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SEXUALITY AND PEOPLE WITH LEARNING
DISABILITIES : A CONFLICT OF IDEOLOGIES

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ABSTRACT

This study addresses the issues of sexuality and learning disability. It is concerned with the views of professionals working with adults with learning disabilities and their parental carers.

The views of professionals and parents regarding relationships, marriage and parenthood are explored. These form the basis of the emerging grounded theory, which incorporates the discrepancies between their ideologies of care. Although the subject of sexuality highlights these inherent differences, it is essentially the issue of sterilisation which magnifies them. It exacerbates the tension and potential conflict between professionals and parents. Furthermore, the focus on sterilisation has ramifications concerning the conflict between public and private concerns. There is controversy regarding the validity of consent to sterilisation by people with learning disabilities. This is because there is a final legal arbiter, which in Scotland is provided by the tutor-dative system.

Ideologies of care have changed principally through normalisation. Although this is now the accepted orthodox philosophy, there remain some professionals who adhere to the superseded ideology of institutionalisation. As a result, they are more similar to those of parents than they are to their professional colleagues.

The wider implications of these disparate ideologies of care are examined with respect to social work-family relations. Although these differences are at present

irreconcilable, suggestions of how to alleviate tension and potential conflict between these two groups are made. Finally, the implications of normalisation with regard to sexuality are also addressed.

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INTRODUCTION

This qualitative study is concerned with the sexuality of people with learning disabilities and the issues surrounding this controversial subject. Of particular importance is the topic of decision-making regarding sterilisation.

Historically, learning disability has been to some extent an area of public concern and responsibility, especially involving sexuality. Despite movements to alter this, the situation remains, to a large extent, in the public domain. The philosophy of normalisation is most influential in advocating independence and self-determination of people with learning disabilities. The former President of London People First said that "self-advocacy enables us to make choices and make our decisions and control the way our lives should be made" (Brandon, 1995). In the U.S.A., the American Disabilities Act was passed in July, 1990. This, according to Brandon (1995) "was the major success for the Disability Movement and its powerful collective advocacy".

It is ironic that in order to allow people with learning disabilities their personal freedom, it must be achieved through public means, such as through professional ideology or through legislation. This is of particular relevance in this study because it involves decision-making of a most personal nature, that is, of sterilisation. In the early twentieth century, sterilisation laws in the U.S.A. reinforced the view that this was a public concern and not a private issue.

In this study the professionals assume that decisions about sterilisation should ideally be made by the individual concerned, but this is challenged on pragmatic grounds by the parents in this study. Problems arise when the person with learning disabilities experiences difficulties in comprehending the long-term consequences of sterilisation. This dilemma is

evident in the data presented in the study. Mills' notions of "the personal troubles of milieu" contained within the "public issues of social structure" (1959) is exemplified within the data. It concerns a conflict between issues of a private nature for individuals and matters of public concern. The problem lies with the principle of personal decision-making in conflict with collective public responsibility for the possible outcome of that decision-making. If, for example, a person with learning disabilities chooses not to be sterilised and as a consequence has a child for whom he or she cannot take care, then it is their relatives or society that is morally obliged to support them. There is evidence to suggest that the matter belongs in the public domain rather than in the private sphere. This is because it is within the legal framework that decisions can be made on behalf of people with learning disabilities. This is only if they are deemed incapable of giving consent to a sterilisation operation themselves and it is believed to be in their best interests. In Scots law, legal provision in such cases is made by the tutor-dative system. This is under review at present.

This study concerns only adults of childbearing age who have mild or moderate learning disabilities, or whose I.Q. level is approximately between 50 and 70. The reasons for this particular level of ability are threefold. One reason is because this group constitutes the majority of the population of people with learning disabilities. Secondly, this particular group of people have some legal capacity and are therefore, in most instances, capable of giving legally valid consent to a sterilisation operation. Finally, as Roos (1975) claims, people with an I.Q. of 50 or above are deemed to have an ability to understand the meaning of sterilisation. It is also salient to note that there is "no relationship between I.Q. and level of care" given to children, if the parental I.Q. level is 50 or above (Roy, Corbett, Newton and Roy, 1993).

Chapter 1: Socio-legal Issues of Sexuality is a historical account of the social circumstances of people with learning disabilities. Social attitudes and expectations are examined from the early twentieth century both in the U.K. and abroad. The Eugenic Movement held great influence over public opinion, being supported by a wide political section as well as by religious, academic and other intellectual groups including the Fabians. It is relevant to examine how similar views were held at that time in the U.S.A. and how they were translated into practical terms through the sterilisation laws. Similar social policies were evident in Germany, although these resulted in the eventual excessive use of involuntary sterilisation during the Nazi regime. It is awareness of the atrocities that occurred in Nazi Germany which brought eugenics into disrepute. Despite increased knowledge and understanding of genetics, people with learning disabilities are still subject to prejudice because eugenic ideas remain. They are, however, disguised under the term "new genetics". This Chapter forms part of the background to the major part of the study.

Progressing from this is **Chapter 2: Sterilisation of People with Learning Disabilities** which complements the first Chapter in providing relevant background information. It investigates the concept of consent in broad terms and more specifically in relation to people with learning disabilities. The implications of this are exemplified in the description of the legal cases involving sterilisation. These two early Chapters therefore offer initial insight in to today's predicament faced by people with learning disabilities, their families and the professionals who work with them. It also has implications for the disparate ideologies of care held by parents and the professionals.

Chapter 3: Study Methods and Procedures explains how the study began initially. It describes its

philosophical as well as its practical development in terms of the fieldwork. Each stage of the investigation with its use of materials is given. It is made clear that this investigation is not one of verification, but instead one of discovery.

In-depth qualitative interviews provide the data for this study. From this data, a substantive grounded theory emerges and is developed throughout Chapters 4, 5, 6 and 7, culminating in its elaboration in the concluding Chapter.

The data is first introduced in **Chapter 4: Tension and Conflict**. This Chapter is an analysis of the relationship between professionals and parents of adults with learning disabilities. It soon became apparent from the data that the relationship between these two groups of people was important. Potentially it could affect any decisions made concerning their sons and daughters with learning disabilities. With possible conflict resulting from "interference" from outside agencies, it is relevant to examine how parents interact with professionals. This is of special interest regarding sterilisation because, as the law cases illustrate, such a decision can become a public rather than a private responsibility.

Therefore, to fully appreciate their interaction, the relationship is explored in some detail. Furthermore, the data reveals inconsistencies among the professionals as a group and as individuals. The prevailing orthodoxy causes some of them a degree of internal conflict. Consequently, **Chapter 5: Professional Ideology** examines both this and its subsequent implications. Chapters 4 and 5 form the basis of an understanding of the relationship. In the light of this, their respective views of the sexuality of people with learning disabilities, including the sons and daughters involved in the study, can be seen with clarity. It is shown how the professionals differ from the parents in their perceptions of

learning disability. An example of this is the idea of hidden competence, which is explored in Chapter 4. The disparity of views in general between professionals and parents is magnified with the subject of sexuality. Other topics, such as relationships, marriage and parenthood will therefore be examined.

Professionals' and parents' views are further analysed in **Chapter 7: Sterilisation and Decision-Making within Scots Law**. This serves as a culmination of all the data with regard to the basic issue of the study. It also reinforces the data collected earlier, reflecting the issues raised in the initial Chapters. It also addresses the problematic issue of the overlap between public and private matters.

Chapter 8: Conclusion summarises the findings of the study and explains the grounded theory arising from the data. It is of particular significance within a wider and more general theoretical context. A suggestion is made that the substantive, informal theory of the study could be developed into a formal theory regarding relationships between professionals and other groups of lay people. Based on the findings in this study, recommendations of how to improve social work-family relations are made. Finally, the implications with regard to the sexuality of people with learning disabilities are examined.

Chapter 1

SOCIO-LEGAL ISSUES OF SEXUALITY:

A Historical Review of People with Learning Disabilities.

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1.i. Nomenclature

Labels used to describe people with learning disabilities have been subjected to considerable change, even over short time periods. They have, of course, reflected contemporary attitudes and knowledge. This is seen particularly when differentiation was made between levels of disability, for example, distinctions between idiots, imbeciles and the feeble-minded. In the Mental Deficiency Act of 1913, for example, classification was made on the basis of I.Q. level. For people whose I.Q. level fell below 20, the label "idiot" was given; between I.Q. 20 and 50, the term "imbecile" was used; for those whose I.Q. level was from between 50 and 70, the term "feeble-mindedness" was used. Various labels have been used by different sources (such as in the Health Acts, Education Acts, the Warnock Report and the World Health Organisation) and in different countries (such as American usage).

Within the context of this study, different groups of respondents have used different labels. Parents of people with learning disabilities, for example, invariably use the term "mentally handicapped". This particular term was used by professionals in the U.K. in the 1970s and 1980s. At present however, professionals tend to use the terms "learning disability" or "learning difficulty". The former term will be used in this study except where there are historical references.

It is interesting however that such terminology has changed and that the concept of learning disability has been redefined. Labels which have been acceptable in the past have become modern terms of derision, reflecting negative attitudes to learning disability. The common usage of such labels as "fool", "stupid" and "idiot" exemplify this (Deeley, 1990).

1.ii. Introduction

The problems of care and protection for people with learning disabilities create similar social and ethical controversies worldwide. Although laws for protection and control of populations differ, the philosophical problems which learning disability presents are invariably similar. In their various approaches to law and social policy, countries are influenced by one another.

Examining social attitudes to people with learning disabilities in a historical context reveals how laws and social policy have been shaped and how they influence present conditions. At the beginning of the twentieth century, the Eugenics Movement strongly advocated the sterilisation of certain groups of people as a means of social and economic control. This particularly affected people with learning disabilities, or the mentally deficient, as they were then known. As well as the growth of this Movement in the U.K. and abroad, its effects are outlined below.

Philosophical changes in attitudes to people with learning disabilities occurred in the 1960s and in the 1970s. In Scandinavia, these changes were encapsulated in the concept of normalisation by Bank-Mikkelsen (1957) and later in 1976 by Nirje. Normalisation became popular in the U.S.A. and was developed further by Wolfensberger (1983), who redefined it as 'social role valorization'.

The principle of normalisation is an embodiment of a reaction against past philosophies. Sterilisation laws in some States of America, however, remain substantially unchanged, despite their underlying philosophy being outdated. A historical review provides an insight into the basis of such laws and the need for refinement, if not their repeal. This is especially pertinent in the U.S.A., where

lawsuits have been made against Judges and other members of the legal system for allowing sterilisation to take place.

This historical analysis also provides a wider geographical context for the later examination of the law in the U.K. with respect to people with learning disabilities.

1.iii. Mental Deficiency in the Nineteenth Century

The causes and effects of mental deficiency were the subjects of religious, moral and educational debate during the nineteenth century. Individuals such as Itard, Seguin, Saegert and Guggenbuhl were major figures influencing methods of teaching. Seguin held the view that the mentally deficient could successfully be reintegrated into society after appropriate training. His influence was largely responsible for small asylums and schools being established in the U.K. These were funded mainly by voluntary and charitable organisations. It was also due to Seguin that similar institutions were founded in the U.S.A. However, the enthusiasm for and interest in training the mentally deficient declined because, contrary to expectation, their condition could not be fully ameliorated.

In addition, the Industrial Revolution had adverse effects on the mentally deficient. This was because the social changes that were brought about by industrialisation made life difficult for families in their attempt to support dependent relatives. Large migrations to the cities for factory and other employment with long hours saw the eventual deterioration of family life for many working class families. The emphasis on the labour market was on fast production and the adherence to strict time-keeping. As Boston (1981) points out, that with "the division of labor came the division of the population into productive and non-productive". It soon became apparent that many of the mentally deficient population could not cope with these demands and consequently they became an economic burden on

their families. The "deterioration of the urban environment (was) one of the most disastrous of the consequences of the Industrial Revolution....(producing) the most atrocious evidence of deterioration- dense overcrowding, cellar-dwellings, unspeakable filth" (Thompson, 1963). There was an imperative need for employment despite the poor working conditions, long hours and low pay. These factors produced mass poverty and slums, with conditions worsening during times of industrial crisis and slump. This contributed to a negative effect on the workers' "bodily, intellectual and moral conditions" (Henderson and Chaloner, 1971). Engels described proletariat working and living conditions in Manchester and the surrounding towns as degrading. He reported that "wherever it is physically possible to do so these subterranean holes (cellars) are constructed and a very considerable proportion of the population lives in them" (Henderson and Chaloner, 1971). The Idiots Act of 1886 helped to alleviate some of this burden by providing custodial care in institutions. It is not surprising that this offer of provision for the mentally deficient was welcomed by poor and over-burdened families.

It was with this Act that a distinction was made between levels of mental deficiency. It distinguished between 'idiots' and the less disabled 'imbeciles'. In 1889 another category of mental deficiency was defined as 'feeble-minded'. This group was regarded as being more capable than imbeciles and idiots. The following year a distinction was made by the Lunacy Act, 1890, between the mentally deficient and the mentally ill. This resulted in an increase in placements for custodial care. The wider definition of mental deficiency which followed suggested that the section of the population in need of social care was rapidly increasing. A factor contributing to this was Binet's development of I.Q. testing and its scientific acceptance as a means of classification.

Another factor contributing to the apparent increase in numbers of the mentally deficient was the

inclusion of many children previously ignored. The Education Act of 1870 had enabled many working class children to attend schools, and in 1885 the Royal Commission on the Blind, the Deaf and Dumb and Afflicted Classes discovered large numbers who were unable to function adequately in the schools. These findings led popular opinion to perceive the mentally deficient as a social problem.

In addition to the insalubrious effects of industrialisation, such as increasing poverty and slums, there was an increase in criminality, alcoholism and prostitution. The cause of these 'social evils' was largely attributed to the mentally deficient (Ryan and Thomas, 1980). Human degenerative traits were linked with social inefficiency and criminality. Giving this idea an element of credibility, Lombroso, the celebrated criminologist, claimed that "social atavism was correlated with physical abnormalities" (Morris, 1969). Thus, traces of deviancy from the norm were regarded with suspicion and were known as defective. Mental defectives were subsequently distinguished from physical or moral defectives. A different, but analogous argument was advanced by Greg, who in 1872 claimed that there was a strong association between levels of intelligence, social class and reproduction. In addition, Cox (1996) states that "definitions of deficiency varied greatly according to gender and social background as well as the attitude and experience of individual doctors".

The mentally deficient were believed to be more prolific than other members of society, being very fertile, amoral and promiscuous. Furthermore, mental deficiency was thought to be inherited. Consequently, Greg reinforced the belief that the mentally deficient were a social problem and therefore unsuitable to reproduce. Ideas such as these were still prevalent years later in America. There was a belief in "the hereditary qualities of mental retardation; the perceived penchant of mentally retarded persons for wanton procreation, which threatened to flood society with deformed

children; the relationship between crime and mental retardation..." (Frohboese and Sales, 1980). These early eugenic beliefs in the U.K. were also held by others, including socialist Hume Clapperton and embryologist Marshall. In 1885 they both believed that socially unfit persons should not reproduce. Clapperton was the first to advocate that mental defectives be segregated from society and sterilised. In 1896, the National Association for the Care and Control of the Feeble-Minded expressed its concern regarding the reproduction of the mentally deficient and consequently recommended their segregation.

It is clear that the mentally deficient were stigmatised, even by those who were in positions of caring for them. This is illustrated by the claim made by the superintendent of the Royal Albert Asylum that idiots bore the "mark of the brute" (Ryan and Thomas, 1980). Such a view reflects those expressed earlier by such influential people as Seguin and Esquirol, who was the senior physician in the Maison Royale des Aliens de Charenton.

Furthermore, there was a popular acceptance of the entertainment value of displaying mentally deficient people in a circus-type environment. This exploitative exhibition of mentally deficient people for "amusement and profit, commonly known as 'freak shows'" (Bogdan, 1986) continued to be well patronised until the 1940s. People with microcephaly, for example, were known as 'pinheads'. Others were made to "scurry (in front of a) brightly painted jungle scene (making) strange gibberish sounds....snapping and snarling, sometimes adorned with chains" (Bogdan, 1986). These shows reinforced the view that the mentally deficient had "subhuman characteristics and animal traits" (Bogdan, 1986) which maintained the justification of keeping them chained in cages and having only beds of straw on which to sleep (Dix, 1843).

Essentially, British social policy regarding the mentally deficient was formed from such ideas circulating in the latter half of the nineteenth century.

1.iv. The Eugenics Movement

In contrast to Darwin's theory that species changed and developed, Mendel emphasised generational continuity of traits through dominant genes or through two combined recessive genes. Although this was primarily relevant to the biology of plant life, other biologists such as Bateson and Spillman developed the concept, basing their work on the theories expounded by Mendel. Eye, hair and skin colour were eventually proved to be genetically inherited. Subsequently, the view that other traits could also be inherited became popular. Controversial issues arose concerning the heritability of behaviour, criminality and intelligence. This had inevitable ramifications for the mentally deficient.

Galton (1904) explained in a debate held by the Fabians and other socialists, that the "experience gained in establishing improved breeds of domestic animals and plants is a safe guide to speculations in the theoretical possibility of establishing improved breeds of the human race". His exposition was discriminatory, saying that "while most barbarous races disappear, some, like the negro, do not." Galton advocated "persistence in setting forth the national importance of Eugenics" with the aim being "to secure (its)...general intellectual acceptance", although he warned against the potential harm that could result from "over-zeal".

