

Sexuality and Individuals who have an Intellectual Disability

“Although the carrot of sexual activity is often held out to students, in reality there is always ‘one more skill’ a person must master before earning the right to be sexual” (Johnson, 1987, p. 63)

Chapter One

1.1 Introduction

At the end of the twentieth century the sexual freedoms of people with an intellectual disability are still, to some degree controlled by laws enacted at the end of the nineteenth century (Section 138, Crimes Act 1961, Government Printer) (see Appendix A). Yet the disability rights movement, which sprang from international rights covenants, has increasingly tried to bring to people with disabilities the same freedoms that other citizens enjoy (Oliver, 1996). There lies a dichotomy. With reference to New Zealand, on the one hand the rights of people with intellectual disability are progressing in line with international covenants and human rights legislation enacted in New Zealand. On the other hand legislation that was enacted a hundred years ago has precedence over human rights legislation (see Appendix B). This review concerns that conflict between the two viewpoints. It will endeavour to clarify the situation regarding people with an intellectual disability that wish to be involved in a sexual relationship.

In 1996 in a landmark case in Wellington a man was convicted of having sex with a ‘severely subnormal woman’ (see Appendix C). Under section 138 of the Crimes Act 1961 it is an offence for a man to have sex with a woman or girl who is severely subnormal. In this particular case, which was held in the High Court in Wellington and so set a precedent for other cases that would follow, the judge decided that any woman defined as mentally subnormal was ‘severely subnormal’. By this decision the judge effectively made it illegal for a woman with an intellectual disability to have a sexual relationship with ‘any’ man including those men with intellectual disability.

1.2 Rationale for monograph

In view of the historical and philosophical issues that deny sexual freedom to people who have intellectual disability the purpose of this monograph is to explore issues and identify how the rhetoric of human rights in this area is not being implemented. This review will discuss the following themes in chapter form.

1.3 Outline of chapters

Chapter One provides an introduction to and the purpose of the monograph, outlining the reasons why the investigator pursued the topic. It will also provide a definition of intellectual disability and definitions of sexuality.

Chapter Two examines the historical and philosophical issues that denied sexual freedom to people who have intellectual disability. Included in the chapter is an overview of the eugenic period that was considered to have ended in New Zealand the 1930’s (Fleming, 1981). *Chapter Two* also examines the

period from the 1950's until the 1970's reviewing the literature on eugenics philosophy.

Chapter Three will then describe the challenges to the denial of sexual expression. It will describe the effect that Human rights legislation and international covenants have had on the right of sexual expression for people with disabilities within the New Zealand context. It will review the impact that the philosophy of Normalisation (Nirje, 1999), the theory of Social Role Valorization (Wolfensberger, 1991) and theories of social oppression (Shakespeare, Gillespie-Sells & Davies, 1996) have had on the lives of people who have an intellectual disability, specifically in the area of sexuality.

Chapter Three will also examine the data concerning the move away from institutional to community care. With the move to empty institutions in the 1980's and 1990's, of the intellectually disabled, segregation of the sexes, which had been common in institutions became more problematic (Shakespeare et al, 1996). With the movement towards integration into the wider community the notion that intellectually disabled people would wish to have sexual relationships has to be faced and dealt with.

Chapter Four discusses whether issues of sexuality are issues of rights, needs, or human nature? This chapter examines the conflicting forces in the field of intimacy and sexual relationships for people with intellectual disability (Craft, 1978, Craft, 1987, Shakespeare et al, 1996). The gathering momentum of human rights for people to enjoy experience and express their sexuality in contrast to the eugenics beliefs surrounding fitness to breed and the stereotypical views that people with an intellectual disability are not competent to engage in sexual relationships nor able to consent to sexual activity will be examined. An issue is whether competency and consent are used as devices to protect vulnerable people from exploitation, often compared with the way children are protected, or whether they are used to prevent intimate relationships from developing. Further that people with intellectual disability are childlike and therefore asexual. *Chapter Four* will also outline the implications for the future.

1.4 Definitions

In New Zealand the definition most commonly used to identify people who have an intellectual disability is that of the American Association on Mental Deficiency. It states that intellectual disability is, "significantly sub-average general intellectual functioning resulting in deficits in adaptive behaviour, and manifested during the developmental period" (New Zealand Law Commission, 1994, p. 37).

Sexuality is variously defined, sometimes narrowly as concerning only the sexual act or the thought of sexual acts (Cornelious, Chipouras, Makas & Daniels, 1982). More widely it is seen as "the total characteristics of an individual, social, personality and emotional, that are manifest in his or her relationships with others and that reflect his or her gender-genital orientations" (Shopes, 1975, p. 3).

1.5 Rationale for the investigation

This investigation occurred as a consequence of the author's work, which has involved her with people who have an intellectual disability and who, are usually

in crisis situations. Such work requires a holistic approach to problem solving. People supported by the author have not obtained socially valued roles within the community. Lack of value is most apparent in the area of intimacy and sexual relationships where people have been denied the opportunity to find and freely experience rewarding intimate relationships, including the right to marry and the right to have and to raise children (Craft, 1978).

Craft (1978) states:

giving and receiving love, including physical satisfaction, is not the prerogative of those above a certain IQ level; being incapable of anything more than a superficial relationship is not an inherent feature of mental handicap (p. 49).

Although the process of normalisation has been in progress for more than two decades, the authors involvement with people who have an intellectual disability tends to reinforce what researchers (Craft, 1978, Shakespeare et al, 1996) assert which is that there has been little progress in either normalising the lives of the intellectually disabled or in protecting their 'human, civil and political' rights with regard to sexuality.

Human rights are based on the belief that all people are human and have inalienable human rights. The United Nations Universal Declaration of Human Rights (1948), states in the preamble "...the people's of united nations having the Charter reaffirm their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women" (p. 1). Human rights documents reviewed in this monograph include, "The United Nations Declaration on the Rights of the Mentally Retarded (1971)", "The United Nations Declaration on the Rights of Disabled Persons (1975)" and "The Standard Rules (1993)". The basic tenor of these declarations is that people with disabilities are entitled to the same rights and freedoms, including sexual rights and freedoms, as other citizens. Also that it is the task of government to ensure these rights and freedoms. New Zealand is a signatory to these declarations. These conventions will be examined more closely later in the review presented in the monograph. The review of literature explores and considers the reasons why people who have intellectual disability are not given the opportunity to freely express their individuality through sexuality (Shakespeare et al, 1996).

