercourse. Persons with intellectual disabilities, who are competent to consent to sexual intercourse, need to receive sex education and information regarding contraceptives, pregnancy and parenting.

The various reasons often advanced in favour of involuntary sterilization of the intellectually disabled were analyzed from the perspective of respect for autonomy. It can be concluded that adherence to the principle of respect for autonomy precludes the involuntary sterilization of any person, since it does not offer clear benefits to the person, nor prevent significant harm from occurring to that person. In agreement with the position taken by Tänssjö (1998), it is argued that society should not interfere in matters of procreation by means of involuntary sterilization. Interference in procreative rights must be limited to (1) protecting those who are incompetent to consent to sexual intercourse from sexual interactions with other beings and (2) protecting children who are known to be maltreated or neglected from further harm.

CHAPTER 7

CONCLUDING REMARKS

Reflection on the impact of and range to which eugenics policies used to be practiced in so-called liberal "Westernized" countries, stimulated renewed interest in the libertarian ideals of freedom, privacy and autonomy in matters of procreation. For instance, Gillon (1998:219) states, "one of the morally objectionable aspects of eugenics is its overriding of liberty and privacy by the state in an area of personal life that is widely perceived as requiring special delicacy and respect for people's choices about such issues as the people they love, those with whom they wish to have children, whether and when they wish to have children, and, in more recent times, for women's choices, once they have become pregnant, about whether or not to continue with their pregnancies".

The libertarian position places emphasis on the requirements of freedom and autonomy. Individuals should be granted the maximal degree of liberty in making reproductive choices with no interference from the state or other authorities. Autonomous actions and decisions should be respected as such (even if these are unwise or foolish), and if decisions were made autonomously, the individual has to take full responsibility for these decisions. In general, people's autonomous decisions regarding contraception, having and raising children are respected and interference only justified when children are maltreated. However, involuntary sterilization practices made a clear distinction between the application of this principle to the intellectually disabled and the rest of society. People with intellectual disabilities are often considered to be globally incompetent and therefore entitled to the principles of beneficence and nonmaleficence, but not respect for autonomy.

In the present assignment it was argued that respect for autonomy is a useful principle to apply to *some* people with intellectual disabilities, especially where reproductive matters are concerned. If society supports the policies of integration, normalization and community living for the intellectually disabled, society also supports freedom and opportunities to express their sexuality in meaningful ways. However, this freedom and acknowledgment of their rights, are limited in practice if it is not accompanied by the granting of and respect for autonomous choices. This creates the opportunity for one of two possible errors, namely (1) granting respect for

autonomy to individuals who are clearly incompetent to make autonomous decisions and (2) excluding people from autonomous decision-making who are in fact competent to make their own decisions on these matters. It is especially the latter error, which often occurred in the past and indirectly resulted in the involuntary sterilization of thousands of individuals that has been problematic. In the foregoing chapters it has been argued that the principle of respect for autonomy (especially in the form of informed consent), must be applied to the intellectually disabled and that competence can be determined for each individual with reference to the complexity of a specific decision to be made. This process may lead to the finding that most people with severe intellectual disabilities are unable to consent to sexual intercourse. The risk of sexual exploitation is very real and therefore it was argued that people who are incompetent to consent to sexual intercourse ought to be protected and prevented from engaging in sexual activities that involve others. Research has shown that most people with severe to profound levels of disability, are uninterested in sexual intercourse unless introduced to it by someone else and that most of them require continuous supervision for other daily activities as well. If good supervision is readily available it should not be too difficult to prevent sexual intercourse from occurring. The purpose of this paternalistic interference is not only to prevent pregnancy from occurring, but to protect the severely intellectually disabled from sexual exploitation, sexually transmitted infections (STI) and HIV/AIDS. Even though a procedure such as sterilization may prevent pregnancy, it does not prevent HIV/AIDS, STI's or dangerous sexual behaviour from occurring. If continuous supervision is provided, involuntary sterilizations in order to prevent pregnancy among the severely and profoundly disabled, becomes unnecessary.

People with mild to moderate intellectual disabilities, who have received the necessary education and information, may be able to consent to sexual intercourse and often show interest in sexual relations and having children. The reasons usually advanced in favour of involuntary sterilization for this group of disabled people, if considered from the perspective of autonomy, are not convincing. Therefore it is concluded that the involuntary sterilization of any person is unacceptable if respect for autonomy is used as the guiding principle. The severely intellectually disabled do not require sterilization if care is taken to prevent sexual intercourse from occurring, and the mildly disabled are mostly able to provide consent for sterilization through normal procedures. If sterilization is regarded as a necessity to prevent highly

inheritable forms of intellectual disabilities to occur, carriers of other genetic diseases should also be involuntarily sterilized.

Sterilization is often used as a mechanism to compensate for other problems in the health and social systems, such as lack of resources to support the intellectually disabled and their caregivers, lack of education regarding reproductive and parenting matters, inadequate training of health care workers regarding intellectual disabilities, lack of respect for the intellectually disabled, lack of tolerance for variety of life styles, etc. These limitations need to be addressed through means other than sterilizing the intellectually disabled person.

The principle of respect for autonomy obligates health care professionals to actively enhance the autonomous decision-making abilities of people with intellectual disabilities. In the words of Cartwright (1994:72): "some people can be helped to make competent choices by searching for a suitable form in which to convey the relevant information to the patient, by gently helping him to understand and explore the implications of the various options and by displaying a sensitivity to his fears and anxieties. A doctor may help a patient to make a decision that can be regarded as competent when, in the absence of such resourceful assistance, the decision could not be reasonably have been so regarded." This seems to be the challenge faced by health care professionals.

Living in a libertarian society requires sacrifices in return for the liberty it protects and guarantees. Although it can be regarded as better in the long run to recognize a general right to autonomy which is always respected than by reserving the right to interfere with other people's lives whenever it is thought they have made a mistake (Dworkin, 1993:232), this may result in being confronted with behaviours and ideas that one may experience as offensive, unworthy, disturbing or silly. Tolerance of others, however, is a necessary aspect of respect for autonomy. According to Mercer (1999:320) tolerance is a virtue that needs to be cultivated by all liberals, since respect for autonomy of rational agents is a deep part of liberalism. The tolerant liberal is concerned that the state should not intervene to reform society through legislation or coercive policy in restrictions of freedom of thought, dress, speech, etc. The liberal society should also show tolerance for people with compromised levels of functioning due to intellectual impairments and should not

intervene unnecessarily. However, caregivers and health care professionals often feel paralyzed by helplessness in caring for the intellectually disabled. In the words of Campbell (1991:111), "respecting the autonomy of patients and seeking to enhance it are highly important moral aims for the practice of medicine, but we must also accept that we are responded to, loved, protected by people we can trust. We need an ethic for modern medicine which guides and sustains professionals and relatives when confronted by helplessness - their own and that of those they care for." There is a need to develop an "ethic for modern medicine" that serves both the need to respect autonomy and the need to take care of people with impaired mental functioning such as those with intellectual disabilities (Verkerk, 1999:358).

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Appendix A

THE UNITED NATIONS DECLARATION ON THE RIGHTS OF MENTALLY RETARDED PERSONS, 1971 (Allen & Allen, 1979:151)

1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.
2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.
3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest extent of his capabilities.
4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.
5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.
6. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offense, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility
7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against any form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.