In 1907, the Eugenics Education Society was formed. Its view was primarily of 'positive' eugenics, whereby 'fit' people reproduced their kind, thus safeguarding against the otherwise "likely decline in the talents of the British people" (Ryan and Thomas, 1980). This idea was developed further by Rentoul, who suggested a 'eugenic tax'. He

recommended that a tax be imposed on 'fit' couples who did not have children. There was no definition, however, of what constituted 'fitness'.

Eugenics became a subject of respectability and was endorsed by the Oxford University Union which "approved by 105 to 66 a motion 'that this house approves of the principles of eugenics'" (Trombley, 1988). Writers and activists from a wide range of political backgrounds supported and contributed to the views held by the eugenicists. These included individuals such as Dr. Barnardo, Alexander Graham Bell, G.B. Shaw, H.G. Wells, R. Langdon Down, Cyril Burt and Marie Stopes. Other members of the Eugenics Education Society included individuals from a variety of backgrounds, such as Caleb Saleeby, Karl Pearson, Patrick Geddes, Harold Laski and Havelock Ellis. The Dean of St. Paul's, W.R. Inge, said that the Church would be "supporting the new science of eugenics" and predicted that "science will soon give us a definite programme of race-hygiene" (Trombley, 1988). Eugenicists Sidney Webb and his wife, Beatrice, were in favour of controlling the fertility, not only of the mentally deficient, but also of the "Irish Roman Catholics and the Polish, Russian and German Jews" who, they believed, were 'breeding freely'" (Trombley, 1988).

Ideas expressed in Britain during the early years of the twentieth century later became embodied in Nazi Germany's social policy. H.G. Wells' concept of the sterilisation of 'failures' to improve racial heritage (1904) was later reflected in Germany's policy of 'Rassenhygiene'. In "A Modern Utopia" (1905) he expressed belief in an eventual need for extermination of undesirable offspring. By contrast, G.B. Shaw favoured 'positive' eugenics. He advocated racial superiority, believing that 'fit' persons ought to be encouraged "to breed the race without being hampered by the mass of irrelevant conditions implied in the institution of marriage". This eugenic breeding, he believed, required "freedom for people who have

never seen each other before and never intend to see one another again to produce children under certain definite public conditions, without loss of honour". Reflecting the earlier views of Nietzsche, this philosophy of selective breeding was later manifested in the "Lebensborn" programme in Germany.

Havelock Ellis believed that 'unfit' people would volunteer for sterilisation if coercive methods were used, such as the threat of withdrawal of Poor Relief. (Incidentally, it is interesting to note that a similar situation recurred in the U.S.A. in the 1970s when Welfare Benefits were threatened to be withdrawn from women who refused to 'volunteer' for sterilisation (Trombley, 1988). Another type of coercive sterilisation was also used in the U.S.A. as a prerequisite of release from a state institution (Edgerton, 1967)). Havelock Ellis also later supported the German sterilisation law, of which a translation was made available within the Eugenics Society. It was this sterilisation law which was later utilised in Nazi Germany's social policy in the 1930s, and which ultimately led to compulsory euthanasia, genocide and the Final Solution.

But the enthusiasm for eugenic solutions was not just confined to the political right. In 1910, the "Eugenics Review" published a statement by Herbert claiming that the "eugenic teachings are essentially communistic in spirit". The following year the "Labour Leader" published Benjamin Kidd's view that the reproductive capacity of the mentally deficient should be controlled. Its popularity resulted from its appeal to those who were influential and articulate. They feared "the deep threat to existing middle-class and respectable working class notions of sexuality and familial morality" (Simmons, 1978).

Leading figures in the Fabian Society, who later contributed to the organisation of the Labour Party, were sympathetic to eugenic views on heredity and sterilisation of the 'unfit'. They believed that abnormality could be

eliminated from society. This could be achieved through the non-reproduction of people who demonstrated undesirable deviances from the norm. These deviances included, not just particular physical or mental traits, but particular social behaviour also. As well as the mentally deficient, inmates of lunatic asylums and prison populations were regarded as being unfit to reproduce because of their "defective germ plasm" (Kevles, 1985). This list of 'undesirables' or 'cacogenics' was also extended to include people who had "alcoholic, and sexually immoral tendencies" (Kevles, 1985). As the Eugenics Movement grew, thirty four classes of such people were differentiated. Such groups of people, especially the mentally deficient, were held with low regard by society.

Mentally defective women in particular were subjected to defamation and denigration. Bullard (1910) stated that children of these women were "apt to be mentally defective, with more or less pronounced animal instincts, diseased and depraved". Moreover, such women were perceived as being more fertile than other women in the population, being "twice as prolific as the normal woman" (Fernald, 1912). Popular beliefs were that such women had "no control over themselves" (Lyttelton, 1912) because they lacked the "moral restraints concerning sexual intercourse possessed by normal women" (Simmons, 1978). In sum, they were sexually amoral (Schlapp, 1915). Furthermore, in some instances "unspecified sexual deviance seems to have been the only 'signification' of mental deficiency" (Cox, 1996).

Because there was little accurate knowledge or availability of contraception, it was believed that the population of the mentally deficient would increase at a tremendous rate and they would therefore constitute a social problem. Bullard (1910) claimed that "there is no class of persons who are more fitted and more apt to spread disease and moral evil than these girls". The eugenicists in particular believed that the need for social control therefore was imperative. Pseudo-scientific studies

reinforced these views. Examples of these are Goddard's observations of the Kallikak family (1912, 1914) and Estabrook's study of the Juke family (1916). These studies purported to show that mental deficiency was hereditary. Furthermore, mental deficiency was believed to produce "juvenile vice and delinquency, adult crime, sex immorality, the spread of venereal disease, prostitution, illegitimacy, vagrancy, pauperism, and other forms of social evil and social disease" (Fernald, 1915). Fernald also stated that "the high grade imbecile (was especially regarded as) a potential criminal" (1912).

Also at this time Rentoul recognised that stringent measures of sterilisation would probably be rejected by popular public opinion. Even by eugenic standards his views were extreme. They included punitive sterilisation for sex offenders and prostitutes, sterilisation for all mentally deficient children and all others who were considered 'unfit', one example being those who suffered from migraine. Others within the Eugenics Society were aware that such proposals might not be easily accepted. However, their attempts to influence social policy were persistent and, on occasions, covert. Their success was apparent in the 1908 Report of the Royal Commission on the Care and Control of the Feeble-Minded, chaired by Lord Radnor. It was unmistakeably eugenic, claiming that mental defectives were insufficiently controlled, "whose wayward and irresponsible lives are productive of crime and misery" and that "feeble-mindedness is largely inherited". In order to decrease the "much continuous expenditure wasteful to the community and to individual families", it recommended detaining "mental defectives of each sex in institutions.....to make procreation impossible". It is pertinent that the President of the Eugenic Education Society, Sir James Crichton-Browne, "testified before the Royal Commission as an expert witness" (Simmons, 1978). Also, medical consultants, Down and Tredgold, played active roles both in the Eugenics Society and the Royal Commission of 1908. Tredgold's report to the

Commission reinforced views that mentally deficient women were more fecund than other women and that their children would inherit their disabilities. Their call for segregation from society and by gender also included other sections of the population, examples being the deaf, dumb, alcoholics and epilepsy sufferers. However, the more fervent eugenisists were dissatisfied with the Report because it did not recommend sterilisation.

The National Association of the Care and Control of the Feeble-Minded believed that the mentally deficient were not suitable for parenthood. Some individuals within the Association openly advocated sterilisation of mentally defective children. A medical and educational officer of the London County Councils, James Kerr, advised sterilising children "at an early age, before it means anything to them" (Trombley, 1988). A member of the Council of National Associations for Promoting the Welfare of the Feeble-Minded, Ethel Dixon, also believed that some children should be sterilised, including those in Poor Law schools.

The impetus for legal change increased with the opinions expressed by leading authoritative figures. Beveridge, for example, was in favour of institutionalisation. Churchill, as Home Secretary in 1910, approved of the segregation proposals and the sterilisation of the 'unfit'. He believed that they were a "very terrible danger to the race" (Kevles, 1985). In 1910, the National Association for the Care and Control of the Feeble-Minded and the Eugenics Education Society formed a Joint Committee to force legislation regarding compulsory institutionalisation and sex segregation. Both organisations "had access to the highest levels of government" (Simmons, 1978), which they utilised prior to the Mental Deficiency Act of 1913 coming into force. There is no doubt that these contacts influenced Members of Parliament.

Opposition to the legislation came mainly from Josiah Wedgwood, M.P., who criticised the Act as being produced by "eugenic cranks" (Simmons, 1978). It is ironic that Wedgwood opposed the eugenists when their source of inspiration lay with his distant relatives, Darwin and Galton. He claimed that the Act discriminated against the feeble-minded in particular. Under this new law, if such a woman gave birth to an illegitimate child, she could be compulsorily institutionalised. Although his main criticism of the Act concerned the compulsory detention, Wedgwood did appreciate that institutional care might be in the best interests of some of the feeble-minded. This is because it could offer an improvement of their present economic situation and living conditions. Some families experienced difficulties in caring for such dependants because of problems stemming from unemployment, demands of siblings, single parenthood, retirement or death. There was therefore a demand by families for institutionalisation on economic grounds. An alliance developed between the family and the State in the "micro-politics of provision" (Thomson, 1996). This was seen in the interaction between institutional care, family care and the community.

The social problem of mental defectives was therefore regarded as being solved by the "social policy that was embodied in the 1913 Mental Deficiency Act" (Simmons, 1978). It is interesting to note that this Act was also used "to control delinquent behaviour of boys", although "sexual factors were still vital in leading to an institutional solution" (Thomson, 1996). However, complications arose regarding the practicalities of the requirements of the Act. The classification of mental defectives into the new categories of idiot, imbecile, feeble-minded and moral imbecile, proved a difficult task. In addition, the funds required to establish new and larger institutions were limited, especially as financial priorities were given to the War. Problems which were in reality due to industrialisation remained unaffected by this legislation. The levels of prostitution, crime and poverty

did not significantly decrease. Contrary to the prediction, the social control of the 'unfit' did not "lower taxation, raise wages, render industry more profitable, and improve the efficiency of the workplace" as predicted (MacNicol, 1989).

Although public interest in mental deficiency lessened, the eugenists persisted in their belief in the need for sterilisation. After the first World War, their attempts to change social policy and law re-emerged and grew more emphatic. This will be examined later.

1.v. Eugenics Abroad

In the U.S.A. at the beginning of the twentieth century, there was a fear of a threat to the nation's health and economic prosperity by what was believed to be the vast reproduction of unfit members of society, resulting in the country being "swamped with incompetence" (Holmes, 1927). This fear was exacerbated when the eugenists suggested that the 'defective germ plasm' could be brought into the country by immigrants. Proponents of stricter immigration policy in the U.S.A. welcomed and reinforced these beliefs as a means to substantiating their own policies.

The development of widespread legalised sterilisation was a direct result of the popularisation of negative eugenics. Prior to this, unlawful castration had been performed on boys held in young offenders' institutions, in an attempt to suppress their sexual activities. Experimentation with vasectomy was also carried out. Two doctors in particular, Carrington and Sharp, both performed vasectomies in the belief that it would reduce sexual drive (MacNicol, 1989).

Several factors were responsible for the increase of the popularity of the Eugenics Movement and of population control. As well as advocating tighter controls

over immigration policy, as previously mentioned, the economic prosperity of the country was also an influential issue. Penal institutions and institutions for the mentally ill and mentally deficient had to be funded. It was believed that such institutionalised care would have to be increased because of the reproduction and importation of such populations. This increase in expenditure by each State was unwelcome.

It was also believed that 'moral degeneracy' and actual sexual offences would decrease, if not be fully eliminated, if there was specific population control as advocated by the eugenisists. It was this particular idea that formed the basis for many of the sterilisation laws which were introduced in the U.S.A. in the early part of the twentieth century. Sterilisation was therefore used not solely for population control, but also for punishment purposes.

Involuntary sterilisation, or sterilisation without the consent of the individual concerned, first became law in the U.S.A. in 1907. The implications of this law were that "any habitual criminal, rapist, idiot, or imbecile committed to a state institution" could be sterilised without their consent (Reilly, 1987). Salpingectomy or tubal ligation operations were later performed on women despite the high mortality rate that resulted. Some eugenists did not support sterilisation of women because of this, preferring them to be segregated in single sex institutions. It was doubtful whether 'institutionalised sterilisation' was a less cost-effective method of dealing with the economic problem. However, there were some who believed that the cost of institutional care was less than the potential cost of care for the offspring of such women (Kevles, 1985).

Although negative eugenics created opposition, overall it was socially acceptable and became increasingly popular. This was due to support by powerful and

influential figures in American society, including the Presidents of Stanford University and the National Prison Association, as well as members of the legal and medical professions. Wealthy individuals such as Rockefeller, Roosevelt, Kellogg and Proctor financially supported the Eugenics Movement. Similarly, another eugenic organisation, the Human Betterment Foundation, was founded by a millionaire. The unique combination of the development of ideas at that particular time with individuals who were prepared to use their personal power resulted in sterilisation laws appearing on the statute books across the U.S.A. Without the substantial financial backing they received, it is probable that the eugenisists would not have achieved the results they strove for.

Within the first decade of eugenics as a popular movement, 17 States passed sterilisation laws. By the end of the 1920s, 24 States had sterilisation laws and these later increased to 30. Sterilisation was not performed consistently however, even within individual States. The rates varied idiosyncratically from one institution to another since the decision to sterilise rested with the management of each institution.

Between 1907 and 1921 one authority reported that "there were 3,233 sterilizations performed under state laws" (Reilly, 1987). There is some dissension about the figures. Reilly believes that Kevles underestimated the number of people actually sterilised because they were performed in States which did not have sterilisation laws or they were not reported, a fact later admitted by the Human Betterment Foundation. Reilly also claims that Kevles mistakenly underestimates the influence and effects of the sterilisation laws. Both Birnbaum (1961) and Kevles believe that there was a decrease in the invocation of such laws by the 1950s, but Reilly refutes this claim, saying that between 1907 and 1963 sterilisation was being regularly and consistently performed in 30 States, with the result that in excess of 60,000 people were sterilised.

It was in the 1930s that most sterilisation operations were performed, "when more than 2,000 institutionalized persons were sterilized each year, a rate triple that of the early 1920s" (Reilly, 1987). At this time the influences of the Eugenic Movement and the sterilisation laws in the U.S.A. were apparent in other countries. The Scandinavian countries of Norway, Sweden and Finland introduced sterilisation laws in addition to countries such as France, Germany and Japan. American influence was also clearly evident in Canada, with sterilisation laws being introduced in Alberta in 1928 and British Columbia in 1933. During these years a successful petition for sterilisation required a unanimous decision by the Eugenics Board. This consisted of a judge, a psychiatrist and a social or welfare worker. Also, consent for the operation had to be obtained from either the patient or his/her parent. The Provincial Secretary was also empowered to give consent. In Alberta, sterilisation operations were performed on patients prior to their discharge from state institutions, the same practice as in the U.S.A. The official statistics of sterilisation operations performed in Alberta and in British Columbia between 1929 and 1967 totalled 2,572. Of these, 1,082 were vasectomies and 1,490 were salpingectomies or tubal ligations.

Also, in the 1930s, the eugenists in Germany wielded authority and the Movement grew rapidly in popularity with those in political power. As a result, physically abnormal people and those with diabetes, for example, were sterilised. According to Reilly, over 50,000 people were sterilised in Germany during the one year following its legislation. After this period there are incomplete statistics because war records were lost. Paul (1968) believes that sterilisation in the U.S.A. declined as a result of the fervour with which the eugenists in Germany had sterilised such large numbers of people in a relatively short period of time. However, Reilly is sceptical of this

and claims that sterilisation continued in the U.S.A. unaffected by events elsewhere, with more than fifty per cent of all sterilisation operations being performed after this period. He states that "No revulsion against Nazi sterilization policy seems to have curtailed American sterilization programs" (Reilly, 1987). A feature of American sterilisation policy was that salpingectomy was performed more frequently than vasectomy, despite this operation being more of a health risk. It was therefore women, the more vulnerable within this controlled population, who had their lives put at risk by undergoing sterilisation.

1.vi. Eugenics during the Inter-War Years in the U.K.

After the first World War, mental deficiency was no longer considered to be a social problem in the U.K. Nevertheless, the eugenists continued their campaign for legislative control over the reproductive abilities of the 'unfit'. This included mental defectives, many of whom were not institutionalised. The Eugenic Movement grew in impetus at this particular time. The sterilisation laws in some States of America encouraged the support for sterilisation in the U.K. World War I had resulted in an increase in nationalism and led the eugenists to declare that their aim was to turn "Pride of race ancestry...to the practical and urgent work of safeguarding our greatest heritage- the blood of Englishmen" (Trombley, 1988). Improvement of the race was a fundamental tenet of eugenic thought and one that was more salient following the slaughter of fit men during the war, what the "Eugenics Review" called the "dysgenic effects of war".

Marie Stopes was an ardent eugenicist who campaigned for the compulsory sterilisation of the 'unfit'. The message she gave in her article published in the "Daily

"Mail" concerned class differences. She warned of indiscriminate breeding which would result in the deterioration and eventual disintegration of the 'Imperial' race. It was this class differentiation that later was to antagonise the Labour Party. Stopes had links with M.P.s including Lloyd George. Such contacts were essential to the Eugenic Movement and their bid for sterilisation legislation.