McLean (1997) describes the 1960's when civil rights for marginalised people became an issue first in the United States and subsequently in other nations. Craft (1987) asserts that the 1960's were a time of societal revolution where the "new social order was aimed at emancipating large and diverse groups" (p. 112). These changes underpinned the changes in the treatment of people with intellectual disability, their place in society and "their rights as fellow human beings in that society" (p. 113). Following on from these points Wolfensberger (1997) takes the view that all people have intrinsic value that cannot be given or taken away by virtue of their humanity.

1.6 Summary

The contention that competency and the ability to consent to sexual relationships seems alien in an environment which is moving towards greater opportunities, rights, and self determination for people with intellectual disabilities including those of a sexual and intimate nature. However the other

view of the competency argument, simply allowing people with intellectual disability to find and form their own intimate relationships, can also be interpreted as a control mechanism because of the lack of opportunity and lack of skills of people with intellectual disability. For instance some people with intellectual disability may be educated in the biological aspects of sexuality but not the social skills needed (Shakespeare et al, 1996).

The third option of providing the supports necessary so that people with intellectual disability can learn to initiate, experience and enjoy intimate relationships seems both sensible and the optimum way to gain success. If people with intellectual disability are to become a real part of the community then forming various types of close personal relationships will become the basis of their acceptance (Johnson, 1987; van Zijderfeld, 1987).

Chapter Two

Historical and philosophical issues that have denied sexual freedom to people who have intellectual disability.

“Opportunities for loving interchange are needs as fundamental to human beings as are sun and water to plants.”(Craft, 1978, p. 22)

2.1 Introduction

This chapter will examine the treatment of people with intellectual disabilities over the last century. It will outline the use of segregation, institutionalisation, sterilisation and the use of law to prevent this freedom from occurring. It will begin with the ‘Eugenics era’ which began at the end of the 1800’s and is considered to have ended during the 1930’s (Fleming, 1981; Trent, 1994). It will then view that period of time after the close of the Second World War seeking to find other methods that may have been used to prevent and justify the prevention of sexual freedom for this group of people.

2.2 Eugenics

The principle of eugenics is that the human race can improve itself intellectually and physically by breeding from ‘fit’ human stock and preventing the breeding of the ‘unfit’ (Craft, 1978; Hardin, 1960). People with intellectual disability have, throughout history, been devalued (Wolfensberger, 1991), though the devaluation was not specifically related to their fitness to breed. However the eugenics era systematised their devaluation and disposal. Wolfensberger (1988) asserts that it was the professional and academic groups that initiated the attack, their purpose being to prevent the degeneration of humanity by preventing ‘the unfit’ from breeding. This period was a calamity for people with intellectual disability (Judge, 1987).

Darwin’s work on evolution in the middle 1800’s is considered to have given rise to other theories regarding human evolution. In fact evolutionary theories were quite common at that time (Kevles, 1985). As an example Spencer wrote in regard to ‘survival of the fittest’ and was concerned with the notion of purifying and perfecting the human race. Judge (1987) asserts that many who followed in Darwin’s wake “came to conclusions more general and facile than Darwin’s intensely scientific study” (p. 40). Francis Galton, a cousin of Charles Darwin

had theorised about hereditary, but his book 'Hereditary Genius' was considered by Darwin to be without intellectual merit (Judge, 1987).

Others whose work supported the theory of eugenics included Gregor Mendel who worked in the area of genes and inheritance (Judge, 1987). Another Cesare Lombroso (Lombroso and Ferrero, 1895) worked towards bringing the fields of biology and criminology together and show that criminal activity could be laid at the door of biological inheritance.

The 'unfit' included the mentally ill, epileptics and the intellectually disabled. They were, at this time, being fitted into a number of devalued categories. Of particular interest is the category known as 'moral imbecile' defined as those unable to control their impulses. It was perceived that these people were criminally and sexually impulsive (Trent, 1994).

2.3 Eugenics movements

Though statistically few people were involved in eugenics movements they tended to wield great political and academic influence. They included politicians, university professors and other academics, health professionals and those involved in the care of the defectives (Fleming, 1981; Trent, 1994).

Research was used to reinforce the perception that the intellectually disabled and other 'defectives' posed a danger to society, through breeding degenerate offspring. Some families of intellectually disabled people had their family trees investigated specifically to prove that point, that marriage and procreation between or with intellectually disabled persons inevitably led to the entire family becoming degenerate. Some of this research used dubious methodologies (Sheerenberger, 1983). Such studies started from the hypothesis that people who were deviant, such as prostitutes and criminals were likely also to be mentally defective. A review of the literature from studies and surveys carried out in correctional institutions validated this hypothesis (Scheerenberger, 1983). It was a case of creating fact out of myth. Two studies often cited at the time were of the families 'Kallikaks' and 'Jukes'. The research into the Jukes actually found that, though there were a large number of the family with mental deficiency, the main cause of their problems had been poverty. However supporters of eugenics believed that the cause of the degeneracy was due to mental deficiency and ignored the parts of the study that did not suit them (Kevles, 1985). Trent (1994) identifies how researchers used new assessment methods to reinforce the already perceived threat from the intellectually disabled, thus reinforcing the myth of 'dangerousness' to society and human advancement.

The need to house ever increasing numbers of 'deficient' people in institutions began at the end of the nineteenth century. Up until this time the 'mentally deficient' had been seen primarily as a burden upon society (Trent, 1994). In the early part of the twentieth century the 'mentally deficient' came to be identified as the principal cause of the evils associated with a perceived decline in the moral and physical aspects of the citizenry (Trent, 1994). It was argued that through heredity the mentally retarded, who were considered to be prolific breeders of other retarded people, were placing the western world in jeopardy (Tennant, 1996). Superintendents of institutions for the mentally deficient used and actively reinforced the fear created by the eugenics movement to gain extra funding for larger institutions and research into the problems associated with

mental retardation. Many of those working in this field were proposing the total institutionalisation of the intellectually disabled as a means of combating the deterioration of the racial stock (Trent, 1994).

Judge (1987) quotes Oliver Wendell Holmes, “the great American jurist” in relation to a court case for sterilising a woman with intellectual disability, who had given birth to an intellectually disabled child and was herself the daughter of an intellectually disabled mother. He is quoted as saying:

It is better for all the world, if instead of waiting to execute degenerative offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind... three generations of imbeciles are enough (pp. 49-50).

Western society continues to lack understanding in how to deal with people who need supervision and care and those with intellectual disability were, in many institutions simply relegated to the ‘back wards’ (Judge, 1987). The institutions where the so-called ‘defectives’ were housed grew larger (Hartley, 1995) and the imagery attached to the institutions helped perpetuate the myth of the inmates being a threat to society (Oliver, 1990).