In late 1923 the Education Minister was asked by Thomas Davies M.P. to form a committee to investigate the possibilities of sterilising 'unfit' children. As a result of continuous lobbying from the eugenicists, a Mental Deficiency Committee was formed in 1924. This was referred to as the Wood Committee. It was comprised of two sub-committees, the Board of Control and the Board of Education and included eugenicists Tredgold and Burt. The objective of the Committee was to examine the efficacy of the Mental Deficiency Act of 1913. In its Report, published in 1929, it maintained that the mentally deficient remained a social problem and that their numbers were increasing, despite institutionalisation. The Report suggested that sterilisation would be an effective adjunct to compulsory institutionalisation. The "Daily Mail" published Julian Huxley's comments in 1930. He said that "We cannot stop them by segregation alone; so we must make up our minds to call in the aid of sterilization as well" (Trombley, 1988).

At this particular time there were no clear party political divisions on the subject of sterilisation of mental defectives. Support for the Wood Report came from a variety of political and social backgrounds, which included the Bishop of Birmingham, the British Union of Fascists led by Oswald Moseley, the Workers' Educational Association, the Manchester "Guardian" and the "New Statesman and Nation". The latter stated in 1931 that "It is better that the law should permit (the mentally deficient and mentally insane) to achieve a permanent state of sterility than that their

children should start life under the grave handicap of a demented mother or a feeble-minded father." This argument introduced a new element into the debate, that of the rights of the unborn. This again reinforced the view that mental defectives were unfit for parenthood. In addition, there were views that the mentally deficient should not be permitted to marry.

In 1930, Huxley claimed that sterilisation of mental defectives would reduce costs within institutions. Berry and Gordon (1931) echoed the popular view of the mentally deficient being "a constant menace to society, inasmuch as his animal passions are abnormally violent and quite uncontrolled". In criticising the "lavish expenditure" of the institutions, they advocated a model institution where financial expenditure could be kept to a minimum. In addition to the cheap labour the inmates could provide, the standard of accommodation could also be reduced to a minimum. Berry and Gordon even went as far as suggesting that the mentally deficient sleep outdoors in "huts of open-air type". They believed that it was "perfectly feasible", even that "nothing...could possibly be better" than for the mentally deficient to sleep outside in the "depths of an English winter, with nothing but a roof over their heads....The open-air sleeping huts at Besford Court....conform to the two absolute essentials (which allow) "an abundant supply of oxygen....with the lowest capital expenditure." They were emphatic that mental defectives "should cost the Nation as little as possible." From such views it is apparent that the mentally deficient were still regarded as a burden on society. It was because of such attitudes that the attempt to prohibit their reproduction was not seen as a particularly significant moral issue.

The Eugenics Society had considered founding a hospital for sterilisation purposes only, but it was acknowledged that such a proposal could be hindered by legal complications. Its General Secretary, Dr. Blacker, writing

in "The Eugenics Review" (1931) was categorical in advocating sterilisation, "not as an alternative, but as an accessory (to segregation)". The Eugenics Society thus formed a Committee for Legalising Sterilisation and, with the help of Lawrence Brock, succeeded in drafting a Voluntary Sterilisation Bill. In 1931 there was an attempt by Major Church M.P. to present it in the House of Commons, but the motion was defeated. Following this disappointment, the Eugenic Society increased its campaigning, mainly in the form of public meetings and pamphlets, for example, "Better Unborn". This was added to Blacker and Huxley's 'buff pamphlet', which was a statement of the eugenic position and had a circulation of about 10,000. The result of this intensive campaign was the forming of a Departmental Committee on Sterilisation in 1932. Its Chairman was also the Chairman of the Board of Control, Sir Lawrence Brock, who later became Lord Brock. The Brock Report, as it was known, was published in 1934 and supported the views that mental deficiency was hereditary and that mental defectives were 'unfit' to reproduce. The Report stated that "Defectives make inefficient parents" but it conceded that it was acceptable to allow "sterilised defectives to marry". The recommendations of the Brock Report had a eugenic basis. There are clear indications that Brock and Blacker had collaborated, with Brock giving advice to the Committee for Legalising Sterilisation. Inherent in the Report are statements denigrating feeble-minded women. It states that "the discharge of sterilised defectives, particularly of women, may have most unfortunate social results", which include "increased promiscuity" and the "spreading of venereal diseases".

The Committee recommended that voluntary sterilisation be legalised. It stipulated 'safeguards' however, in the form of consent by the parents or guardians of the individual concerned if he or she were incapable of giving consent. In practice, therefore, sterilisation could be performed on an involuntary basis. By endorsing the views of the eugenicists, the Brock Report brought them

increased respectability and furthered their popular acceptability. The problems facing sterilisation legislation became "ones of party politics rather than a lack of political will or popular support" (Trombley, 1988). Blacker astutely recognised the potential political difficulties. In 1934, he formed a Joint Committee on Voluntary Sterilisation to strengthen their case. He assessed that legislation would have to be introduced that same year. This was because a general election was expected to take place in 1936. The Government was reluctant to introduce controversial initiatives near an election date because of the risk of losing votes. Blacker realised that if legislation was not formed in 1934, another attempt to introduce it would have to be made after the election when the new Government was in office.

Blacker's Committee received support from a variety of sources. These included the Health Minister Sir Hilton Young, the Bishop of Durham and other eminent individuals from the judiciary and the universities. A long list of organisations in support of the Voluntary Sterilisation Bill included the National Association for the Feeble-Minded, the National Association of Blind Workers, the Royal Colleges of Surgeons and Physicians in addition to the Women's Co-operative Guild and the National Council for Equal Citizenship.

In 1934, the Brock Report was debated in the House of Commons but with no definite result. Following this, Blacker realised that the possibility of legislation on this issue would be delayed until after the General Election. He therefore created a National Workers' Committee for the Legislation of Voluntary Sterilisation to gather support for eugenic ideas. The National Conference of Labour Women "voted overwhelmingly" in favour of sterilising the 'unfit' (Trombley, 1988). In 1937 the Brock Report was again debated in the House of Commons, with Labour members being unable to agree with each other on the subject. Ernest Thurtle M.P. is reported as saying that the

"Labour movement as a whole is strongly in favour of the proposal" (Trombley, 1988). The debate was centred on the idea of its being voluntary. Due to a technicality, no vote was taken.

By 1938, the question arose of whether a law was even necessary for voluntary sterilisation to be performed. The judiciary commented that if consent was obtained then sterilisation could be regarded in the same way as any other operation. The impetus for further action toward legislative change was greatly lessened by this. Combined with another threat of impending war, the welfare of the mentally deficient became low priority and as a consequence there were no further debates on a Voluntary Sterilisation Bill. The failure of a Bill, however, was not solely due to these factors.

MacNicol (1989) suggests other reasons which contributed to legislative failure. One of these was the failure "to establish the genetic basis for mental deficiency or social inefficiency". Furthermore, the choice of language in the Parliamentary debates was emotive and lacking in factual substance. Church M.P. inadvertently prejudiced the chance for legislation when he stated the aim was really the "compulsory sterilisation of the 'unfit'". Although there was collaboration between the American and British eugenicists and the Nazi Germans, the excesses and fervour with which the sterilisation law in Germany was applied did not receive public support in the U.K. and therefore hindered the later progress of the Voluntary Sterilisation Bill.

Support from the Labour movement was mixed until there was a direct accusation that the Bill was aimed at the working classes and not just the mentally deficient. Cautiously, Blacker had not openly associated the 'social problem' with working class people. Caradog Jones was, however, more specific, revealing that this was, in effect, 'class legislation'. He claimed that the "lower social

classes (were) generally sub-normal in characteristics which are vital to the achievement of personal well-being and successful social adaptation" (Caradog Jones, 1932). The idea that the Bill was anti-working class alienated the Labour movement and consequently lost its support. Political promises that social control of the mentally deficient would lead to improvement in society and "greater economic efficiency" (MacNicol, 1989) could not be honoured. Disillusionment therefore lessened credibility of further legislative proposals.

Although "one cannot underestimate the influence of the Eugenic Movement" (Simmons, 1978), the actual "explicit policy outcomes of eugenics were few" (MacNicol, 1989). The general widespread support given to the Voluntary Sterilisation Bill may have resulted in legislation had there not been the outbreak of war in 1939. British eugenicists also influenced their American counterparts, who, in turn, established sterilisation laws as noted earlier, and some of which remain on the statute books. Alexander Graham Bell, for example, was employed by the Eugenics Record Office in the U.S.A. with Harry Laughlin. Such were the eugenic connections and influences, that it was Laughlin's draft of a sterilisation law that was adopted in Nazi Germany. It is interesting to note that Laughlin received an honorary degree from the University of Heidelberg on the basis of his work.

Nazi Germany also adopted the ideas that had been expressed by British eugenicists, H.G. Wells and G.B. Shaw in particular, as mentioned earlier. The progression from compulsory sterilisation to euthanasia, to genocide and then to the 'Final Solution' is not surprising in the ethos of that time, especially when there was also the implicit approval from the U.S.A. and the Eugenics Society in the U.K. The Americans were displeased that the Germans had usurped them of their leading role in the numbers of sterilisations performed on the 'unfit', and were reported

as saying that they "are beating us at our own game" (Trombley, 1994).

1.vii. Modern Policy

In the U.S.A. sterilisation had been performed on habitual criminals but this was later claimed to be unconstitutional. As a result, some sterilisation laws were repealed. It was reported in the law case *Skinner v. Oklahoma* (1942) with the report that "sterilization provided for is cruel and unusual punishment and violative of the Fourteenth Amendment." Eventually, doubt was cast on eugenic theory regarding the heritability of mental deficiency. Consequently, the rate of sterilisation operations in the U.S.A. gradually declined to its lowest level in the 1960s, at which it has remained. In 1961, however, there were still 28 states with sterilisation laws. Over the following 15 years, laws were repealed or amended until only 19 states had sterilisation laws. Some states prohibit sterilisation completely. The U.S.A. therefore became, and remains, representative of a variety of laws and social policies with regard to the sterilisation of people with learning disabilities. The reasons for these gradual changes are discussed below.

Changes in societal attitude

Societal attitudes to people with learning disabilities have been in a gradual process of change. After the Eugenics Movement and the sterilisation laws in the U.S.A. there was an increase in medical knowledge and genetic information about learning disability. Subsequently, social policies were questioned and reassessed. This occurred worldwide but was especially prevalent in Scandinavia, where the principle of normalisation developed. The term 'normalisation' was

originally used in 1950 by Montessori. It was also later used in 1958 by Shakow and in 1966 by Olshansky. However, it was not until 1969, in Denmark, that normalisation was defined as a fundamental principle for service provision. Bank-Mikkelsen explained normalisation as a means by which the mentally subnormal could live as normally as possible. Against the background of control and repression manifested in institutionalisation, normalisation was a liberating reaction. Consequently, this concept marked a radical change in the ideology of care for people with learning disabilities.

In Sweden, Nirje (1976) clarified the aim of normalisation, saying that it meant, "making available to all mentally retarded people patterns of life which are as close as possible to the regular circumstances and ways of life of society". This was unequivocal, meaning that institutionalisation was not the most appropriate form of care for the mentally retarded. The aim was to improve their quality of life. This could only be achieved by experiencing the basic "normal conditions of life" (Nirje, 1985). Nirje described these as consisting of "four definitions of the basic patterns of the normal rhythms of life (which constituted) the most original and basic part of the normalization principle" (1985). The four definitions were that the mentally handicapped should experience "the normal rhythm of the day, the normal rhythm of the week, the normal rhythm of the year, and the normal development of the life cycle" (Nirje, 1985). He expanded this to include normal economic and environmental conditions. Furthermore, he added that "normal respect and normal sexual patterns of culture" should also be accessible to the mentally handicapped. Nirje again redefined his statement of the principle of normalisation, saying that it meant "making available to all other persons with disabilities or other handicaps, patterns of life and conditions of everyday living which are as close as possible or indeed the same as the regular circumstances and ways of life of society" (1985). According to Nirje, disability is multi-faceted.

Primarily, there is the disability per se. Secondly, there is the awareness of the disability by the individual concerned. Finally, there is the disability which is imposed on the individual by society. This latter concept of disability emanates from societal attitudes and practices, and is especially salient with regard to the sexuality of people with learning disabilities. The dearth of sex education and the lack of opportunities for an 'ordinary' sex life are examples of this. As a result, their disabilities are exacerbated and they are thus additionally socially disadvantaged. Normalisation seeks to ameliorate, indeed eliminate, such imposed disability.

In the U.S.A. Wolfensberger emphasised this particular aspect and in so doing redefined the principle of normalisation. His attempt to provide a "scientific theory that is universal, parsimonious, and congruent with social and behavioural science" led him to rename the concept as "social role valorization" (Wolfensberger, 1983). This is because its "most explicit and highest goal" he claims, "must be the creation, support and defense of valued social roles for people who are at risk of social devaluation" (1983). There are potential problems with this definition because it does not allow for people with learning disabilities to choose a 'deviant' lifestyle or to engage in 'deviant' sexual behaviour. Perrin and Nirje (1985) disagree with Wolfensberger's version, saying that it "cannot be considered as a reformulation" of normalisation because it "deviates in many significant ways from the original concept of the principle". Their main criticism of Wolfensberger lies with his belief in normative behaviour being of paramount importance, regardless of individual choice. It is therefore apparent that normalisation can be widely interpreted. At a practical level, it is not surprising that confusion results from such interpretations. This view is supported by Brown and Smith (1992) who claim that there are divisions within the profession regarding the meaning and usage of normalisation. It is such divisions which are investigated in this study. This exercise

provides insight into the effects of the orthodoxy and how tension can develop between professionals. Remnants of past ideologies have not been completely eradicated by the prevailing ideology of normalisation. Brown (1994) believes such views are evident in "current thinking and (that they) provide subliminal rationales for contradictory practices".

Furthermore, additional problems arise when the views of parents are incompatible with those of the prevailing professional ideology. Unlike professionals, parents are not imbued with the prevailing orthodoxy, but remain within an environment of traditional family protective care. As a result, this creates opposition regarding attitudes to care and to learning disability itself. Therefore, while normalisation replaces the paternalism of control associated with institutions, it also challenges filial control within families. Moreover, Wolfensberger claims that the "enhancement of the social role of persons or groups at risk of social devaluation" (1983) is of paramount importance. This is a public issue and in practice is often discordant with the position of people with learning disabilities within private family life. It is within this private sphere that they are protected from professional ideology. This unresolved dilemma is explored later in detail.

Against the background of control and repression of people with learning disabilities, normalisation was a liberating reaction and a refutation of institutionalisation. It clearly demonstrates the change in attitude to people with learning disabilities. Its all pervading influence can be detected in specific legislation in different countries. Examples of this are reviewed later. Normalisation also reflects wider developments concerning the protection of human and civil rights.

On December 10th, 1948, the General Assembly of the United Nations officially produced the Universal Declaration of Human Rights. This was in recognition of a

need for regulations, or moral codes, to safeguard individual rights and human dignity. These regulations were not bound by law, but were first established as guiding principles. The aim was to provide a base for development and education. The Universal Declaration of Human Rights was first proclaimed by the United Nations. The International Bill of Human Rights was later produced and consisted of four International Covenants. Once agreed to, member states are legally bound to implement them (Cole, 1983). The International Covenant on Civil and Political Rights states in Article 1 that "All people have the right to self-determination." Involuntary or coerced sterilisation therefore contravenes this Covenant.

The European Commission developed the idea of protecting human rights. Membership of the European Parliamentary Assembly is conditioned by Article 3, which requires "the principle of the rule and law and of the enjoyment by all persons within its jurisdiction of human rights and fundamental freedom." Failure to adhere to these principles can lead to eventual exclusion from the European Commission. European unity was originally based on reasons of economy and politics, unification "under the blatantly anti-communist arm of NATO" (Beddard, 1980). The unintended result of this unity however was the European Convention on Human Rights, the authority of which can be reinforced through the European Court of Justice. The Convention therefore represents more than mere guidelines. It produces a safeguard for individuals who are enabled to seek justice from the European Commission when their own government has failed to do so. However, the Convention only applies to those member states which have declared that they will accept it under international law. National laws can therefore be subject to Community rules. If there is a conflict between them, the rules of the Community claim superiority. This has ramifications for the U.K. as the Supremacy of Parliament is no longer absolute (MacQueen, 1993).

The European Convention on Human Rights is intended to include all members of the population. Article 8 (1) states that "Everyone has the right to respect for his private and family life." Article 12 states that "Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right." These articles are significant for people with learning disabilities with regard to their choices of contraception, sterilisation and other medical treatment. The Commission can decide how to balance the rights of individuals against the interests of a member state. With regard to sterilisation without the consent of the individual concerned, it is possible that a decision to sterilise could be upheld on the grounds that it is "justified for the economic wellbeing of the country" concerned (Beddard, 1980). It seems unlikely that this decision would be taken because of its being reminiscent of past eugenic policy, although recent events in countries such as China, Serbia and Bosnia, would suggest otherwise. Rousso (1984) and Ward (1990) both hold the view that economics has no ethically justifiable role to play in the decision-making procedure of such matters.

Effects in the U.S.A.

Although the view that heredity directly causes all cases of mental deficiency was finally disproved, the legislation in the U.S.A. did not change drastically. As stated earlier, the number of sterilisations decreased generally but there were still reports of eugenic sterilisation operations as late as the 1970s.

In 1973, there were two significant changes in the U.S.A. The first was in Alabama where a committee was established to review all requests for sterilisation. The second was that a judge claimed that the department of Health, Education and Welfare could no longer legally perform involuntary sterilisation operations. In 1978, people deemed mentally incompetent or unable to give legally

valid consent, and people under 21 years of age could not be legally sterilised. This has resulted in a legal dilemma.

The principle of normalisation advocates the self-determination of people with learning disabilities. This has been demonstrated in a situation where a woman with learning disabilities and her husband took legal action against the State Court Judge and others in the U.S. District Court for damages following her discovery that she had been sterilised. The operation had been performed without her knowledge and her consent (*Stump v Sparkman*, 1978). The case was referred to the U.S. Court of Appeals for the Seventh Circuit after the complaint was rejected by the District Court. The case then went to the Supreme Court. The Judge was not found to be liable for damages. A legal case such as this, where consent to the operation is questionably valid, inevitably results in caution among legal and medical practitioners. This particular case has had far-reaching effects and has influenced practice in Canada.

With the Developmentally Disabled Assistance and Bill of Rights Act, 1975, legislation in the U.S.A. attempted to protect the rights of people with learning disabilities. Guardianship procedures were outlined to enhance the independence of such adults. The guardianship appointments are made by the Courts and are now periodically reviewed. Provision can be made for full guardianship or partial guardianship depending on individual needs. The decision-making powers of both the full and partial guardians are limited with regard to certain types of medical treatment, including sterilisation (Ward, 1990). It is possible, however, that consent to therapeutic sterilisation is within the power of a guardian.

Sterilisation can still be performed legally in some States, although not on a eugenic basis. Therapeutic sterilisation is possible if it is in the best interests of

the learning disabled person. This can take the form of hysterectomy, on the basis of the person being unable to manage menstruation or that pregnancy and childbirth would be detrimental to her mental health and welfare. There appears to be no medical reasons however for a man to undergo therapeutic sterilisation.

The Situation in Canada

In Canada it has been acknowledged that therapeutic sterilisation or essential medical treatment that resulted in sterilisation, was legally acceptable and continues to be so. Contraceptive sterilisation poses more difficult and ethical problems for which doctors may not necessarily be legally protected. Sharpe (1978) states that doctors are advised to proceed only with "extreme caution" in such cases. The concept of informed consent plays an influential role in this situation. A written declaration of consent must be signed before a sterilisation operation can be performed and the approval of the spouse (if applicable) is desirable although not legally necessary. The doctor is obliged to inform the patient of the consequences of the operation, but must also caution that the operation may not be 100% effective in all cases. (A fuller examination of the issue of consent is made in the following Chapter.)

Canadian doctors are advised against sterilising minors and those with learning disabilities because of the possible legal consequences. A Working Party examined the concept of third party consent to sterilisation when a patient cannot give legally valid consent. It was argued that this would be a form of involuntary sterilisation without any legal safeguards for the individual.

The controversy regarding involuntary sterilisation was apparent in the 1970s. In 1976 there were 686 involuntary sterilisation operations in Ontario alone, of which 308 were performed on children and of which a total

of 636 were performed on females (Evans, 1980). There was a reaction against this by the Official Guardian of Ontario, Lloyd Perry, in 1978. He claimed that any sterilisation without consent from the individual, upon whom the operation was being performed, was illegal. Sharpe (1978) supported this view and added that parental powers should not include the giving of consent to the sterilisation of their offspring. The sterilisation of under 16 year olds was later prohibited and the question of who could give consent after the age of majority in cases of doubtful legal capacity has remained debateable.

The course of events in Canada is similar to that in the U.S.A. It was feared that similar circumstances could arise concerning legal action as in the *Stump v Sparkman* case in America. These fears were exacerbated in 1979 with the case of "Eve". A mother requested the sterilisation of her learning disabled daughter (Eve), but the petition was refused. The Judge ruled that as informed consent could not be given by Eve, then the operation would be illegal. His decision was later overturned by three Appeal Judges who approved the request for a hysterectomy operation for Eve. The case then went to the Supreme Court of Canada, where nine Judges reviewed the case. They were concerned whether the Court was authorised in giving consent under its power of *parens patriae*. *Parens patriae* is of English origin and is used in the Supreme Court in Canada. It is a successor to the powers of the English Court of Chancery, which date back to King Edward I (Marshall, 1987). On the basis of this historical link, the Court ruled that sterilisation was not in Eve's best interests or welfare and the request was finally refused.

In safeguarding her right to procreate, Dickens (1987) believes that the Court has done a "serious disservice" to Eve. As a result of the Court's decision, contraceptive sterilisation has become illegal for many people with learning disabilities in Canada. The Court did not accept that non-therapeutic sterilisation held benefits

for this section of the population. It is indicative of a cautious, and possibly self-protective, motive that the Court cited the U.S.A. case, *Stump v Sparkman*. The Court claimed that non-therapeutic sterilisation held a stigma for people with learning disabilities, which reflects the findings in Edgerton's study (1967). It did accept, however, that a different operation performed bona fide but resulting in the sterilisation of the patient would be acceptable.

The legal controversy surrounding this subject eventually led Alberta to redraft its legislation, taking into consideration the situations in other countries. In the Dependent Adults Act there is now provision for the appointments by the Court of plenary or partial guardians. A plenary guardianship order will only be made if a partial guardian does not fulfil the needs of the disabled person. Plenary guardianship powers are the same as those of a father of a child under 14 years of age and the orders are reviewed periodically. There are certain powers given to partial guardians by the Court. These are given on the basis of what is considered to be in the best interests of the learning disabled person. With regard to medical treatment, the decision-making powers include "the right to consent to any health care that is in the best interests of the dependent adult" (Ward, 1990). If contraceptive sterilisation is considered to be in the best interests of the disabled person concerned, then there is clearly a potential legal conflict. Each request for sterilisation would have to be considered on an individual basis. This is similar to the present situation in Scotland, which will be discussed later.

Legislation in New Zealand

The Protection of Personal and Property Rights Act, 1988, was designed to meet the needs of adults with learning disabilities. Prior to this Act, New Zealand's legal system did not cater for this section of the

population. It did not therefore have to repeal any laws and it had the advantage of being able to learn from the weaknesses apparent in other legal systems. Because it is relatively new, it is useful to examine its basic outline.

The code is based on the presumption of competence of the disabled individual and therefore only the least restrictive intervention is required in the first instance. This law is based on the principle of normalisation. It acknowledges the potential of people with learning disabilities in that their abilities can be developed and increased. In New Zealand, a lawyer must always be appointed with regard to manage the affairs or to assume personal guardianship. Unless the disabled person can finance this appointment, legal aid is always available. The Family Courts deal with guardianship appointments through pre-hearing conferences and hearing procedures which can include contributions from the disabled individuals concerned. For decisions affecting the dependent adult's personal life such as medical treatment, the guidelines are only specific in circumstances involving life-saving treatment or procedures involving brain tissue or experimentation.

Consultation with the person with learning disabilities is always recommended and any action that is taken must be in their best interests. The powers of the guardian include "any aspect or aspects of personal care and welfare" (Ward, 1990). The legal position, with regard to consent to sterilisation, is similar to that of other countries. Each request must be considered on an individual basis and in the best interests and welfare of the individual concerned if they are unable to give legally valid consent. This is also the present practice in the English Courts.

The British Situation

After the second World War there were gradual changes in provision for people with learning disabilities. The Royal Commission on Mental Illness and Mental Deficiency of 1954-7 referred to the responsibilities of local authorities, using the term 'community care'. Awareness of the inadequacies of old, large institutions was publicly heightened by Enoch Powell in 1961 and in 1963 by the Community Care Blue Book (Whitehead, 1992). In 1971, the government published "Better Services for the Mentally Handicapped", which clearly recommended residential and day services as improved alternatives to segregated institutionalisation. These are clear indications that the influence of normalisation was rising steadily, replacing the paternalism of control inherent in institutional life.

In 1975, the "Committee of Enquiry into Mental Handicap Nursing and Care" was established. Its remit included appraisal of the Briggs Committee, which had called for a separate profession to care for people with a mental handicap (Race, 1995). By March, 1979, its recommendations were published in the Jay Committee Report. This heralded a public acceptance of the need for change in services for people with a mental handicap. It was, as Ryan and Thomas (1981) claim, a "ground-breaking enquiry". The Report presented a model of care, based on the principle of normalisation. Essentially, this stated that people with a mental handicap should be treated as individuals, having the opportunity to experience 'normal' patterns of life but with additional support if necessary. The Report also recommended 'service principles'. These were based on the mentally handicapped using 'normal' community, professional or specialised services if necessary. To be effective, however, the services would require to be co-ordinated. The Report also recommended that an advocate be available to obtain the services needed on behalf of the person with a mental handicap. The concept of community care was established and was the focus of the White Paper of 1981,

under Thatcher's government. Although the closure of large institutions was mandated, local authorities were not financially empowered to offer satisfactory alternative forms of care. The impact of the Jay Report, according to Ryan and Thomas (1981) was consequently lessened and, instead, its innovatory impetus was "quietly buried".

The Community Care Act of 1990 legally obliged local authorities to assess the needs of people requiring care in the community. It was also necessary for them to provide services or to purchase them from private enterprise, thus engaging a freemarket philosophy. Legislation also ensured that establishments were inspected for quality assurance. This is in contrast to the situation in the 1970s when "Departments and agencies had become obsessed with systems approaches to service development, addressing problems by large-scale reorganisations, which paid scant regard to the impact of their services on the lives of people, or the wishes of those seeking help" (Whitehead, 1992).

What constituted a systems-led service therefore gradually changed to the present needs-led system. However, Rowley, Welsh and Reid (1994) advocate a further process of change towards a rights-led system. This type of service is exemplified by the 1976 Lanterman Developmental Disabilities Act in California, whereby service provision is met on the basis of common, protective and special (additional) rights. Provision is purchased from public and/or private enterprise. People with learning disabilities and their families have the rights and opportunities to articulate their own needs and choice of provision to meet those needs (May and Hughes, 1987).

Although changes occurred with regard to attitudes to people with learning disabilities and the provisions made for them, the area of sexuality, and specifically sterilisation, remained controversial. Sir Keith Joseph's "Birmingham Speech" in 1974 was reminiscent

of views held earlier by the eugenists. His speech was "probably the strongest statement which might be contended to be eugenic made by a national politician since World War II" (Trombley, 1988). It contained references to women 'unfit' for parenthood "producing problem children" resulting in the "human stock" being "threatened". He also linked together "the educationally backward and the criminal population" (Trombley, 1988). The right wing of the Conservative Party supported Joseph and, not surprisingly, there was much opposition to his speech from the Labour Party.

It was also in 1974 that Sir Keith Joseph said that the National Health Service would begin to provide family planning services. Although therapeutic sterilisations were available prior to this time, from 1974 contraceptive sterilisation became freely available in some areas of the country. The following year the question of sterilisation arose again in the House of Commons. The Labour Health Secretary, Dr. David Owen, was questioned on the medical policy of sterilising minors. Owen stated that there were no general guidelines, but that each case would be considered individually. Kilroy-Silk, M.P., raised the issue of sterilisation being performed on social grounds and asked if this ever occurred. Owen did not give a direct reply, but instead referred to the recommendation that surgeons seek the advice of the Medical Defence Union. By 1987, this organisation and the Medical Protection Society "each (received) about one enquiry a month on this subject" (Dyer, 1987). This suggests that sterilisation remained a contentious and relevant issue, but one that social policy and law clearly did not cater for.

At a subsequent debate on this subject Trombley (1988) claimed that finally "Owen accepted that cases of eugenic sterilisation were 'arguable'." Specific law cases that have since occurred demonstrate that not only is the law unclear on matters of sterilisation, but also the medical ethics of the right to reproduce have not been

sufficiently and satisfactorily explored. Examples of these law cases are examined in the following Chapter.

A Voluntary Sterilisation Bill is no longer on the political agenda, although sterilisation is now a socially acceptable form of contraception. In 1977 and 1979, contraception sterilisation operations increased. This was directly due to reports of the oral contraceptive pill increasing the possibility of heart disease and thrombosis. Sterilisation operations also increased because of "improvements in the ease and availability of the operation" and because of the "dissatisfaction with other contraceptive methods" (F.P.A., 1992).

Sterilisation "was particularly encouraged by the Scottish medical profession during the 1970s" (Trombley, 1988). The recorded numbers of female sterilisation operations alone amounted to almost 10,500 in 1972 in Scotland, rising to almost 11,000 in 1974. These are large numbers within the relatively small population of Scotland. The Family Planning Association confirms that by 1975 as many as one in four partners were sterilised before the woman was 35 years old.

There is little doubt that attitudes to sexuality have changed with the advent of reliable contraceptive methods and continue to do so. The Royal College of Obstetricians and Gynaecologists is considering their endorsement of the proposed availability without prescription of Schering PC4, the morning-after pill (Sunday Times, 1994). It is now possible and socially acceptable to "separate the social and recreational aspects of sexuality from the reproductive aspect of sexuality" (Spicker, 1987). Whether this separation is meaningful for people with learning disabilities, or whether they remain encompassed within a eugenic sterilisation debate remains open to dispute.

1.viii. Conclusion

The influence of the eugenists on social policy in the U.K. and abroad has been outlined. It was first evident in British legislation in the Mental Deficiency Act of 1913. The eugenists were, however, unsuccessful in securing further legislation, although their ideas were undoubtedly popular. This was because they received support from eminent and wealthy individuals. Support also came from different sections of all the political parties and from a wide variety of organisations. The growth of their power was therefore multifaceted. The lack of valid scientific and reliable data to support eugenic claims revealed the inherent weaknesses in their philosophy.

Despite the popularity of eugenics, there was an undercurrent of opposition, the most resistant of which has emanated from the Catholic Church. It took an active role in lobbying against Sterilisation Bills in America. With regard to Catholic marriage, "Casti Connubii", the 1930 Papal Encyclical, condemned sterilisation. This inevitably influenced many Catholics against eugenic ideas. This opposition by the Catholic Church had long-term effects. In Britain, voluntary sterilisation was opposed until the 1970s with the Catholic Church actively pursuing its prohibition and continuing to advocate against it. A loophole has been created however by Pope Paul VI who claimed that "therapeutic means" of sterilisation are not "illicit" if they are "necessary to cure diseases of the organism, even if an impediment to procreation, which may be foreseen, should result therefrom" (*Humanae Vitae*).

Even as early as 1919, eugenic theory was not exempt from criticism. Fernald believed that the mentally deficient were not more fertile than the 'normal' population, but were perceived to be so because they had been grouped together with low economic status groups which tended to have larger families. Myerson supported this

theory, producing a study which revealed that mental deficiency was evident in all social classes in proportionate numbers (Reilly, 1987).

There were other critics of the eugenists such as Jennings and Muller in the 1920s and Haldane in the 1930s, although their criticism had little impact on popular opinion. In 1934 and in 1936, the American Neurological Association criticised eugenic sterilisation. It claimed that the large number of the mentally deficient was due to their increased lifespan. This, they stated, was due to improved medical care. The Association also refuted claims that this section of the population reproduced at a fast rate. Nevertheless, sterilisation operations continued unaffected. In the U.K. opposition to eugenic ideas came consistently from G.K. Chesterton and a growing number of the scientific community. Eugenic claims were treated sceptically by them as their knowledge in genetics increased. In addition, there was an increase in public awareness of human and civil rights. With normalisation came a radical development in societal attitudes to people with learning disabilities and dramatic changes occurred because of its influence.

Fundamentally, it affected ways of thinking about people with learning disabilities and the treatment they received. As a result, service provision changed and developed. Its influence was also apparent in different legal systems. Its all-pervading influence has had repercussions however. This is because tension and subsequent difficulties have been created between those who are imbued with normalisation and those who adhere to a superseded philosophy. It affects the professional-carer relationship and the relationships between professionals. These are examined in detail in later Chapters.

A historical viewpoint allows a clearer insight into how these relationships and their inherent problems have occurred. Furthermore, a historical viewpoint allows a

clearer insight into the predicament of the mentally deficient. This leads to an understanding of the present situation in respect of sexuality for people with learning disabilities. To the majority of the population, especially among the lower social classes, knowledge of and access to contraception was severely limited. Sterilisation, for contraceptive purposes, was legally prohibited in addition to its being socially unacceptable. It is interesting to note that in 1910 the "unions and the Labour party had promoted a birth control campaign, proposing that health visitors should instruct the poor in the means of limiting their families" (F.P.A., 1982). Despite Stopes' eugenic beliefs, her books, in particular "Married Love", and clinics helped to relieve many women of the burden of large families and the concomitants of poverty and hardship.

Although sterilisation as a form of contraception is now popular, most people undergoing the operation are in stable relationships and have completed their families. Only 1% of these operations are performed on single and younger patients. In the light of this, it is interesting that sterilisation for young, single people with learning disabilities is an option seriously considered by those who care for them (see Chapters 6 and 7). It is vital to note however that contraception is an issue of importance to this group within the population. "The Family Planning Service's motivation to be involved (in providing a contraceptive and well-woman service to women with learning disabilities) came from an increase in pregnancies amongst women with learning disabilities" as well as to accommodate "the needs of all women in society" (In Touch, 1995).

Trombley (1988) claims that sterilisation does not benefit people with learning disabilities, but that it relieves "the imagined burden of the fertility of the 'unfit' on those around them: parents teachers, social workers, heads of institutions, the medical profession, the state". Particular law cases in the U.K. will therefore be

examined in the following Chapter to ascertain if Trombley's statement is justifiable in the light of the criteria involved in the decision-making process regarding sterilisation.

Chapter 2

STERILISATION OF PEOPLE WITH LEARNING DISABILITIES:

An Analysis of Legal Issues.

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2.i. Introduction

The assessment of competency of people with learning disabilities and their legal capacity are central issues in giving valid consent to medical treatment. This Chapter will therefore examine the legal framework in respect of its protective role. This is with regard to the decision-making process involved in the sterilisation of people with learning disabilities. The concept of consent is of vital importance within this issue. It is, in fact, also essential to those in the 'normal' population. Particular cases demonstrating this will be discussed. This examination will highlight and clarify the complex and various issues involved. Ultimately, these have particular relevance for people with learning disabilities with regard to sterilisation.