2.4 The New Zealand experience

In New Zealand the scientific data from England and America on Eugenics was accepted without question by supporters of Social Darwinism (Fleming, 1981). What was done to the intellectually disabled was almost entirely the responsibility of people in powerful positions who supported the eugenics theory (Fleming, 1981).

New Zealand believed that its problems were the same as those of the British Empire (Fleming, 1981). New Zealand believed that the very safety and security of the empire depended upon responding to a perceived threat from Asia, but to do this required the Empire to deal with internal threats first. A major threat was identified as the increasing number of people defined as ‘unfit’ (Fleming, 1981). Such theories had a very harmful effect on the way people with intellectual disability were viewed (Tennant, 1996).

As occurred overseas, the professional, academic and political powers became extremely interested in eugenics (Fleming, 1981). Fleming describes a work by a New Zealand born surgeon, W.A. Chapple, who went on to become a politician. The book titled, “The Fertility of the Unfit” was described as being hair-raising (Searle, cited in Fleming, 1981). However more concerning was that leading political figures accepted its arguments, among them “the Chief Justice, Sir Robert Stout” (p. 12). In this work the author drew together the strands of “crime, insanity and pauperism” and identified the cause as “that society was breeding from ‘defective stock’” (p. 12). The book called for the state to play a role in preventing the breeding of the ‘unfit’.

Amongst other recommendations made by Chapple was the creation of a board that would issue marriage certificates, but only to the ‘fit’. Fleming (1981) asserts that it is difficult to know the extent of the influence of Chapple’s work, though he does identify that New Zealand doctors were still quoting the book twenty years after its publication.

New Zealand Eugenics societies had the support of very prominent people including university professors, vicars, doctors and politicians. The Wellington committee included a city mayor, MPs from both government and opposition parties, medical and academic leaders, the Inspector-General of Mental Hospitals and other civic leaders, including Truby King and Sir Robert Stout (Fleming, 1981).

The Eugenics Education Society of New Zealand had access to ministers of the crown and was able to promote the message of eugenics. It also used public forums on other issues to advance the message. Fleming (1981) cites one such meeting, where the then Attorney-General of New Zealand, the Honourable J.G. Findlay, used a speaking opportunity on urbanisation to discuss the problem of the falling birth rate of the 'fit' and "the steady multiplication of weeds and degenerates" (p. 23). He was also coincidentally the President of the Eugenic Society.

2.5 Social policy

The eugenics movement in the United Kingdom had difficulty recruiting members and supporters from the ranks of politicians. This was not the case in New Zealand. The movement in New Zealand enjoyed a strong relationship with politicians and during parliamentary debates on the Mental Defectives Bill (1911) the Eugenics Society received much praise from the Prime Minister, William Massey, who identified with pride his Honorary vice-presidency of the Eugenics Society (Fleming, 1981). This interrelationship between politicians and the eugenics movement allowed the dissemination of the threat of the 'unfit' to be maximised and to have the idea taken seriously. Fleming (1981) also identifies the natural expectation, on the part of the eugenics movement, for the state to 'do something' because of its previous record in enacting social legislation.

Reinforcement of the problems of the 'unfit' came due to the First World War, when approximately two thirds of the "recruits for the New Zealand Expeditionary Forces...were rejected as unfit- a sign that the country's pioneering stock had rapidly deteriorated" (Fleming, 1981, p. 33).

2.6 Sterilisation and other responses

Though in reality the perceived deterioration of human 'fitness' to breed had nothing to do with the intellectually disabled they were included as a major cause of the problem, primarily the intellectually disabled female (Fleming, 1981). The levels of concern continued to rise and led to a Committee of Inquiry into Mental Defectives and Sexual Offenders in 1924 and in 1928 to the Mental Defectives Amendment Act. Again the females were seen as the main problem because of their propensity for criminal behaviour, prostitution and prolific breeding (Fleming, 1981).

Options were discussed and advocated for the prevention of further degeneration of New Zealand society which included sterilisation of the mentally deficient, having to obtain marriage certificates from medical boards identifying the couple as 'fit' to breed, and sterilisation of sexual offenders (Fleming, 1981).

In 1923, the triple concerns of sexual crimes, incipient mental illness and the breeding of the mentally defective prompted the New Zealand Government to establish a committee to examine mental defectives and sexual crimes. The

committee called the Committee of Inquiry into Mental Defectives and Sexual Offending (Fleming, 1981) was comprised of many medical, political, justice and health professionals. Many witnesses were called and questionnaires were also sent out. Replies from health professionals clearly called for euthanasia to be the main response to the problem of the mentally defective. In line with the overseas pseudo research into families of mentally defective people 'evidence' was given of New Zealand counterparts. The final report was ambiguous in that it asserted on one page that through the use of sterilisation and segregation mental deficiency could be eliminated from society, and on another identified that it could never be totally eliminated (Fleming, 1981). The report was decidedly biased in favour of a eugenics answer such as sterilisation and segregation. It quoted a great deal of eugenics material in support of its findings and reinforced again the connection between the intellectually disabled and criminal offending, primarily sexual. Sexual offending must also be examined in the context of the times. The main purpose of sexual activity was identified as primarily for procreation. This moral code was in line with Victorian standards. In this era there were women's patrols that checked parks and such like places to prevent promiscuity among the younger population (Fleming, 1981).

Van Zijderfeld (1987) discusses how that even in institutions males and females with intellectual disability were kept separate "in such a way that men and women never met each other" (p. 112). People with intellectual disability were educated to understand that they were barred from engaging in sexual relationships and were taught to fear the consequences of sexual activity. Van Zijderfeld identifies that for women the consequences included pregnancy and violent and painful experiences, while for the men it meant criminal charges and the probability of going to prison.

Though the period of eugenics appeared to end in the 1930s it did not end for all people with intellectual disability and others described as defective. During the Second World War 70,000 mentally deficient people were put to death in Germany, the first groups by firing squad (Kevles, 1985). Such carnage can be attributed to the idea of eugenics and the extermination of the 'unfit'.

2.7 The new eugenics

The barbarousness of NAZI policies eventually provoked a powerful anti-eugenic reaction, but the reaction, perhaps because of its pervasive power, obscured a deeper historical reality: many thoughtful members of the British and American public had already recognized that a good deal was wrong with mainline eugenics (Kevles, 1985: p. 118).

Though eugenics as a term fell into disrepute after the Second World War the theories that it encapsulated have been brought into the second half of the century using different names. Such subjects as 'biological determinism', 'Germinal Choice' may be described as the 'New eugenics'.

2.7.1 Prejudice

Before examining the themes relating to the 'new eugenics' it is important to recognise the role that prejudice has had in the treatment of people who have an intellectual disability. Wolfensberger (1991) states that it is universal and has been found in all societies throughout recorded history and remains so to the present day. If that is so then it remains a negative force in the lives of people

with intellectual disabilities. Wolfensberger (1991) asserts that there are many negative roles that have defined the existence of intellectually disabled people. Some of these roles include pre-human, menace, object of ridicule, object of pity, charity, childlike, diseased, dying and dead. It would be a mistake to understate the impact that prejudice has upon the lives of people who have an intellectual disability. These people have been made inferior, powerless and dependent.

2.7.2 Legislation

Section 138 of the Crimes Act 1961 is a direct descendent of legislation passed during the eugenics period and remains in force today (see Appendix B). The section prohibits males whether or not they are intellectually disabled from engaging in sexual activities with 'severely subnormal women or girls'. The legislation and precedents set in the High Court of New Zealand clarifies severely subnormal to mean any woman with intellectual disability who is not able to care for herself ("Severely Subnormal," 1996). The decision in that particular case (Bogard, 1995) centered on the mental incompetence of the woman to consent to sexual activity. In a case regarding the same person the court found that she was also unable through mental incompetence to consent to marriage. Bogard (1995) states that:

a marriage made in 1991 was declared void in 1994 (even though it was nearly four years later, and the marriage had produced a child) because the woman involved clearly had no idea what marriage meant because of her disability and she had not been able to consent to it (p. 96).

Though couched in terms of protection for the woman the effect of this legislation is to prevent women with intellectual disability from engaging in sexual behaviour with males. One can speculate that as it is descended from eugenics legislation its real intent is to prevent the breeding of the unfit. This section 138 of the Crimes Act, 1961 also reinforces the idea that people with an intellectual disability are seen as being the 'eternal child' and children are not considered to be sexual therefore it follows that people who have an intellectual disability cannot be sexual (Craft, 1987; Gates & McCarty, 1998).

New Zealand continues to permit the sterilisation of females who have an intellectual disability. A High Court decision in 1990 in New Zealand found that parents of young women with intellectual disability did not need a court's permission to have their daughters sterilised ("Court Rules," 1990).

2.7.3 Biological determinism

Biological determinism is the belief that biological influences determine human actions (Kevles, 1985). As previously shown the eugenics movement suffered a reversal in popularity at the end of the Second World War because of the slaughter of 70,000 people considered mentally or physically defective carried out in Nazi Germany between 1934 and 1945 (Kevles, 1985). However work in eugenics did not cease at the end of the Second World War. Believers in the theory still participated in working towards strengthening the eugenics movement but changed the language that they used.

One example is that of Konrad Lorenz a German biologist who worked in the field of eugenics in Nazi Germany. Lorenz continued his work after the Second

World War and became a leader in the field of genetics. In 1973 he was awarded the Nobel Prize for this work. Lerner (1992) quotes Lorenz who said “I am by inheritance obsessed with eugenics” (p. 51).

The field of genetics provided the eugenics movement with a way forward. The 1960's and 1970's saw numerous prominent scientists asserting those eugenic ideas should be applied to social policy. Hermann J. Muller, a Nobel Prize winner in the field of genetics, pleaded for germinal choice. This meant the storing and use of sperm from 'fit' humans with the inevitable result in the increased breeding of 'fit' stock. His plan involved improving the quality of human stock by storing only the sperm of Nobel Prize winners (Kevles, 1985). Some years after his death a sperm bank, named after him was set up in the United States with that intention. Hardin (1960) calls the use of sperm banks 'positive eugenics', a mechanism he supported.

Another scientist Robert L. Sinsheimer, a distinguished molecular biologist believed that a new eugenic era was beginning. He asserted that human beings would be able to design their descendants (Kevles, 1985). Ripley (1998) argues that a prerequisite for happiness is a healthy body. By using this justification, the prevention of unhappiness, society can preclude the existence of imperfect fetuses.

Ripley goes further and argues that to prevent the unhappiness and disadvantage of imperfect people society should prevent their existence. He supports the belief of Sinsheimer and asserts that soon society will have the ability to “determine exactly what future generations will be like” (p. 265).

Arthur Jensen, a noted psychologist believed that there was a connection between race and intelligence and that it could be proved. Research that he undertook in IQ testing showed a marked difference in scores between white and African Americans (Jensen, 1977). This was an influential finding and it allowed supporters of eugenics to use scientific evidence to strengthen their arguments that intelligence was related to heredity. William Shockley, argued that welfare programmes in the United States were causing racial degeneracy in the United States. However the resurgence of this kind of thinking was not confined to America. Kevles (1985) identifies Sir Keith Joseph, Minister for Education in a Thatcher government, who contended that the poor were leading Britain down the path to a similar degeneracy.

2.7.4 Socio-biology

Socio-biology is the study of the biological basis of the social behaviour of all creatures, including human beings. Edward O. Wilson wrote at length concerning socio-biology in the 1970's. He maintained that a formula could be devised to indicate the probable behaviour of people through the genetic evolution of their ancestors (Kevles, 1985). In other words if women are mentally deficient or have criminal tendencies then their offspring are likely to be of a similar nature. The similarities between eugenics and socio-biology are quite apparent. Lerner (1992) supports this view and asserts that the basis of eugenics and socio-biology are in essence based on the same doctrine of biological determinism.

This generalised but dispersed tendency toward thinking in terms of creating improved human beings has added to the pressure placed on 'parents to be'. Economic and peer pressure has been put on parents who had defective

foetuses to abort them (Kevles, 1985). This is a mixture of positive and negative eugenics. Positive eugenics means supporting increased breeding of the fit. Negative eugenics depicts the need for preventing the breeding of the unfit. The mixture combines pressure on fit parents not to have unfit offspring. This continues at the present time in the medical process of amniocentesis. Ripley (1998) in relation to preventing the birth of disabled offspring states “the greater the danger of serious disability, the more justifiable considerable sacrifice is” (p. 273). By this he means that parents should abstain from procreation if their offspring are likely to be born with serious impairments.

In the United States a 1975 report from The Presidents Committee on Mental Retardation asserted that there had been little change concerning the belief in eugenics, regarding the intellectually disabled except that the language was being used in a less degrading and condemning manner (Kevles, 1985). Kevles also reports that there were scientists in the United States who believed that eugenics programmes and practices might again be mandated by legislation.