English law cases concerning sterilisation of women with learning disabilities will be critically examined. Despite the differences in the Scottish legal system, these cases have provoked legal interest by serving to heighten the awareness of the difficult moral, ethical and legal problems which inevitably arise in such circumstances. Although there have been no similar test cases in Scots law, it cannot be assumed that they would have the same results as the English cases.

Compounding the complexity of the issue in Scotland is the possibility of substitute or surrogate consent being given by a tutor-dative. It is believed, however, that the revived ancient Scots law is "an imperfect stopgap pending reform" (Ward, 1991). It is therefore one which the Scottish Law Commission is presently reviewing with particular regard to the legal capacity of people with learning disabilities to give valid consent to medical treatment such as sterilisation.

Finally, there will be an analysis of the present situation in the light of the law cases studied and how this affects people with learning disabilities. It is pertinent to note that the law in the U.K. is rarely of an innovatory nature, instead changes are made as a consequence of societal changes or demands. However, the "present legal regime governing adults with mental disabilities is rooted in perceptions and social conditions of 150 years ago or more" (Ward, 1991). The law concerning sterilisation of people with learning disabilities and their ability to give valid consent, remains unclear. As exemplified in the previous Chapter, the general conditions and lifestyles of people with learning disabilities have changed dramatically over recent decades because of the principle of normalisation. The radical change in ideology and perceptions of learning disability have rendered a patriarchal and paternalistic legal framework archaic and obsolete.

2.ii. The Issue of Consent

The law acts as a form of social control. It applies to all citizens and, as a beneficial return, all citizens are protected by it. Some members of society, the severely learning disabled for example, receive additional legal measures to compensate for their vulnerability. Also, legal provision is made for the business and monetary affairs of anyone who is considered to have legal incapacity. In Scotland, for example, a curator bonis may be appointed by the Court to deal with such matters. In these instances the procedures are clear and unequivocal.

The situation becomes more complex when personal matters, such as medical treatment, arise. Usually regarded as a permanent state, sterilisation epitomises many complex issues and problems. Being such an important issue

therefore, it is vital that the individual concerned gives their consent to the operation. When the individual has a learning disability, the validity of their consent is crucial. In addition, a person's ability to withhold consent is also important. These factors are particularly relevant to people with learning disabilities because studies have shown that they are vulnerable to coercion and often respond submissively to authority figures (Rosen, Floor and Zisfein, 1974). Exacerbating these difficulties for people with learning disabilities is the abstract notion of sterilisation and its consequences. If, however, their consent to such an operation is accepted as valid, then it is lawful for the operation to take place.

It is the concept of legal capacity of people with learning disabilities which is one of the major problems concerning consent. Individuals with mild or moderate learning disabilities are in a different legal situation to those who have severe or profound learning disabilities. The latter group, for example, have complete legal incapacity and are therefore unable to give valid consent to sterilisation. It is unlikely that such an operation would be requested for non-therapeutic, that is contraceptive, purposes. This is for two reasons. Firstly, there is a high rate of infertility among this section of the population. Secondly, their condition usually only limits them to auto-erotic behaviour, thus making contraception unnecessary. The law does not recognise people with severe learning disabilities as having an ability to give valid consent in these circumstances. The legislation pertaining to this is contained in the Mental Health Act, 1983 and the Mental Health (Scotland) Act, 1984. A lacuna in the law is its obfuscation regarding boundaries between one category of learning disability and another.

Adults with mild or moderate learning disabilities have partial or full legal capacity, depending on the situation. Ward (1984) explains that the law "will define whether a particular individual has legal capacity

for one particular purpose, at one particular time, and in one particular set of circumstances." It is therefore difficult for accurate generalisations to be made regarding this section of the population.

Legislation which alters the legal status and rights of minors has been introduced in Scotland (Nichols, 1991). The Age of Legal Capacity (Scotland) Act, 1991 states that a medical treatment, if the child is able to understand both the nature and the possible risks of the treatment. Although it is not made explicit, it would seem possible that the child could withhold his or her consent. The problem inherent in this Act is the possible conflict which could arise between the child and his or her parent. Also, under the terms of this Act, it is not clear whether the same legal application could be made if the child had a learning disability. This could have serious ramifications if a petition for sterilisation was the cause of conflict. The legal status of minors with learning disabilities remains to be clarified in this case.

Consent is a "contemporary issue" (Bean, 1986). For the treatment of patients under the protection of the 1890 Lunacy Act, for example, consent was not deemed necessary. The influence of this state of affairs, however, can still be found in the present Mental Health legislation. The organisation, MIND, has campaigned against this and as a consequence the Government has accepted the notion of consent "as a worthy principle" (Bean, 1986).

Consent is a relevant issue in many different aspects of modern life, particularly in the sphere of physical contact both socially and medically. In the narrowest sense, any touching of another person's body without their consent can be construed as an assault. If this is interpreted literally, however, many social situations could create vast legal complications. Indeed, some social interactions require an element of physical contact, but this is socially acceptable and usually consensual. Elements of life in

public places, for example, may also involve physical contact which is accidental and as such is usually followed by an apology.

The essential meaning of consent is important, therefore, in that it protects individual bodily privacy and integrity. If self-determination is to be a highly esteemed value in society, it follows that individuals must have the opportunity to make their own decisions as far as possible. This is a particularly salient issue of concern to people with learning disabilities. In relation to the physical, Judge Cardozo (1914) reinforced this view in a Court of Law, saying, "every human being of adult years shall have the right to determine what shall be done with his own body." Medical treatment invariably involves physical contact which begins with an examination. In many of these instances, consent is not given explicitly, but is implied. Another example of implied or presumed consent is emergency treatment undertaken on an unconscious patient in order to save their life. Consent that has been refused can, however, be vitiated in order to save life or to guard against serious permanent injury or to avoid prolonged pain or suffering (Skegg, 1974).

If consent has not been given to medical treatment then in law this can be perceived as either a criminal offence or a civil wrong (tort), (Scottish Law Commission, 1991). The "common law has protected the personal and bodily interests of the individual through the law of trespass" (Bean, 1986). This can result in criminal proceedings against a doctor, for example, following charges of assault or battery. Damages may be awarded to the plaintiff if the case is proven. This situation was exemplified by a woman "who had been suffering from endometriosis, an ovarian illness, agreed to a hysterectomy after she was told by doctors she would never have children" (Nelson, 1993). During the operation the surgeon discovered that she was in fact pregnant and he aborted the foetus. The prosecuting counsel said, "He could have stopped there and

then, but he decided to proceed with the hysterectomy in the knowledge that it would have the inevitable consequence of terminating the pregnancy. He did it without her consent" (Guardian, 1995). The Crown Prosecution Service consequently accused the doctor, who was an obstetrician and gynaecologist, "of unlawfully procuring a miscarriage under the 1861 Offences Against The Persons Act, a charge which carries a maximum sentence of life imprisonment" (Guardian, 1995).

In some instances, consent cannot be given as a defence, for example, in the case of murder. In the U.K. euthanasia is a crime and is therefore another situation where consent cannot be given (McLean, 1986).

The tort of negligence is usually dealt with under civil law. If, for example, it is claimed that consent was obtained on the basis of insufficient information as to the risks involved, the doctor may be liable under the tort of negligence. It must be proved that the doctor was negligent in his duty of care. In these circumstances difficulties may arise if the doctor mistakenly assumes that the patient had received sufficient information to understand the nature and risks of the treatment. For litigation to be successful, it must be proved that the plaintiff would not have consented to the treatment had they been given the necessary information on which to base their decision. A doctor may be charged with negligence if a patient suffers harmful effects from surgery and had not been warned of the risks, despite the doctor not being negligent in the area of his surgical skills and care.

In *Bolam v Friern Hospital Management Committee* (1957), the plaintiff received electro-convulsive therapy (ECT) as treatment for his mental illness. The risk of fracture was not conveyed to the patient when he consented to the treatment. Evidence of such a risk was placed at "one in ten thousand". Manual control and relaxant drugs, which carried a mortality risk, were not used. As a result,

"the plaintiff sustained severe physical injuries consisting in the dislocation of both hip joints with fractures of the pelvis on each side which were caused by the head of the femur on each side being driven through the acetabulum or cup on the pelvis". As a consequence, Bolam sued the hospital concerned for negligence on the basis that no information was given to him regarding the risks involved and because relaxant drugs and manual control during treatment were withheld. The jury did not uphold his action, returning a verdict for the defendants. The reasons for this were that the possible risks of injury had been very small and it was believed that the patient had received appropriate medical care at all times. It was asserted that "we must not condemn as negligence that which is only a misadventure".

Although there was some difference of medical opinion as to the safest procedure of ECT, the hospital won the case on the basis that the doctors were acting "in accordance with the standards of reasonably competent medical men at the time". The importance of this legal case lies in its clarification of aspects of medical negligence. It also predicates the issue of consent to medical treatment in the U.K. A doctor, for example, is not necessarily being negligent if he fails to provide information to the patient concerning all the risks inherent in the proposed treatment. This is a particularly salient point which can have serious ramifications for a patient with a learning disability. The disadvantages for such patients are exacerbated in that they may lack the necessary skills to enquire of the risks or side-effects of the proposed treatment. They are also less likely to question the authority of medical opinion within the imbalanced power structure of the doctor-patient relationship.

One of the problems facing doctors is that of giving information of the possible risks to patients, which could lead to their refusal of beneficial treatment. In *Chatterton v Gerson* (1981) legal proceedings were taken

against the doctor and the hospital for trespass and negligence. Chatterton claimed that she had not been given full information of the risks involved in her treatment. Prior to the treatment she had been experiencing "chronic intractable and unendurable pain in a post-operative scar in her right groin". To relieve the symptoms, she underwent two similar operations. The latter resulted in the loss of sensation in her right leg and no relief from "acute agony in the scar area". The plaintiff could not prove that she had not been warned of the risks and unfortunately, the surgeon was deceased at the time of the litigation. The impression was of someone "desperate for pain relief" and, had she been aware of all the possible risks "she did not say she would have refused" treatment. Chatterton consequently lost her claim for damages. Both this and the case concerning Bolam demonstrate the possible interpretations of consent.

Kloss (1965) believes that such litigation in the U.K. is discouraged because a consent form must be signed prior to medical treatment. This view is also asserted by Brazier (1979) who reports that the Health Service Commission receives numerous complaints by patients that they have not been informed of risks before giving their consent. The amount of information given relies on clinical judgement, or what otherwise is known as a doctor's "therapeutic privilege" (Robertson, 1981). To some degree such a privilege protects the medical profession from serious litigation. This situation differs from that in the U.S.A. As a result of the "contractual relationship" ethos in America within the medical profession, there are larger numbers of legal proceedings taking place in the U.S.A. than in the U.K. (Kloss, 1965). This could adversely affect doctors' prognoses, leading them to be over-cautious for fear of litigation.

In the U.K., patients are given information regarding treatment according to a "professional medical

standard", not according to a patient standard, as pointed out by Dodd, Donegan, Kernohan, Geary and Mollan (1993). If additional information is required, then it is the patient's responsibility to request it. Articulate middle-class patients would have less difficulty in this situation than working-class patients and those who are less articulate, for example, people with learning disabilities. This is because they would be more likely to request information. As Le Grand (1982) states, there is evidence "to support the view that there are considerable problems of communication between working-class patients and doctors". These problems could be exacerbated if there were also ethnic and racial differences.

There is a legal requirement, however, to inform patients of risks of medical treatment. In situations where the risks are considered minimal or controversial, it would ultimately be for the Court to decide whether the responsibility of disclosure had been neglected. Kloss (1965) believes that the greater the risks are, the greater is the requirement to inform the patients of such risks. Clearly the reason for this is to "enable (the patient) to decide whether to undergo that treatment" (Jackson and Powell, 1982). Bean (1986) agrees with this view claiming that there exists a "moral commitment on behalf of the professionals and others to enable genuine consent to take place." McLean (1986) also believes that there is a "moral duty" to give information to patients. Although the law does not stipulate minimum requirements regarding the level of information, there is a consensus of opinion regarding a moral obligation of doctors. Brazier (1979) sees this moral obligation as an integral part of the duty of care.

Ironically, the justification for withholding information is encapsulated within this concept of moral obligation. It is based on the premise that certain knowledge of risks could cause distress to the patient and lead to

refusal of treatment, as referred to earlier. The burden of responsibility in assessing a patient's state of receptivity to information regarding risks is disputably in excess of the doctor's duty of care. Brazier (1979) predicates the view, however, that the "condition of the patient and his capacity to judge what he is being told must be relevant in the reaonable exercise of the doctor's judgement as part of his duty to the patient". The Royal College of Psychiatrists (1986) believes that it is within the duty of care of a consultant psychiatrist to decide whether or not an individual is capable of understanding the implications of giving consent.

Jackson and Powell (1982) reaffirm the issue regarding limited disclosure of information, stating that there is "not a duty to warn the patient of every risk", nor is there a "duty to give warnings or explanations to a patient whose condition is such that he would not understand them". In this instance, the power of choice lies with the doctor and not with the patient. The concepts of autonomy, self-determination and privacy are eroded with the ideology that the medical profession is justified in assuming a paternalistic role. Jackson and Powell (1982) exemplify this role saying that the "medical practitioner may find it necessary on occasions not merely to withhold the truth, but to tell a positive untruth". They demonstrate this paternalistic situation with the legal case *Hatcher v Black* (1981) where "Denning L.J. directed the jury in strong terms that they should not regard this (untruth) as negligence". In *Chatterton v Gerson* (1981) it is clearly stated, that "if information is withheld in bad faith, the consent will be vitiated by fraud". The doctor therefore has freedom of choice in the amount of information he discloses to the patient and whether or not it is truthful. A Court of Law retains the ultimate power to decide, however, whether or not such information is sufficient in the circumstances and whether or not it has been given in good faith.

The doctrine of 'informed' consent is particularly controversial in the U.S.A. Although the term does not have the same legal recognition in the U.K., there is evidence to suggest that this situation is changing (Re D (A Minor) 1975; Sidaway v Board of Governors of the Bethlem Royal Hospital (1985)). In the U.S.A., informed consent is accepted legal terminology. It requires full information of proposed treatment, with all the inherent risks involved being given to a patient. Breach of this duty to inform vitiates consent and it can therefore be construed as negligence.

In Sidaway v Board of Governors of the Bethlem Royal Hospital et al (1985), the case rested on whether or not the surgeon had informed the patient, Amy Sidaway, of the inherent risks of her proposed medical treatment. As a result of her operation, she was severely disabled. In giving her consent, the plaintiff had not been aware that the operation was not essential treatment. The medical procedure involved "a 1 per cent risk of paralysis" (Brahams, 1985), which, with the risk being slight, would not normally under U.K. law have obligated a doctor to disclose this fact. The Sidaway case therefore invoked "the transatlantic doctrine of informed consent". The questions were thus raised in the House of Lords:

"Has the patient a legal right to know,
and is the doctor under a legal duty to
disclose, the risks inherent in the treatment
which the doctor recommends? If the law
recognises the right and the obligation,
is it a right to full disclosure or has the
doctor a discretion as to the nature and
extent of his disclosure?"

While the Law Lords accepted that patients have a right to make a final decision regarding treatment that involves "disadvantages or dangers", the doctor retains his prerogative in deciding "what should be said and how it should be said" to the patient. It was found therefore that the doctor in question had not been negligent because "he acted in accordance with the practice accepted at the time as proper by a responsible body of medical opinion." This was in accordance with the 'Bolam' test and as a consequence the case was dismissed.

In the U.K. consent cannot be described therefore as a single doctrine. Indeed, both Skegg (1975) and Robertson (1981) believe the concept to be complex because it depends on various levels of information. Robertson refers to the 'Canterbury' test as taken from the case *Canterbury v Spence* (1972). The Court recommended a more objective perspective on what could be considered adequate information on which to base a decision to consent. "The test of materiality (that is, what risks a person would perceive as important), and hence disclosure, is not whether the patient himself would have attached significance to the risk, but rather whether a reasonable person in the patient's position would have done so".

The amount of information regarding medical treatment and the way in which it is conveyed to the patient, without fraud or coercion, for example, constitutes one section of the tripartite nature of consent (Kanjilal, 1989). The remaining two sections constitute the understanding of such information and the response to that information, that is, the actual consent itself. Skegg's view of consent adds a further dimension to this concept. He believes that it is important to take into consideration the patient's ability to understand the information given. If there is sufficient reason to doubt this ability, for

example, the patient has a learning disability, then it ought to be within a doctor's duty of care to ensure that remedial care is taken of this problem.

Consent is not an amorphous concept. For it to be meaningful, it must have an object, that is, consent can only be given for a specific act. In their examination of consent, Meisel, Roth, and Lidz (1977) extrapolate necessary aspects of consent such as "voluntariness", "provision of information", "competency" and "understanding". They also discuss what they describe as 'objective' and 'subjective' models. If consent is given voluntarily and is based on sufficient information, the 'objective' model accepts the decision depending on how closely the individual corresponds "to an objectively reasonable person", so that their "actual understanding does not affect the validity of the decision."

Alternatively, the 'subjective' model depends entirely on the individual's understanding of the treatment and risks involved. This reflects Skegg's idea. In this model, whether or not the individual has an adequate level of comprehension is a decision made by the doctor. Roth et al (1977) accept that this "determination may be extremely difficult to make in practice". Mencap (1989) dispute that such a decision should be made by one person and recommend that a multi-disciplinary team be established for such a purpose.

The 'subjective' model more successfully preserves the autonomy of the individual than the 'objective' model. The Department of Health and Social Security in England and Wales follow the 'subjective' model. Consent is accepted as valid if an ability "to understand the nature, purpose and effect of the proposed treatments" is perceived in the patient (Bean, 1986). Thus competence is an essential element of the doctrine of consent.

2.iii. Competency and Learning Disability

Receiving information alone is not necessarily an adequate basis for giving consent. There must be sufficient processing of that information to be able to make a reasoned choice or decision. The Scottish Law Commission (1991) affirms this, categorically stating that the "capacity of a patient to give effective consent depends on his or her ability to comprehend, from information supplied by the doctor or others, the nature of the proposed treatment and its effect and risks, to come to a decision and to communicate that decision to the doctor".

Bean (1986) describes this capacity as "a level of responsibility, for consent cannot be given by someone....who is unable to make meaningful decisions". This process of understanding is inextricably linked with the level of the patient's knowledge of the options available. Mencap (1989) describes 'competence' as the understanding of the reasons why treatment is proposed, in addition to its nature, benefits and risks. Also included is the comprehension of the possible consequences of not receiving treatment.

The final outcome, that is, the resulting decision, cannot, in itself, be an indication of competence. Melton and Scott (1984) agree with this view, saying that this "approach to a validity of a decision is least respectful of individual autonomy in that 'reasonableness' is in the eye of the beholder." Mencap (1989) also reject this notion of incompetence which may be claimed if an individual "makes a health care decision that reflects

values not shared by the carers, or that rejects conventional wisdom about proper health care". They recommend that a person should be deemed competent to make personal decisions regarding medical treatment if that person demonstrates an "ability to function as an adequately thoughtful decision-maker".

Melton and Scott (1984) state that there is "no research on the reliability and validity of evaluations of competence to consent to sterilization". There are, however, certain criteria that may help to distinguish between those who are and those who are not deemed competent. Roth, Meisel and Lidz (1977) examine the factors delineating competency. These are "tests for competency" which include the capacity to comprehend the information regarding the nature, benefits and risks of the proposed treatment. They admit that what actually constitutes understanding is, at best, vague. They also conclude that if understanding is lacking, it could be attributable to the way in which the information was conveyed by the doctor.

Appelbaum and Grisso (1988) also prioritise the individual's ability to understand the information as a sign of competence. They suggest that to test this ability would require the patient to paraphrase the information. This also tests memory. They recognise, however, that the "ability to understand cannot be equated with the extent of one's vocabulary." This is a particularly salient point with regard to people with learning disabilities.

Another indication of competence is that of expressing or indicating a preference. The abilities to choose and to make decisions must essentially be free from the coercive actions of others. Roth et al (1977) advocate a test for competency being "set at a very low level and (being) the most respectful of the autonomy of patient

decision-making". The communication of consistent choices is not necessarily a prerequisite for an indication of competency. It is acceptable that a person can change his or her decision, although frequent and irrational changes in decision could indicate some impairment of the patient's mental state. High anxiety levels, for example, can adversely affect the competence of individuals, resulting in "pseudo-incompetency" (Appelbaum and Roth, 1981). Macklin and Gaylin (1981) believe that competence varies according to several factors. These include the type of decision to be made, the person's age, other "transient conditions involving emotional or motivational variables" and whether or not the individual can be trained to be competent. Appelbaum and Grisso (1988) claim that the ability to make decisions can also be affected by other "unrelated factors such as fatigue, the effect of medications, or the occurrence of an unpleasant event immediately before the evaluation". This reinforces the idea that competence, as with other mental states, is not a static fixed phenomenon. This is an important point because it is in direct contradiction to the legal perception of competency.

The Committee on Bioethics (1990) explains further that the "impairments of communication skills and mental abilities" of people with learning disabilities "vary from person to person and in the same person over time." It thus recommends "multiple interviews" in order to assess their decision-making competence, a view also advocated by Appelbaum and Roth (1981) and Appelbaum and Grisso (1988). There is no evidence to indicate that this procedure has taken place in any of the U.K. legal cases regarding sterilisation of women with learning disabilities. These will be referred to later.

Similarly, the process by which a decision is made can also be used as a measure of competence. This aspect focuses on the reasons for choice and the underlying

rationale. Inherent difficulties lie with this, because the choice or decision which is made may not necessarily be the result of the specific rational reasons. Roth et al (1977) warn of the dangers of such "emphasis on rational reasons" because it can too easily justify "widespread substitute decision-making" for people with learning disabilities.

Finally, an indication of competence is revealed in the resultant decision. If it is one which is close to, or the same as, a decision which would be made by a 'reasonable' person in similar circumstances, then it would be regarded as competent (the 'objective' model). As Roth et al (1977) affirm, the "benefits and costs of this test are that social goals and individual health are promoted at considerable expense to personal autonomy". It would also be difficult to ensure that a patient with a learning disability had arrived at their decision freely. This is of particular concern as studies have shown that generally they are vulnerable to coercion, often submissive and anxious to please others, especially those in authority, as mentioned earlier (Rosen, Floor and Zisfein, 1974).

Difficult problems consequently surround the subject of competence. Although competency and consent are closely inter-related, it is not clear what levels of competence are actually required in the decision-making of people with learning disabilities regarding sterilisation. What is clear, however, is that higher standards of regulation are deemed necessary for this group of people than with the 'normal' population. There is no consensus as to who should decide matters of competence. Melton and Scott (1984) refute that such determination should be made by individuals in the medical profession because it involves legal and ethical considerations. They recommend that "an interdisciplinary team" be used for this purpose. The Committee on Bioethics (1990) recommends the identification of "personnel who are familiar with the individual patient

and who are experienced in communication with persons with diminished mental capacity." Mencap (1989) further extend this idea with the suggestion of an "ethics committee" to decide issues of competency. They suggest that this committee consist of several people mainly from the Health and Social Services, but, notably, Mencap makes no reference to any legal representation.

If it is unequivocal that a person with a learning disability is *sui juris*, or incompetent to give valid consent to sterilisation, then the question is raised regarding substitute or surrogate consent. Essentially this is an issue for the Courts because it is an area where the legal authority of parents, guardians or tutors-dative has not been clarified. Ward (1990) warns that parents of minors with learning disabilities ought not to assume that they have complete jurisdiction over their children. The legal authority of parents lessens as their child's competence increases. This is clarified in the Age of Legal Capacity (Scotland) Act, 1991. In England, a minor can be made a Ward of Court under the *parens patriae* jurisdiction. This jurisdiction does not now extend after the age of majority (F v West Berkshire Health Authority, 1989).

The statutory guardian in England and Scotland has an "interventionist role" (Ward, 1990) and cannot give consent to medical treatment such as sterilisation. At present, in England, there is no provision for any individual to be given authority to consent to sterilisation on another person's behalf. Any request for sterilisation of a person with a learning disability must therefore go to a Court of Law. The situation differs in Scotland. This is because of the law concerning tutors-dative, which was revived in 1986. The term was originally 'curator-dative' and dates from the fifteenth century. Tutors-dative differ from tutors-at-law in that they do not have to be related to

the person with a learning disability, but, similarly, they must be appointed by a Court of Law.

Unlike statutory guardians, tutors-dative can give consent to medical treatment. There is doubt whether their consent is now legally valid if it concerns treatment such as sterilisation. Thomson (1988) believes that the "approval of the Court of Session may be necessary before a tutor-dative can validly consent" to sterilisation. However, such consent has been given in the past for this operation. According to Ward (1992) there have been at least two cases and in each "the petitions were granted without any hearing or discussion". Concern has been expressed at this because the operations were requested for social rather than for medical reasons. Also, in both cases there were "signs of sexual awareness", but there was no evidence of any sexual relationships in either of the cases.

In the proposed draft of the Dependent Adult Act there is a clause recommending "the right to consent to any health care that is in the best interests of the dependent adult" (Ward, 1987). This would apply to contraceptive use, including sterilisation. Nevertheless, the legal situation remains to be clarified and, at present, the Scottish Law Commission is reviewing the system. For non-therapeutic sterilisation, it states that the "consent of a tutor-dative, relative or personal guardian should not be sufficient" (1991). It is in this lacuna of law and social policy throughout the U.K. that the legal test cases arise.

2.iv. English Legal Test Cases

To describe a person with a learning disability as having a particular mental age is misleading. It is often the case that their mental age is younger than their

chronological age. This serves to reduce societal expectations of them in respect of their capacity for autonomy. It is also misleading and inappropriate to compare adults with learning disabilities with normal children. As Khan (1985) points out, the aspirations of these two groups differ because of "their biological and social development", which for adults includes the emotional and physical "desire for sexual relations". This is only one of the differences that Khan identifies, but one which is relevant in this context. It is also notable that a learning disability can be ameliorated to some degree through a gradual process of maturation, training and education. "Studies have shown that IQs (can) change...in the direction of improvement" (Money, 1973).

It is therefore interesting to examine the legal cases where these factors have not been considered in any depth and where assumptions have been made regarding the future abilities of individuals with learning disabilities. Some of these assumptions disregard the possibility of improvement in and the "critical autonomy" (Doyal and Gough, 1991) of the person with a learning disability. The first and earliest case to be examined reveals however a more liberal and optimistic attitude towards learning disability.

a. Re D. (A Minor) 1975

An eleven year old girl, D, "had a dull normal intelligence" and suffered from an obscure causal group of congenital abnormalities called Sotos syndrome. Sterilisation was sought on her behalf by her mother, who feared that D might become pregnant. It was the doctor's clinical judgement that recommended an immediate operation, rather than waiting until D was eighteen and no longer a

minor. The basis of this proposal was on medical and social grounds. These included the possibilities of a baby inheriting D's genetic disorder, D's incapacity to care for a baby, and the ineffectiveness and unsuitability of alternative forms of contraception.

Although it was stated that D "would have sufficient capacity to marry", the social grounds for sterilisation were that she would not be able to cope with a family of her own and that, without support, her behaviour would probably deteriorate. According to her doctor, this would result in her being institutionalised "for social and criminal reasons in the future". D was made a Ward of Court. This then meant that the consent of the Court was required for sterilisation to take place.

In her judgement, Judge Heilbron stated that D was unable to give consent, but would probably be able to do so by the time she attained her majority. This is a positive assessment of 'future consent'. Also, at the age of eleven, D was not showing signs of sexual interest and her "opportunities for promiscuity (were) virtually non-existent". Judge Heilbron clearly stated that the decision for non-therapeutic sterilisation could not be "within the doctor's sole clinical judgement". It was therefore declared that the operation was neither therapeutic nor in D's best interest. It could also "have a serious and material bearing on a future marriage and its consequences". This type of situation occurred in the U.S.A. in 1978. Litigation was pursued by a woman with a learning disability who had been sterilised without her consent (*Stump v Sparkman*).

More importantly, Judge Heilbron described the proposed operation as involving "the deprivation of a basic human right of a woman to reproduce, and, therefore, it

would be, if performed on a woman for non-therapeutic reasons and without her consent, a violation of such right". The operation was consequently prevented from taking place. This ruling by a female judge was later referred to in a similar case involving sterilisation, but was rejected by the male judge concerned. In the resulting analyses of these cases there have been no references to the gender of the judges. Taking into consideration that each individual carries a personal set of values and attitudes which affect their perception, it is possible that even among judges there exists gender bias. A female judge may have a more empathic attitude to the rights of women to reproduce, regardless of a learning disability.

b. Re B. (A Minor) 1987

Prejudices are revealed when the cases of Gillick v West Norfolk and Wisbech Area Health Authority and Re B (A Minor) are compared. The former case reinforced parental control over contraceptive services for minors. Although after this case it was clear that parents could not assume "unlimited right to decide on whether their children may receive any medical treatment" (de Cruz, 1988). The latter case denied such parental control because the Court took the responsibility in permitting the sterilisation of a minor with a learning disability. Lee and Morgan (1988) assert that "mentally handicapped young women (are treated) in a manner quite distinct from other young women". They go on to say that this could result in a different legal process being established "for women whose understanding of contraceptive treatment is impaired by a lack of maturity, compared with those impaired by disability".

The controversy over parental rights also exists in the U.S.A. An example of this is the legal case A.L. v G.R.H. (1975) where a petition for sterilisation was sought by a mother on behalf of learning disabled 15 year old son, but was refused (Dickens, 1982).

In the U.K., a request for sterilisation was sought for B, a 17 year old minor with a moderate learning disability. Her mental age was claimed to be about five or six. She could not give consent to the operation and was consequently made a Ward of Court under the *parens patriae* jurisdiction. The case went to the House of Lords, where Lord Hailsham admitted that there was "some doubt whether some residual *parens patriae* jurisdiction remains in the High Court after majority". Lord Justice Dillon claimed that there was no statute or common law power of the Court to consent to sterilisation after the age of majority (Dyer, 1987). This is a matter of crucial importance because if the *parens patriae* jurisdiction did not exist after the age of 18, in English law no person would be able to give valid consent to B's sterilisation. Lord Hailsham denied that this factor had any effect on the ruling of this case. Despite his assurances, the entire case, through the High Court, Court of Appeal and the House of Lords, took only a matter of three months, and closed less than three weeks before B attained her majority. It is interesting to compare this time span with a similar case, heard in the Supreme Court of Canada (Re Eve) which took seven years to complete.

One reason for sterilisation was the claim that other contraceptive measures were medically unsuitable for B. There were no indications of a sexual relationship, although it was claimed that she exhibited a "normal sexual drive and inclinations". Lord Hailsham stressed that B did not understand and could not link the act of sexual intercourse with pregnancy and childbirth. The absence of sex education for B was not queried, although it is possible

that this would have solved the problem of B's lack of understanding.

Due to her obesity and the irregularity of B's menses, Hailsham also believed that it would be difficult to detect an early pregnancy, which would give the option of an early abortion. Her unpredictable mood changes and outbursts of violence had earlier resulted in the administration of an oral contraceptive, Microgynon 30. This stopped because it had resulted in an increase of her weight. However, her treatment indicates a contradiction to statements made in the case concerning the difficulty, if not impossibility, of administering contraceptive pills. In Court, it was not explicitly stated that B had already been on a course of contraceptive pills. Testing for an alternative contraceptive chemical was estimated to take between 12 and 18 months. This could still prove unsuitable for B and the option was discounted.

Another contradiction in the evidence given for sterilisation was B's predicted trauma of the "pains of pregnancy". Presumably this refers to childbirth. Lord Oliver of Aylmerton described the "behavioural feature of significance (of B) is her high tolerance of pain". He claimed that B could bite herself and prevent wounds from healing by opening and probing them. Medical evidence suggested that B would panic during childbirth and thus require heavy sedation. Vaginal delivery would therefore be unsuitable for a baby and a Caesarian section would be necessary. It was feared that B would interfere with the healing process of her resulting wound. However, with her high pain threshold, it would appear that childbirth would not cause B undue suffering. This aspect was not mentioned in Court.

In summary, pregnancy for B would be an "unmitigated disaster" (Lord Bridge of Harwich). Other statements were made to reinforce the argument that B should be sterilised by consent of the Court. Examples of these were that B had no maternal instincts and would never have the capacity to experience them in the future, that she had no desire to reproduce and that she was unlikely to be able to care for a child.

In the light of historical events, there is an inevitable ideological association between non-therapeutic sterilisation and eugenic theory. Lord Hailsham emphatically strove to deny that their ruling had any eugenic implications. Lord Bridge of Harwich also stressed "that this case has nothing whatever to do with eugenic theory". He also denied that their judgement in the case had any consideration for those caring for B because it was entirely the promotion of her "welfare" and "best interests" that concerned the Law Lords. They compared this case to the Canadian Case, *Re Eve* (1986) and refuted the relevance in distinguishing between therapeutic and non-therapeutic sterilisation. The judgement regarding B was based on the 'welfare principle'. The case *Re D* (1976) was also referred to regarding the right to reproduce. Lord Oliver of Aylmerton claimed that "the right to reproduce is of value only if accompanied by the ability to make a choice". According to de Cruz (1988) this argument "is neither logically sound nor morally tenable". He refers to the rights of children where the existence of some of their rights depend on parental duty and not on the child's appreciation of those rights. Similarly, B's "basic human rights should exist regardless of her capacity to appreciate them". Referring to the sterilisation petition regarding Lee Ann Grady in the New Jersey Supreme Court, Lottman (1982) also states that the "entitlement to the full panoply of human rights does not depend upon their ability to articulate or even understand those rights".

The Law Lords' approach to the problem in the 'B' case consisted of possible risks and consequences. They emphasised B's vulnerability and decided that she would be incapable of future consent, thus negating any possibility that she could develop or mature at a later stage. In the jurisdiction of *parens patriae*, the Court consented on behalf of B to her sterilisation. The case received much publicity and was criticised for its short duration. It is possible that had the case taken longer, which would have allowed a more thorough investigation, anomalies in the evidence might have been resolved, resulting in a different outcome.

Lord Oliver made the assurance that the case involved "no general principle of public policy." Hinchliffe (1987) reinforced this, stressing that the ruling was not to be interpreted as a 'charter' for treatment of people with learning disabilities. Taking an opposite view, Edwards (1987) claimed that the case set a precedent in the prevailing vacuum of legislation. This case revealed that consent to sterilisation of a minor with a learning disability could be given by a Court if it was agreed to be in the minor's best interests or welfare.

Lee and Morgan (1988) criticise the Law Lords' decision as being one based on convenience and inextricably linked to a covert social policy. They claim that sterilisation was the most convenient method of dealing with B's sexuality and was recommended because of the "lack of effective strategies within the budgetary constraints of the community care programme". This view is reiterated by Heginbotham (1987), who believes that the case demonstrates "how the lack of appropriate services leads to demands for such extreme measures". This political interpretation was

notably overlooked by the media, which at the time expressed a keen interest in the case of B.