In a front page article in the New Zealand Herald (“Warrant of Fitness”, 1996), Sir Roger Douglas, President of the ACT political party, advocated for a 'warrant of fitness for parenthood' and identified the Plunket Society as the organisation which could best supply such warrants. The Plunket Society was created on the eugenic assumption that New Zealand's human stock was degenerating. It was led by a prominent member of New Zealand's' eugenics movement, Sir Truby King.

2.8 Summary

Chapter two has examined the historical and philosophical beliefs that have had the effect of denying sexual freedom to people who have intellectual disability. The chapter began with a discussion on the ‘Eugenics era’ and included a brief outline of the movements that were created in the name of eugenics and the people who were involved in supporting and implementing eugenic principles. It looked at the government of the day's response to the perceived problems and the apparent threat from people with intellectual disability to society. These responses included sterilisation, segregation, institutionalisation and legislation. It viewed the continuation of negative attitudes towards people who have an intellectual disability regarding sexuality.

The chapter also examined eugenic thinking since the Second World War and the different sciences that bear a close resemblance to eugenics, such as germinal choice and socio-biology and has also outlined the continued search for ways to prevent imperfect humans being born. The study of genetics has opened a Pandora's box of possibilities for modifying human beings and another Pandora's box of ethical issues.

Chapter Three

Challenges to the denial of sexual expression

“Rights and responsibilities are not ‘natural’ or ‘inalienable’ but have to be invented through human activities and built into the notions of communities, citizenship and identities.” (Plummer, 1995, cited in Shakespeare et al, 1996, p. 150).

3.1 Introduction

The eugenic period was considered to have ended during the 1930's (Fleming, 1981; Trent, 1994). As was described in the previous chapter however, eugenic thinking did not end there but continued on using different disguises and different terminology. Nevertheless as also shown the horror visited upon the powerless in Nazi Germany created a backlash. The United Nations Charter on Human Rights (1948) had as its impetus that backlash. Later documents, including the 'Rights of the Mentally Retarded (1971)' and the 'Rights of Disabled People (1975)' are two examples of declarations specific to people with disabilities issued from the United Nations. Philosophies and theories came out of the driving force that was provided by the United Nations Declaration of Human Rights and also infused later United Nations documents with its philosophy.

3.2 Human rights

As the impetus for later international and domestic declarations, covenants, and philosophies, parts of the UNIVERSAL DECLARATION OF HUMAN RIGHTS are quoted below. For example the New Zealand Bill of Rights Act (1990) states that it is “an Act (a) to affirm, protect, and promote human rights and fundamental freedoms in New Zealand; and (b) to affirm New Zealand's commitment to the International Covenant on Civil and Political Rights” (p.1).

3.3 Preamble

The Universal Declaration of Human Rights begins with the words:

- Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world.
- Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and what has been proclaimed as the highest aspiration of the common people.
- Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law.
- Whereas it is essential to promote the development of friendly relations between nations.
- Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger

freedom.

- Whereas Member States have pledged themselves to achieve, in co-operation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms.
- Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge, now, therefore.

3.4 The General Assembly

Proclaims this Universal Declaration of Human Rights as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

The effects of the Second World War can be seen in the determination outlined in the preamble to create a better world where everyone has basic human rights and freedoms.

Article 1 declares that “all human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in the spirit of brotherhood”.

Article 2 declares:

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

Article 3 declares that “everyone has the right to life, liberty and the security of person.

The United Nations Declaration on Human Rights led to other international covenants of human, civil and political rights. Of these some specifically concerned people with disabilities. One can assume this to be the case as the United Nations has its own Disabled Persons Unit dealing with policy (Standard Rules, 1993).

The United Nations Declaration on the Rights of Mentally Retarded Persons (1971) asserted that people with intellectual disability have, to the maximum degree of feasibility, the same rights as other human beings. It also declared that they have the right to develop to their full potential.

In 1975 the United Nations Declaration on the Rights of Disabled Persons stated:

Disabled persons whatever the origin, nature and seriousness of their handicaps and disabilities have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.

The philosophy of Normalisation had begun to be inserted within International Covenants on Human Rights. In 1993 the UN “The Standard Rules on the Equalization of Opportunities for Persons with Disabilities”, went further. It identified that normalisation was a philosophy that needed to be taken into account. Rule 9, which related to ‘family life and personal integrity’, declared that:

states should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood (p. 28).

It goes on to state that they must not:

be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood... states should promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities (p. 28).

3.5 Normalisation and Social Role Valorization

People who have intellectual disability have received very substantial support from Bank-Mikkelsen’s and Nirje Philosophy of Normalization (Wolfensberger, 1999b). This philosophy was developed in Scandinavia during the 1950’s and 1960’s. Nirje (1999) identified that a basis for the Normalisation concept arose out of his early studies when “we were concerned with human rights” (p. 18). This philosophy was influential and fashioned the concept of human rights into a usable tool. International covenants made reference to it. It was a blueprint for what life for people with intellectual disability should be like. It is applicable to present the normalisation philosophy in full and then to discuss the ramifications that it held and holds for governments, their agencies and human service providers. There are various other implications for the community at large. These will also be discussed.

3.6 Normalization

Following is Bengt Nirje’s definition of Normalization and the conditions necessary for its implementation.

*Normalization means...*A normal rhythm of the day. You get out of bed in the morning, even if you are profoundly retarded and physically handicapped; you get dressed, and leave the house for school or work, you don’t stay home;

In the morning you anticipate events, in the evening you think back on what you have accomplished; the day is not a monotonous 24 hours with every minute endless.

You eat at normal times of the day and in a normal fashion; not just with a spoon, unless you are an infant; not in bed but at a table; not early in the afternoon for the convenience of the staff.

Normalization means... A normal rhythm of the week. You live in one place, go to work in another, and participate in leisure activities in yet another. You anticipate leisure activities on weekends, and look forward to getting back to school or work on Monday.

Normalization means... A normal rhythm of the year. A vacation to break routines of the year. Seasonal changes bring with them a variety of types of food, work, cultural events, sports, and leisure activities. Just think... we thrive on these seasonal changes!

Normalization means... Normal developmental experiences o the life cycle: In childhood, children, but not adults, go to summer camps. In adolescence one is interested in grooming, hairstyles, music, boy friends and girl friends. In adulthood, life is filled with work and responsibilities. In old age, one has memories to look back on, and can enjoy the wisdom of the experience.

Normalization means... Having a range of choices, wishes, and desires respected and considered. Adults have the freedom to decide where they would like to live, what kind of job they would like to have, and can best perform. Whether they would prefer to go bowling with a group, instead of staying home to watch television.