There are further implications in a case such as this. Questions have arisen which remain unanswered. Examples include, in what circumstances should there be Wardship and who should assume responsibility for the Ward, namely the parent, doctor, local authority or Court. The best interests and welfare concepts remain vague and can possibly result in discriminatory action. de Cruz (1988) believes that "clearer legal guidelines will be the only safeguard for the protection of the basic human rights of all those who are unable to look after themselves".

c. F v West Berkshire Health Authority (1989)

The case of F v West Berkshire Health Authority concerned a petition for sterilisation of a 36 year old woman, F, who had a 'serious mental disability'. This case differs in two fundamental ways from the previous cases in that the woman concerned was over the age of majority and, secondly, because she was involved in a sexual relationship. Other forms of contraception for her were considered unsuitable. It was claimed that she would not be able to cope with pregnancy, nor would she be able to care for a child. Such a situation would be "disastrous" for her (Lord Brandon of Oakbrook). Sterilisation was therefore proposed, but F was unable to give consent to the treatment. The Court ruled that it could not give consent on her behalf, as in 'Re B', because she was over 18 years old and the *parens patriae* jurisdiction could not be applied. In this situation it appeared that sterilisation could never be deemed lawful, but this was unsatisfactory. The Court, applying a wide interpretation of the necessity principle, claimed that if

the operation was performed in the best interests of the patient, it would not be unlawful.

Lord Brandon questioned the Court's involvement, its jurisdiction and procedures in this matter. He summarised the Court's involvement as being a "matter of good practice" rather than being "necessary as a matter of law". This would be to ensure that the best interests of F were being served and the 'Bolam' test could be applied to the case. This meant that what was "accepted as appropriate treatment at the time by a reasonable body of medical opinion skilled in that particular form of treatment" should be lawful. A Court's ruling would lessen the risks of such treatment being performed for "improper reasons or with improper motives". Court involvement could therefore play a protective role in safeguarding a disabled woman's right to reproduce. More poignantly, it would serve to protect the medical profession from possible negative criticism and, more importantly, from litigation claims.

Lord Griffiths believed that to perform such an operation in these circumstances, the High Court must first give its consent. He conceded however, that this would in fact be making a new law and therefore approval of the Court would suffice. Although this would not be obligatory in law, it would certainly be considered 'good practice'. In the case of F, the Law Lords ruled that it would be in her best interests to be sterilised. By this ruling, the welfare principle was applied. It extended the principle of necessity, in which case does not require the consent of the patient. Ashton and Ward (1992) describe necessary procedures as ones that "save life or....ensure improvement or prevent deterioration in physical or mental health".

Lord Brandon defined as necessary that which "the general body of medical opinion in the particular speciality

would consider to be in the best interests of the patient". This is clearly a case of medical paternalism, the justification of which ought to be more closely scrutinised when it results in the denial of the reproductive rights of women with learning disabilities. In the F case, Lord Brandon refers to consent given by guardians. As noted earlier, guardians are unable to give substitute consent to medical treatment. The assumptions made in the F case are consequently and, according to Ward (1990), "factually wrong".

There have been no test cases of this nature in Scots law, but the significance of the English cases has been acknowledged. Ashton and Ward (1992) claim that while the F case "may be referred to in Scotland, the Scottish courts may interpret it more restrictively: they are most unlikely to go further than the English test." Certainly, until there is satisfactory legislation catering for this need, it is recommended throughout the U.K. that approval of the Court be sought before sterilisation is performed. The protection of the right of the learning disabled to reproduce must be balanced against their right to be sterilised. These options are open to the normal population but if they are to be denied to others it must be adequately and morally justified. Care must be exercised so that the law, according to Lord Jauncey of Tullichettle, does "not convert incompetents into second class citizens" by denying them appropriate medical treatment.

2.v. Implications of Legal Cases.

Because there has not been specific legislation in this area, it has been the Courts' responsibility to

interpret the evidence of each case. This has proved to be unsatisfactory and therefore recommendations are presently being reviewed by the Scottish Law Commission.

The Law Lords' decisions have been conservative to the point of reneging on the opportunity to challenge the law. The result of the 'F' case, has, however, altered the interpretation of the principle of necessity to the wider connotations of 'best interests'. This solved their immediate decision-making problem, but has implications for other sterilisation operations and other medical treatment such as abortion. The ruling in a case concerning the legality of an abortion for a woman with a learning disability, stated that "it was not essential as a matter of practice to seek a declaration from the High Court" (Times, 1991). The Courts have said that such treatment performed in the best interests of the patients is lawful and that it can be consented to by a doctor without time-consuming Court involvement in every case. This is important regarding abortion, where the age of the foetus is of vital concern.

Therapeutic treatment is considered to be in the 'best interests' category. Further complicating the matter is where treatment is carried out, not for the sole purpose of sterilisation, but results in infertility as a side-effect. An example of this is therapeutic hysterectomy, which is "to relieve extremely distressing symptoms" such as "extremely heavy and erratic menstrual periods" (Times, 1991). In a case reported in "The Times", infertility was a result of the proposed operation. Nevertheless, a prior declaration by the High Court was not deemed necessary in this case. Parental consent on behalf of their minor daughter with a learning disability, was accepted as legally valid. A similar situation was reported in the F v F case (Times, 1991) when two gynaecologists advised that hysterectomy would be "in the best interests of the patient for therapeutic reasons". These situations have created a

legal loophole, where women with learning disabilities can, in effect, be sterilised without their consent, or even knowledge, and without legal safeguards.

It is interesting to note that such a distinction between therapeutic and non-therapeutic sterilisation is not made in South Australian legislation. If medical treatment incidentally results in infertility, that treatment is not differentiated from non-therapeutic sterilisation. In the U.K. this type of situation would necessitate stricter controls over medical practice and it would depend on a supportive legislative network for its successful implementation.

In cases regarding sterilisation for people under 18 years old, it is recommended that there be High Court involvement. In situations where a patient with a learning disability is over 18 years old and unable to give valid consent, it is recommended that a petition be made. However, which treatment is to be regarded as therapeutic as opposed to non-therapeutic, and the vagueness surrounding lawfulness of the treatment, has placed many doctors in a dilemma, as referred to earlier. This is made apparent by the Medical Defence Union and the Medical Protection Society each receiving "about one enquiry a month on this subject" (Dyer, 1987). These organisations have advised doctors to work under the 'best interests' ethic only until it has been made absolutely clear that sterilisation on social grounds is lawful.

In all the cases considered, the High Court has stressed that treatment should only be considered in the best interests of the patient and not the carers. Ward (1990) contests this, believing that parents, or other carers, should be taken into consideration in a decision regarding the proposed sterilisation of a woman with a

learning disability. The argument for the reproductive autonomy of such women fails when advocates of their rights take this stance. As justification for his view, Ward claims that the burden of any possible offspring would probably lie with the grandparents. Social policy, as with legislation, could alleviate such burdens if specifically designed to do so.

Further philosophical problems arise concerning the children of parents with learning disabilities. An example of this is a notion of a right not to have a learning disabled parent (Macklin and Gaylin, 1981). Elkins and Andersen (1992) also explore this idea of the "best interests of fetus or offspring". In the present climate this has wide implications with widespread occurrence of the acquired immuno-deficiency syndrome (AIDS) virus.

The issues addressed by the Court cases concern only women and their reproductive 'rights'. It is of fundamental concern and is no less important because it involves women's bodily integrity, privacy and reproductive capacity being decided by men. Inevitably, it is a feminist issue in the face of medical and legal paternalism. Male judges have claimed that pregnancy and childbirth would be psychologically harmful to specific women with learning disabilities. In these circumstances, no account was taken of the possibility of psychological harm that could result from infertility. In the 'F' case this was especially relevant because she was involved in a sexual relationship. Edgerton's study (1967) revealed that many people with learning disabilities regretted having been sterilised because they expressed desires to have children after having found a sexual partner. Also sterilisation carried a stigma, because it was a sign that the individual had been institutionalised at a time when this operation was performed as a prerequisite to release into the community.

People with learning disabilities are recognised as sexual beings, at least through the process of law. The question of their experiencing parental desires has not been addressed to the same extent. This leads to the problem of whether such emotions are psychologically or physically based, or indeed a mixture of both. There has been very little research into emotions and people with learning disabilities (Strongman, 1985).

Although these cases all concern women, the English Law Commission has made some concession towards the legality of sterilisation of men with learning disabilities who are unable to give consent. It is rare for sterilisation to be considered in their best interests, but, nevertheless, it is proposed that this treatment be included in a special category making the provision legal.

2.vi. Conclusion

The existing legal situation has been examined with its implications for people with learning disabilities and the medical profession. The situation is clearly unsatisfactory where the lawfulness of sterilisation depends on a doctor's opinion of the patient's best interest. This medical paternalism is probably less desirable than legal paternalism in that there are no opportunities for a hearing or an appeal. There are also ethical considerations involved when decisions are made on behalf of another person, because there is a risk that "when we seek to do good we risk harm" (Manning, 1989).

It is possible that reliable reversible sterilisation will be established in the future. This may be conditioned by the changing nature of marriages and family life, with divorces and re-marriages increasing. This would help to alleviate moral problems in decision-making of contraceptive methods for people with learning disabilities.

For the present, however, the valued issues of autonomy and self-determination have yet to be reconciled with societal attitudes to people, especially women, with learning disabilities. This will be explored later, within the context of ideologies of care for people with learning disabilities.

PAGINATION AS IN ORIGINAL

Chapter 3

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3.i. Nomenclature

The terms used in this study to describe groups of respondents are of a generic nature. For clarity of meaning therefore a fuller explanation of them is necessary. The term 'parent' includes other carers of people with learning disabilities. For brevity the term 'parent' is most frequently used, although it is occasionally substituted by the term 'carer' in some specific examples.

The term 'professional' is used to include staff at Adult Training Centres, or other establishments under the control of the Social Work Department. It also includes other social workers professionally involved with people who have learning disabilities. The terms 'staff' or 'member of staff' are sometimes substituted for the term 'professional'. This is justified by Wilding's examination of the prerequisites and constitution of "professionalism" (1982). He conceded that social work is a profession, but of a lower order than the medical and legal professions. Staff working in Adult Training Centres are employed by the Social Work Department, but their individual training experiences vary. For the purposes of this study, all the respondents, who are employed to work with people with learning disabilities, are referred to generally as 'professionals'. The group are compatible, however, with the definition of professionals given by Rowley, Welsh and Reid (1994). They describe them as a "group of people who have a specialist knowledge that is recognised as belonging to them by other people. They have taken specific courses and have exclusive rights to act in particular situations."

3.ii. Introduction

This research owes its origins to an earlier study by the author concerning sex education for adults with

learning disabilities (Deeley, 1990). It was revealed that this section of the population lacked sexual knowledge and a vital issue which arose was their misinformation regarding

sterilisation. A sex education programme had been initiated at an Adult Training Centre in Scotland. Attending this course was a woman with learning disabilities who only realised that she had undergone a sterilisation operation after she had gained knowledge about sterilisation by attending the sessions on contraception. It was clear that she had not given valid consent to the operation because she had been unaware of its nature.

This incident prompted further interest in the sexuality of people with learning disabilities and more specifically, the decision-making regarding sterilisation. This descriptive study therefore involves examining attitudes to and perceptions of sexuality and sexual needs which are integral to the ideologies of their care.

Initially, it is relevant to identify the section of the population involved in this research. There are inherent problems within the classification of learning disability because the subject has important philosophical and moral implications (Kopelman and Moskop, 1984). Historically, various terms have been used to describe people with learning disabilities. More recently there have been moral conflicts resulting from what has been called a "labelling theory" (Jaffe, 1967; Whitehead, 1992). Confusing the issue is the use of similar labels to refer to different levels of ability. In 1968 and 1977, for example, the World Health organisation used the term "moderate retardation" to denote an I.Q. level of between 35 and 50. By comparison, "moderate learning difficulties" was a term used in the Warnock Report, 1978, to denote an I.Q. level of between 50 and 70 (Clarke and Clarke, 1985).

It is important to note that I.Q. levels do not constitute a "fixed state" (McCullough, 1984) and that

they can be increased (Money, 1973; Baum, 1994). Care must be taken therefore regarding "the appropriateness of attaching to an I.Q. the precision suggested by its numerical form" (Berger and Yule, 1985). It has also been claimed that the capabilities of people with low I.Q. levels are often underestimated and that I.Q. levels are "not the major psychological feature of the individual" (Baum, 1994). It is therefore important that caution is exercised where labels are used. Compounding the matter is the problem of assessing disability with regard to socially acceptable behaviour and social competence. The divisions between the levels of mental disability are "unclear", "whilst the terminology (of the legal definitions) does not provide particularly clear guidelines" (Gunn, 1986). Clarke and Clarke (1985) express the view that dividing lines are inaccurate because "intellectual abilities, and...social competence, form graded continua". It is, however widely acknowledged, that people with learning disabilities have an I.Q. of 70 or below (W.H.O., 1977).

This study involved people with learning disabilities whose general level of ability and functioning could be attributable to having an I.Q. of between 50 and 70. This was for several reasons. Firstly, this group of people with mild or moderate learning disabilities comprises 95% of all those with learning disability (Roos, 1975). In addition to the findings of this study having more relevance and value to the majority of this population, there was a higher probability of access being gained than if there were a limited number of respondents available. Secondly, it was important also that the section involved in the study was outwith the category of "severe mental impairment" as referred to in the Mental Health (Scotland) Act, 1984. This was to avoid complications or dubiety arising from the validity of their consent. It is possible for those who are not classified as severely mentally impaired to give legal valid consent. It is pertinent to note that Swedish social policy acknowledges the ability of people with I.Q. levels of 50 or above, to understand the nature and consequences of

sterilisation. This is reiterated by Roos (1975), who believes that the mildly and moderately learning disabled are able to understand the meaning of parenthood and sterilisation if parental I.Q. is 50 or above. It has also been claimed that there is "no relationship between I.Q. and level of care" given to offspring if the parental I.Q. is 50 or above (Roy, Corbett, Newton and Roy, 1993).

The nature of this study also required that the subjects should be of child-bearing age and of legal adult status. For convenience, the age range from 18 to 45 years was chosen, although it is acknowledged that both sexes are fertile both before and beyond these age limits. The 18 year lower age limit was chosen for two reasons. The first was to avoid legal obfuscations concerning the validity of consent. Secondly, educational responsibility ceases at this age and the subjects then come under the auspices of the Social Work Department. The upper age limit was chosen because of its proximity to the average onset of the female menopause.

Difficulties were anticipated in obtaining a representative sample of adults with mild to moderate learning disabilities. The statistics of this population are incomplete because only service-users can be identified. Only those receiving support from the social, health or education services can be counted. Inevitably, there are people who have learning disabilities but who remain unidentified solely because they do not use these services. Consequently there are limited statistics available from which estimates can be made of the population. It is accepted that between 1% and 3% of the whole population are affected by learning disability (Ward, 1991).

It was not relevant to involve the Education Department in gaining access because the lower end of the age range of the required sample was of school leaving age. The age of earliest entrance to an Adult Training Centre, or A.T.C., or other related establishment is usually 18. For access purposes therefore, this study sought the necessary

approval of the Social Work Department, from where the A.T.C.s are ultimately controlled.

Clarification of the legal position of people with learning disabilities in the area of sterilisation and its incumbent decision-making, was sought from the Scottish Law Commission. The legislation in Scotland concerning the capacity of a tutor-dative to give valid consent to sterilisation on behalf of a person with learning disabilities is presently under review.

The Information and Statistics Division of the National Health Service in Scotland was also contacted to obtain information regarding the numbers of sterilisation operations performed on both men and women with learning disabilities. Acquiring this information was estimated by the Health Analytical Services Unit as being "a long and costly process" and no information has been made available to date.

There are inherent problems in interviewing people with learning disabilities to ascertain their view about sterilisation. In addition to their vulnerability and acquiescence, there is a general lack of sexual knowledge within this section of the population (Deeley, 1990), as mentioned earlier. These aspects could hinder the obtaining of reliable data. It was also anticipated that there would be difficulties in gaining access to them because of the sexual nature of the enquiry, although as the study progressed some access in this area was successfully gained. Attitudes of defensiveness and suspicion were anticipated and therefore it was necessary to ensure that a sensitively tactful and diplomatic approach was adopted.

It was recognised that parents usually have most control and influence in the lives of their sons and daughters with learning disabilities. Their position enables them to make day-to-day decisions for them, and other decisions that are of a more intimate nature and have

far-reaching consequences, such as sterilisation. Due to the sensitivity and the emotive content surrounding the research questions, it was acknowledged that a self-selection process would be most effective in terms of response. On balance however this has disadvantages in the possibility of a bias in the findings. The study began on an essentially exploratory basis, with in-depth qualitative interviews being held with parents who had volunteered to participate.

3.iii. Methods Used to Collect Data

Prior to local boundary changes, Strathclyde was the largest and most heavily populated region in Scotland. The study included respondents living mainly in North Ayrshire, but others also involved in the study came from other parts of Ayrshire and Dunbartonshire.