Normalization means... Living in a world made of two sexes. Children and adults both develop relationships with members of the opposite sex. Teenagers become interested in having boy friends and girl friends. Adults may fall in love, and decide to marry.

Normalization means... The right to normal economic standards. All of us have basic financial privileges, and responsibilities, are able to take advantage of compensatory economic security means, such as child allowances, old age pensions, and minimum wage regulations. We should have money to decide how to spend; on personal luxuries, or necessities.

Normalization means... Living in normal housing in a normal neighbourhood. Not in a large facility with 20, 50, or 100 other people because you are retarded, and not isolated from the rest of the community. Normal locations and normal size homes will give residents better opportunities for successful integration with their communities (Flynn & Lemay; 1999; pp. 112-113).

Wolfensberger took Normalization to the English speaking world after a visit to Scandinavia in the late 1960's. He wrote widely on the subject of Normalization, though initially he had trouble getting his work published. Wolfensberger (1999b) discusses his personal movement towards support for the principle of Normalisation. He states, "my own odyssey toward Normalization started in 1956, when my sense of justice was outraged by the conditions in the so-called 'back ward' of a mental institution in which I was then working" (p. 58). In 1972 his work was published in Canada. However his work on Normalization differed from Nirje's in that his definition included both the goal and the process (Hartnett, 1997). This definition was that Normalization utilises "means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible". Hartnett describes how Wolfensberger discovered that the term "valorization sociale" was being used by the French Canadians to describe a facet of normalisation. Wolfensberger proposed using a new term Social Role Valorisation. He asserted the term 'Normalization' was open to personal interpretation and misinterpretation. Also because of the name it was not understood to be based on scientific theory.

3.7 Social Role Valorisation

The Social Role Valorisation philosophy was widely disseminated in the 1980's, hereinafter referred to SRV. Wolfensberger (1991) argued that both by inquiry and intuition human beings perceive subjectively. They evaluate on the basis of good and bad including judgement at the conscious and unconscious levels. When their evaluation is negative, devaluation occurs. Wolfensberger makes the point that "social devaluation is universal, it is found in all societies at all times" (p. 3).

Wolfensberger (1991) discussed the significance of having socially valued roles, his definition of SRV is "the enablement, establishment, enhancement, maintenance, and/or defence of valued social roles for devalued people and those at risk of being devalued, by using as much as possible culturally valued means" (p. 21). For instance living in a normalised and valuing home environment provides a person with a homeowner's role and going out to work the role of a working person. When a person is involved in intimate relationships, these lead to the creation of additional valued roles including wife, husband, father, and mother. Wolfensberger argues that social roles for devalued people are improved through image and competency enhancing practices. When socially valued roles are provided for people with intellectual disability they confer status and increase the opportunities for social integration.

Wolfensberger has continued to work extensively developing theories that relate to how societies, human services and individuals approach and work with intellectually disabled people. His research includes the wounding process, death-making, morality, ethics and values, high order concepts, universal assumptions, modernism and leadership.

3.8 Social theories of disability

The move to recognise the value of all human beings and their inherent rights has been followed by theories of disability that identify the causes of disabled peoples marginalisation within the able bodied community. Oliver (1996) identifies two models of disability. These are the individual or personal tragedy theory and the social model of disability. He asserts that society disables people with impairments by the way they are isolated and excluded from the wider community. Fulcher (1989) asserts that there are four discourses relating to disability. These are the medical, charity, lay and rights discourses. The medical discourse entails the individualisation of disability as Oliver asserts, whilst the charity discourse identifies the need to succour the disabled. The lay discourse describes the public perception of disabled people, and the rights discourse concerns equality and citizenship.

Munford and Sullivan (1997) identify that the social theory of disability is grounded within the sociological tradition that defines disability and disabled people as having been both socially created and socially constructed. Similarly Trent (1994) asserts that intellectual disability itself is a social construct. This social construction is the result of the perception of impaired people by non-disabled people. The creation of disability is caused by the barriers that non-disabled people put up to oppress impaired people.

3.9 Disability theories and sexuality

Shakespeare, Gillespie-Sells and Davies (1996) assert that the problems of disability are not to be found with the person but with society. They argue that though the philosophy of Normalisation has been the trend in other areas of socialisation it has not been the case in the area of sexuality, an area filled with a complex combination of fears and prejudices about people with disabilities and sexuality. Shakespeare et al (1996) also contend that these prejudices cause family members and human services to deny the sexuality of people with disabilities, to ignore the social aspects of sexuality in sexuality education and to create barriers to sexual expression. Brantlinger (1987) affirms that through the normalisation philosophy service staff should assist people with intellectual disability to experience normal life experiences including sexual expression. Nevertheless service staff generally deal with the area of sexuality on a basis of personal attitude and prejudice. Shakespeare et al (1996) support the view that the civil rights of sexuality comprises the core of the move for acceptance.

3.10 New Zealand Legislation

As a western democracy New Zealand Governments have conformed with international leadership pertaining to human rights as previously noted. International Covenants have been the basis of New Zealand human rights legislation. Legislation has included the New Zealand Bill of Rights Act, 1990, which is defined as “an Act...to affirm New Zealand’s commitment to the International Covenant on Civil and Political Rights” (p. 1).

The Human Rights Act, 1993, prohibits discrimination on the basis of disability and the Protection of Person and Property Rights Act 1988 implies that when a person is unable to protect their own rights due to disability another person may do so. Further legislation has also been enacted to protect the rights of the sick and the disabled. This legislation is known as the Health and Disability Commissioner’s Act, 1994. Such legislation expresses and promotes the need for people with disabilities to be entitled to experience and enjoy long term social relationships.

3.11 Implications for government

International covenants on human rights and the principle of Normalisation have had far reaching implications for the New Zealand Government, their agencies and human service organisations. Many people with disabilities, including the intellectually disabled and those with severe physical disabilities had resided in institutions. The concept of providing culturally normative home environments, lifestyles and relationships including sexual relationships are a far cry from institutional care. Yet beginning in the 1980’s people were brought out of institutions and placed in community homes. Senescall (1997) states that, “from the mid-1980s in New Zealand, as a result of the influence of advocacy groups and the philosophies of normalisation and social role valorisation, services for people with intellectual disabilities were becoming more community-oriented” (p. 129).

The philosophy of normalisation presupposed deinstitutionalisation, which was seen by many as the liberation of people with intellectual disabilities (Schwartz, 1992). However deinstitutionalisation did not become New Zealand Government policy until 1990 (“Ministry of Health,” 1990). Prior to this service providers had begun the transition of moving people with intellectual disabilities out of institutions. For instance the first major human service provider was initiated by

the Society for Intellectually Handicapped Children an organisation comprised of parents who wanted better opportunities for their children than institutional care (Senescall, 1997).

3.12 Deinstitutionalisation

The process of deinstitutionalisation saw people with intellectual disability being moved into the community. This transition meant that other services needed to be created for example sheltered workshops. As more people were brought out of institutions and community services expanded the need arose to evaluate those services. This expansion of evaluation, perhaps fuelled and guided by the philosophy of normalisation and the increased awareness of human rights, led to other technologies designed to improve the lives of people who have an intellectual disability (Millier, 1999). Enhanced living environments, for example, supported living, different work opportunities, for example supported employment have provided forward momentum in improved living for people with intellectual disabilities.

3.13 Summary

Chapter three discussed the challenges to the denial of sexuality for people who have an intellectual disability. International covenants on human rights such as the Universal Declaration of Human Rights, The Rights of Mentally Retarded Persons and the Rights of Disabled persons were carefully examined in relation to the right to express oneself sexually. Normalisation and Social Role Valorisation were also briefly outlined for the same purpose.

Disability theories especially in relation to the issues regarding sexuality for people with disabilities were considered. New Zealand legislation in relation to human rights was mentioned as was its implications for government such as the requirement to continue the process of deinstitutionalisation.

Chapter Four

Contradiction surrounding issues of sexuality for people with intellectual disability.

"It is best to love wisely, no doubt; but to love foolishly is better than not to be able to love at all." (Thackeray, cited in Craft, 1978, p. 43).

4.1 Introduction

Shakespeare et al (1996) believe that sexuality rights are not normally granted to people with intellectual disability and those who achieve sexual relationships are achieving them in opposition to expectations placed on them by the wider community. International covenants assert that people with intellectual disabilities should be entitled to engage in the same kind of relationships as do other people. The philosophy of normalisation argues that people with intellectual disability should engage in the pursuit of normal goals including those of a sexual nature (Nirje, 1999). Yet Shakespeare et al (1996) assert that normalisation for people with intellectual disability appears to stop at sexuality. Information relating to biology may be given but the social aspects of sexuality are withheld (Johnson, 1987). Social Role Valorisation argues that being part of

a family, being seen in roles of father and mother, are valuing. Why then are people with intellectual disability denied the right to engage in intimate and sexual relationships? There is little doubt that people who have an intellectual are denied the right to express their sexuality in normative and appropriate manners which suggests their continuing devaluation.

Chapter three summarised the arguments and the forces that have challenged the denial of rights of people who have an intellectual disability. Specifically in the area of freedom of expression regarding sexuality and intimate relationships this is the case. Where arguments are made and covenants proclaimed regarding rights they are often worded in terms of “wherever possible” their rights should be enforced. As an example in the Declaration of Mentally Retarded Persons (1971) it states, “the mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings” (Gunn 1994 p. 117). The point made here is that rights tend to be qualified for people with intellectual disabilities. In contradiction to this Craft, (1978) the amount of love one person feels for another cannot be quantified.

Chapter four will discuss these conflicting ideologies. It will then review the effect that they have had on the opportunities for people with intellectual disabilities in the area of intimacy and expressions of sexuality.

4.2 Barriers to sexuality

“People who live with mental handicaps cannot become ‘real’ because their reality is denied” (Friere, cited in Johnson, 1987, p. 64). As was outlined in chapter two there are many forces, which have, prevented the integration into the community of people who have an intellectual disability. Though they may be in the community, people with intellectual disabilities are still by and large not integrated into it. The majority experience community contact with their peers and contact with neighbours is not common (O’Brien, 1999). However the most potent barrier to sexual freedom, especially in the latter part of this century has revolved about the issue of mental incompetence. Discussed in chapter two were issues of marriage, sexual relationships and sterilisation. One high court case set a precedent in New Zealand regarding sexual relations. Section 138 of the Crimes Act (1961), which relates to males having sex with severely subnormal women, is significant because the judge in that case equated severely subnormal with mentally subnormal, which in effect includes all women with intellectual disability.

Ashman (1990) identifies that females with an intellectual disability are still being sterilised in significant numbers. Sterilisation has been increasingly performed in the last decade in New Zealand on young women with intellectual disability (see Appendix D). As previously mentioned a high court decision in 1990 a judge decided that parents of the young woman were not required to seek judicial approval before having their daughter sterilised. In effect the judge was making a decision based upon the presumption that young women with intellectual disability are mentally incompetent and therefore that others must make substitute decisions for them. This is a serious obstacle, as a person’s intellectual disability will always render them incompetent if present criteria for competence remains the accepted standard. Therefore unless the criteria is changed people who have an intellectual disability will stay forever incompetent.

In contrast to the New Zealand decision Australian courts took a different view and decided that only the courts could make a decision regarding sterilisation. That decisions of such importance were beyond the scope of parental power (Warnick, 1999).

Gunn (1994) indicates that in law there is a presumption of competence and to prove a person incompetent requires a challenge to that presumption. However, as can be seen in the New Zealand court cases regarding sterilisation and marriage that the presumption of competence has been turned upside down and is now the presumption of incompetence.

Defining competence however is not such a simple matter. Gunn (1994) asserts that depending upon the definition used a person with intellectual disability may be considered competent or incompetent. Gunn also discusses the options for a re-evaluation of the definition of competency either through a tidying up of existing ideas or of a complete investigation into all of the aspects of decision making. He does not discuss related issues such as is competency an essential element of decision making.

Johnson (1987) identifies that there is a clear recognition in the social sciences of a need for intimacy. He discusses Maslow's hierarchy of human needs and how a person's "desire for love and belonging must be fulfilled before a person can experience a full measure of self-esteem" (p. 62). Johnson lays the reason for a lack of opportunity for really intimate relationships for people with intellectual disability at the door of the Eugenics movement of the late nineteenth century. He also describes how people with intellectual disability have to learn to have relationships and that there is always something new to learn and thus the effect of this is that they are prevented from having an intimate relationship. Johnson (1987) states, "Although the carrot of sexual activity is often held out ... in reality there is always 'one more skill' a person must master before earning the right to be sexual" (p. 63).

4.3 Attitudinal barriers

"Meaningful sexual expression- is rarely, if ever, granted; or rather it continues to be taken away from the persons we designate as retarded" (Heshusius, 1987, p. 52).

A different barrier to sexuality for people who have intellectual disability relates to opportunity. For example bringing people out of institutions and into the community might be expected to have increased the opportunities for sexual relations for people with intellectual disability. Further, taking into account the expectations put on service providers by the philosophy of normalisation, that is to "develop relationships with members of the opposite sex...adults may fall in love, and decide to marry" it might be expected that more normative intimate relationships would have occurred during this time. McCarthy & Thompson (1995) make the point that such thinking is a common assumption whereas "in fact, there is no evidence to support this and the opposite may be true" (p. 278). Brantlinger (1987) adds that "even in community-based facilities, such as group homes, which are reputed to be progressive and normalized residencies, denial of sexuality and prohibition of sexual behaviour is often the case" (p. 177).

Aimes and Samowitz (1995) assert that the problems of sexuality for intellectually disabled people are caused by caregivers weighing their opportunity for sexuality against the need to be protected. They believe too

often that they are over protected. In the realms of informed sexual consent they argue that people with intellectual disabilities can give consent but to do this an evaluation tool needs to be designed which will be comprehended by them.

Craft (1987) argues that people who are in care pose a problem with both staff and service systems in relation to issues of sexuality. The attitudes of staff and of the service therefore play a large part in the arena of opportunity for sexual expression of people who have an intellectual disability. Shakespeare et al (1996) makes the assertion that staff have the power to regulate sexuality and create sexual boundaries in the lives of people with intellectual disability. Craft (1987) asserts that supervisors and staff may maintain double standards the regarding the differences in sexuality between 'normal' and intellectually disabled people. It may include notions of 'eternal innocence' and 'childlike'.

Other myths and fears held by staff about the intellectually disabled such as being over sexed and/or perverted contribute to service inability or an unwillingness to create opportunities for them (Shakespeare et al, 1996). Such myths are a direct descendant of eugenics era beliefs (Craft, 1987). Another important aspect of management and staff in the opportunities for sexual expression of intellectually disabled people may depend on "the 'gut' feeling of staff about what is right or wrong, appropriate or inappropriate and allowable or forbidden" (Brantlinger, 1987 p. 177).

4.4 Alleviating the barriers

Craft (1987) discusses Perske's "telling phrase 'the dignity of risk' which, in our concern for their well being, we may deny to those with mental handicaps" (p. 23). Craft argues that in making relationships people with intellectual disability will also break them and that it is not the task of others to "protect those with mental handicaps from every relationship" (p. 23).

One view in bringing down the barriers is to provide the necessary supports so that people are able to make good decisions for themselves. The United Nations Declaration on the Rights of Mentally Retardation Persons (1971) requires that states to support people with intellectual disability to make good decisions for themselves (Gunn, 1994; Craft, 1987). Gunn asserts that by helping the person make good decisions helps to resolve the complex issues of "incapacity and consent" (p. 117). He also believes that in this way a person's ability to make good decisions becomes enhanced. Craft also poses the question "in the context of sexuality ... what do individuals... need to know? (p. 30).

Another view is offered by Craft (1987) who makes the decision to equate rights with values and then argues that people with intellectual disability have "six main rights which impinge on their value as sexual beings" (p. 15). The rights referred to are:

The right to grow up: i.e. to be treated with the respect and dignity accorded to adults

The right to know; to have access to as much information about themselves and their bodies as those of other people, their emotions, appropriate social behaviour, etc, as they can assimilate

The right to be sexual and make and break relationships

The right not to be at the mercy of the individual sexual attitudes of different care-givers

The right not to be sexually abused

The right to humane and dignified environments (p. 15).

Craft (1978) discusses the success of people with intellectual disability in marital situations and argues that “there was little or no correlation between degree of handicap and success of the partnership, either in subjective or objective terms” (p. 52) This statement tends to refute the need to be competent to consent to marriage.

In comparison to Craft, Cummins (1997) takes a different ‘softer’ viewpoint regarding people with intellectual disability and risk taking. He argues that people with intellectual disability will need assistance in finding and maintaining long-term relationships. They are already at a disadvantage because of their disability and their lack of opportunity to meet with people with whom to form relationships. He argues that without assistance it would be foolish to expect the intellectually disabled to cope as well as other people.

In ‘The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities’ the United Nations in 1993 stated, in rule 9, “that persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood” (p. 28). The article demands that the state, support people with disabilities in this respect and “ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood” (p. 28).

4.5 Conclusion

“There are many barriers, some which stem from impairment and many more which stem from society, to disabled people developing healthy sexual identities and living fulfilling lives” (Shakespeare et al, 1996, p.43).

This chapter has shown that myths and attitudes held towards people with an intellectual disability continue to act as a barrier to normalised living conditions. There is still fear of their sexuality and this gives cause for concern. Today people with intellectual disability are not openly blamed for human degeneracy. Attitudes are more diffuse as if the public is not exactly sure why people with an intellectual disability should not be allowed the right to express their sexuality in a similar manner to other people.

There remains a conflict between the legal aspects of competence and the views expressed by Craft (1987) that all people have a right to express their sexuality. Harsh legislation and negative attitudes appears to keep in place the barriers to sexual expression of people who have an intellectual disability.

At issue here is whether competency and consent are being used as devices to protect vulnerable people from exploitation, often compared with the way children are protected, or whether they are used to prevent intimate relationships from developing.

Epilogue

Death by suicide might be preferable to a prolonged lack of close human contact. Such a statement is quite devastating in terms of the unmet needs of many handicapped people (Morris, cited in Johnson, 1987, p. 62).

To be accepted and valued by society one must act, function and perform in a culturally normative manner as deemed by society. People with disabilities are subjected to endless efforts to achieve this end. Sexual relationships are an important and integral part of society. It must be clear from the dearth of normative relationships that people who have an intellectual disability need assistance to advocate for their right to participate in this important area of social activity. There is a need to assist them in overcoming the myths and attitudes that bar them from full participation. Advocates must act to have laws repealed or rewritten in ways that provide opportunities not barriers for people with intellectual disability.

Lastly there is a need to raise the profile of this barrier by conducting further research into all of the issues relating to sexuality and people who have an intellectual disability.

Numerous international covenants express the need for and significance of the rights of disabled individual's to be upheld. These covenants profess the right of the intellectually disabled to live normal lives and to enjoy and experience intimate relationships. Normalisation and Social Role Valorisation together with these international covenants provides society with a set of standards for the care and the liberation of people with disabilities. The Principle of Normalization insists that people with intellectual disability be entitled to experience intimate relationships and express their sexuality (Nirje, 1999).

By acknowledging the sexuality of people with intellectual disability, we give them back their birthright; by allowing them to learn how to be men and women responsible for their own sexuality, we empower them to take up legitimate roles in society (Fegan, 1993).

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