Access through the Gatekeepers

The District Manager of the Social Work Department within the North Ayrshire Headquarters was contacted by letter in the first instance. His approval of the proposed research was essential. It resulted in contact being made with a District Officer in the 'Community Care' section of the Department. It was fortunate that this professional already had an interest in the subject area of this research. She had begun work on guidelines regarding issues of sexuality of people with learning disabilities and was part of a Regional Working Party on "Sexual Abuse of Adults with Learning Difficulties". A meeting was arranged with her to discuss contact with potential respondents. This resulted in her becoming a key informant, contacting managers of various establishments, such as an A.T.C., a Work Resource Centre and a hostel for people with learning disabilities. She also wrote to a local carers' support

group to inform and reassure them about this study. The secretary of this group replied, naming six parents who were willing to participate. An unexpected advantage was gained through the involvement of this group. The informal contacts between these parents and others increased the local awareness of this study. One parent in particular was very helpful in this respect, suggesting that contact be made with a professional with whom she had been in recent communication and suggested other carers who might be interested in participating. It was found that the recommendation from a parent was more powerful and effective than one from any other source. Her support for this research proved to be invaluable. As a consequence of this, contact was also made with the secretary of a neighbouring District's parent support group. The secretary of this latter group believed that the members would be unwilling to participate since they tended to deny their adult children's sexuality. She was fairly accurate in her perception, however, one parent from this group finally did offer to be interviewed.

Simultaneously, contact was also being made with Social Work establishments. A hostel for people with learning disabilities was contacted by telephone, but the Manager believed that the client group was inappropriate to this study. He explained that there was no parental involvement in the lives of these respondents. Any important decisions were made, he said, by the "client and a multi-disciplinary team". He did suggest however two Managers of other establishments who might be of assistance. One Manager of an A.T.C. was reluctant to provide assistance and contact was consequently lost. The second contact was with the Manager of another A.T.C. After an initial telephone call a meeting was arranged with her. She agreed to assist the research by sending the parents a letter explaining the nature of the study and requesting volunteers to participate. The letter contained a tear-off slip to allow the parents to reply easily (see Appendix 1).

Following several telephone calls the final outcome was that seven parents agreed to be interviewed.

Meanwhile, contact was also made with two more establishments. One of these was a small residential home. Its main aim was training people with learning disabilities to live independently. The Manager suggested two or three carers who might be interested in participating in the study. They were duly contacted by letter, followed by telephone calls. Two of the parents were willing to participate, albeit reluctantly. They did not eventually take part in the final study. The second establishment was a Work Resource Centre. Following several telephone calls and visits to the Centre, it was agreed that letters could be sent to parents from the establishment. It was advantageous that the Depute Manager was a former colleague of the author. A total of 54 letters were sent to the clients' parents. Out of 28 replies that were received, there were a total of 21 parents who agreed to be interviewed.

A list of 37 potential respondents was therefore compiled, although not all of these participated in the final study. It was preferred that the in-depth qualitative interviews would take place within the respondents' homes wherever possible and that each interview would be audio-recorded. It was anticipated that each interview would last about 45 minutes.

3.iv. The Pilot Study

Five parents were randomly selected from the list. They were contacted by telephone and interviews were arranged at a mutually convenient time. From the outset, these five semi-structured interviews were planned to be the pilot study. At this early stage, the data collection contained as much an element of discovery as a demonstration

of a range of responses. It was hoped that after an initial analysis, themes might emerge which could be explored and expanded in subsequent interviews.

To give quantitative elements to the study and to allow direct comparisons to be made between respondents, a vignette was devised. The vignette (see Appendix 3) was about a developing sexual relationship between a man and a woman with mild learning disabilities. The respondents were asked to choose at which of the six stages, if any, of this relationship the couple should use contraception or be sterilised. If such action was chosen, the respondents were asked to decide whether the operation should be performed on the man or the woman, giving reasons for their choice (see Chapter 6). A multiple-choice question (see Appendix 4) was also included to determine which group, would be the most appropriate to give consent to sterilisation on behalf of a woman with learning disabilities whose own consent was deemed legally invalid (see Chapter 7). Each parent was also asked to assess their son or daughter's ability level, by choosing a general category from a given list (see Appendix 5). This was not used in the later interviews because it was deemed to be ineffective.

A basic interview guide was devised to give some structure to the meetings. This interview guide was devised to determine parental views on various aspects concerning their adult sons' and daughters' sexuality. These included:

1. Sexual interest.
2. Marriage potential.
3. Parenting potential.
4. Existing contraceptive provision:
 - i. Whether sterilised, ie. vasectomy/ tubal ligation.
 - ii. Whether they had had a hysterectomy, ie. for medical reasons.
 - iii. Whether they were using other contraception (which form).

5. Decision-making regarding choice of contraception.
6. Sexual awareness with no access to contraceptive provision.
7. Knowledge of tutor-dative system.
8. Details of tutor-dative if there is one or more appointed.
9. Choice of decision-maker(s) if consent to sterilisation cannot be given. (Multiple choice answer).
10. Vignette:
 - i. Choice of stage at which contraception is recommended.
 - ii. Choice of stage at which sterilisation is recommended.
 - iii. Choice of male or female sterilisation.
 - iv. Reasons given for the above.

It was expected that much could be learned from these initial interviews regarding the approach to the subject, the most effective probing techniques and resolution of each interview. There were several factors compounding the sensitive nature of the interviews. These involved openly discussing matters of sexuality, the issue of the sexuality of their own son or daughter and the inherent problems surrounding learning disability, especially when their sexuality is sublimated or completely denied (Greengross, 1976; Stewart, 1979).

Four of the five respondents in the pilot study were women. The adults with learning disabilities consisted of four daughters and one son, whose ages ranged from 19 to 34 years, with a mean age of 25.6 years. Each interview began with a personal introduction of the interviewer, the topic of research in general and the particular topic for discussion at the interview. The respondents were assured of confidentiality and anonymity. It was also stressed that their frank replies were valuable and were essential to the study. After following the interview guide, which included the multiple-choice

question, and on completion of the vignette, the respondents were encouraged to express their views or discuss any aspects of the issues which most concerned them. It was at this point in the interview that the respondents appeared more relaxed and de-sensitised to the subject of discussion. As confirmed by Gorden (1969), "the need for catharsis increases the spontaneity of the interview once an atmosphere of sympathetic understanding has been established".

When the interviews had been completed, they were transcribed verbatim. These transcripts, in addition to the fieldnotes, revealed that there were some issues raised during the guided section and other matters that arose only during the 'informal' talk. During the guided section, some of the respondents' attitudes to the sexuality of people with learning disabilities seemed inextricably linked to their attitude to sexuality in general. These views were consistent with their responses to the vignette. The use of the vignette clarified and confirmed the respondents' views towards decision-making.

The first part of the interview also revealed that none of the respondents had any knowledge of a tutor-dative. One respondent was aware that there could be legal difficulties involved in a person with learning disabilities having a sterilisation operation. Nevertheless, all the respondents were confident in their belief that it would not be a difficult procedure to arrange for the operation to be performed on their own son or daughter.

The 'informal' talk revealed areas not covered by the guided interview. These included attitudes to outside agencies, in particular the Social Work Department. Other topics were raised, such as the rights of the learning disabled and the Nazi sterilisation policies. One parent acknowledged her change to a positive view of the sexuality of people with learning disabilities after witnessing successful relationships developing between them.

The amount of sexual knowledge that people with learning disabilities generally have was also discussed in the pilot study. Another respondent expressed the problems parents commonly experience in "letting go" of their children. This problem seems to be exacerbated if the child or adult has a learning disability.

None of the respondents believed that the decision to sterilise a person with learning disabilities should lie with the law courts or tutor-dative alone. The most salient point of all the interviews was the very strongly expressed belief that such a personal decision as sterilisation was the prerogative of every parent. There was strong resistance to any suggestion that outside agencies should be involved in this type of decision-making.

3.v. Sequential Analysis

The analysis of the pilot study was necessary to identify themes which could be explored further. Even at this early stage, the parents were similar in that they all described how their views differed from those of the professionals. The differences in opinion were based largely on the expectations and perceived abilities of their sons and daughters with learning disabilities. It was therefore decided that the professionals working with the adults with learning disabilities involved in the study should also be interviewed. This was to ascertain if indeed there were differences between the attitudes and expectations of the two groups and if so, to identify them. Social work establishments were again contacted to arrange interviews with the appropriate keyworkers.

This led to an interest in professional and parental ideologies of care. Since ideologies can often be inferred from what professionals do as well as what they

say, it was decided to observe their interactions in addition to interviewing them. Subsequently, the interview guide for parents was refined (see Appendix 6) and a separate guide was devised for the interviews with the keyworkers (see Appendix 7). As the data collection proceeded, it became increasingly apparent that there were marked differences between parental and professional views. These did not solely concern individuals with learning disabilities, but reflected wider issues and ultimately, different ideologies of care. Consequently, there are conflicting influences acting on people with learning disabilities. A further exploration of this situation was deemed valuable. Accordingly the interview guide for the parents was again revised (see Appendix 8) and meetings between various groups were observed. These included meetings between professionals and parents; professionals, people with learning disabilities and their parents; professionals and people with learning disabilities. There is an analysis of these observations in Chapter 4.

Further interviews were also arranged with professionals who did not play a keyworker role, but who held managerial or senior positions. This was to ascertain how strongly they adhered to the prevailing orthodoxy, especially in the light of their having more professional training and experience. An interview guide was specifically designed for these meetings (see Appendix 9). In addition, there were questions devised to elicit information from professionals involved in the sex education of people with learning disabilities (see Appendix 10) in order to explore further discrepancies between the parental and professionals (see Chapter 5).

In total, twenty one interviews were conducted with professionals. This was a greater number of interviews than were conducted with parents. It was because the nature of the study developed to necessitate a clearer insight into professional ideology. The range of positions held by the professionals was as follows:

<u>Professional Role</u>	<u>Number of Respondents</u>
Managerial/ Senior	7
Keyworker	7
Care Staff	3
Sex Education Tutor	3
Inspector	1

Total: 21

As the interviewing of professionals proceeded, it became clear that their views were not uniform. The differences were not random however, but were related to duration of service. Those who had been in the profession longest tended to have views more similar to parents, in that they were more protective and held lower expectations of the abilities of people with learning disabilities. By contrast, the professionals who more recently joined the service tended to reflect the prevailing orthodoxy. Variables such as gender or age of these respondents did not affect their views. With further investigation, it became clear that the distinctions between them were consistent with a past ideology and a superseded model of orthodoxy. This was reflected in the language and terminology used by the different professionals.

This was clearly demonstrated by members of the Inspection Unit who were also contacted for information. They represented the most ardent advocates of the prevailing orthodoxy, responsible for shaping services to fit the model of normalisation practices.

Another dimension to the study was to interview a few people with learning disabilities. Contact was made with them through the professionals who had already been interviewed. The purpose of these interviews was to ascertain their attitudes and views as well as to increase awareness of their position within the potentially conflicting relationship between their parents and the professionals with whom they were most in contact. A group interview was conducted with people with learning

disabilities with members of staff present (see Appendix 11). It is interesting to note here that although these individuals lived semi-independently away from the family home, parental influence was very strong. Equally, they regarded the staff in a similar authoritative light and were also duly influenced by them. This was the case despite the professionals encouraging them to be independent in their decision-making and in their life-styles.

Only two one-to-one interviews were conducted with a man and a woman with learning disabilities. Access to such respondents was limited and difficult. Unfortunately, the period of time necessary to pursue this line of enquiry was in excess of the limits of this study. The woman had requested a sterilisation operation, which had been performed. An interview guide was devised for these meetings (see Appendix 12). Although dealing with an abstract concept, it was important for comparative purposes that the vignette was used in these circumstances. In order to allow for easier comprehensibility and thus eliciting reliable data, a pictorial version of the vignette was made for the individuals with learning disabilities (see Appendix 13). This was shown to them while the 'story' of the vignette was told. The exercise was repeated to ensure that they had understood the problems involved in the decision-making in the vignette. Their responses remained consistent. Simplifying the vignette for people with learning disabilities was useful in that it clarified the issues concerned. As a direct result, the written vignette that had been used with the other respondents was subsequently simplified (see Appendix 14).

It was clear that there were issues of concern for parents that involved sterilisation but which also extended beyond it. Sterilisation provided the focal point, magnifying underlying problematic factors. These were directly related to the influence of professionals in their lives and the subsequent relationship with them.

Their disparate ideologies became apparent, confirming that the differences between them were irreconcilable. The discovery within the study arose from the data collection and not from preconceived ideas. It is from this data that a grounded theory is based (Glaser and Strauss, 1967). In order to develop and expand the grounded theory, the data was coded for similarities and differences on the emerging themes and particular issues. This is described below.

3.vi. Coding the Data

In total there were 39 "slices of data" (Glaser and Strauss, 1967), 35 of which were transcribed verbatim. The remaining four interviews were written reports from notes taken at the interviews. These were with professionals; three of whom did not wish to be audio-recorded, while the fourth interview was not taped because of a technical fault. The number of interview transcripts belonging to each group were as follows:

Interviews with Parents.....	12
" Professionals.....	21
" People with learning disabilities...	2
Group Interview: Professionals and People with learning disabilities.....	1
Observations: Professionals and People with learning disabilities.....	1
" Professionals and Parents.....	1
" Professionals, Parents and People with learning disabilities.....	1
TOTAL.....	39

The interview guides were essential in codifying the data. Their refinement was, as Glaser and Strauss (1967) describe, the result of the "analytic procedure of constant comparison". They clarified particular issues and ensured they were discussed in each interview. The vignette

and the multiple-choice responses to a hypothetical situation were coded separately.

The main strategy in generating grounded theory is a "general method of comparative analysis" (Glaser and Strauss, 1967). This theory is generated by the data collected from the respondents. It explains their situations, while also predicting their possible future interactions. According to Glaser and Strauss (1967) data can be analysed using categories and properties. The former are a "conceptual element of the theory" from which properties are devised. A property is "a conceptual aspect or element of a category". These are indicated by the data. In this study, the coding and analysis were done simultaneously which, according to Glaser and Strauss (1967), enhances the systematic generation of theory.

The transcripts were numbered and cross-referenced with their corresponding audio-tape. Each quotation taken from a transcript thus bears a reference, for example, "(10,3,17-21)". The first number identifies the transcript; the second refers to the page number and the final figures refer to the line numbers. In this way, quotations can be easily retrieved and cross-referenced.

Categories and properties were extrapolated from each transcript. Relevant quotations from the data, complete with references, which illustrated the themes were entered on to index cards and filed under the appropriate corresponding categories. Some of the data were appropriate to more than one category. In such cases, the quotations were cross-referenced. The qualitative element throughout the interviews was also assessed in respect of the nature of tensions and conflicts, attitudes, emotions, their uniqueness and idiosyncrasies. In the light of this, the data were coded into the following properties:

CATEGORY 1: PROFESSIONALS- Views expressed by Parents

PROPERTIES:

- a. Appreciate their job.
- b. To the staff it is just a job.
- c. Professionals are impractical.
- d. Professionals are unrealistic.
- e. Expectations of Professionals are too high.
- f. Professionals are unapproachable.
- g. Professionals know more than parents.
- h. Professionals' attitudes to parents, as seen by parents.

CATEGORY 2: Professionals- Views expressed by Professionals

PROPERTIES:

- a. Helplessness.
- b. Indifference.
- c. Sexuality.
- d. Working together.
- e. Fears.
- f. Hindrances.
- g. Responsibilities.
- h. Realism.
- i. Passivity.

CATEGORY 3: PARENTS- Views expressed by Professionals

PROPERTIES:

- a. Parents see Professionals as help and vice versa.
- b. Parents see Professionals as interfering.
- c. Parents avoid Professionals.
- d. Sexism.
- e. Perceived parental views of sexuality.
- f. Aggression.
- g. Overprotectiveness.
- h. Apprehension (felt on meeting parents).
- i. Professionals' role.
- j. Active parents.
- k. Hindrances.
- l. Other views of parents.
- m. Financial concerns.
- n. Parental power.

- o. Typology.
- p. Fear.
- q. Empathy with parents.

CATEGORY 4: PARENTS- Views expressed by Parents.

PROPERTIES:

- a. Assertiveness.
- b. Passivity.
- c. Professionals' role.
- d. Communication.
- e. Parents know their sons/ daughters best.
- f. Anxiety.

CATEGORY 5: RELATIONSHIP BETWEEN PROFESSIONALS AND PARENTS-
as seen by Professionals

PROPERTIES:

- a. General relationship.
- b. Sexuality.
- c. Communication.
- d. Professionals as 'experts'.

CATEGORY 6: RELATIONSHIP BETWEEN PROFESSIONALS AND PARENTS-
as seen by Parents

PROPERTIES:

- a. General relationship.
- b. Annoyance.
- c. Communication.
- d. Professionals as 'experts'.
- e. Disappointment.
- f. Challenge/ Confrontation.

CATEGORY 7: RELATIONSHIP BETWEEN PROFESSIONALS AND PARENTS-
through observations of their interactions

PROPERTIES:

- a. Unwelcoming.
- b. Business-like/ formal.
- c. Apprehension.
- d. Tension.

- e. 'Expert' model.
- f. Jargon.
- g. Active Parents.
- h. Cynicism.
- i. Defensiveness.
- j. Challenges.
- k. Conflict.
- l. Appeasement.
- m. Complaints.
- n. Support network.
- o. Embarrassment.
- p. Empathy.
- q. Pragmatism.
- r. Positive aspects.
- s. Anxiety.
- t. Lack of communication.
- u. Reassurance.

CATEGORY 8: SEXUALITY AND SEXUAL NEEDS- Parental views
 PROPERTIES:

- a. People with learning disabilities and sexual interest.
- b. Sexual knowledge.
- c. Decision-making (general).
- d. Incidents.
- e. Seen as a problem.
- f. Physical needs.
- g. Emotional needs.
- h. On promoting sexuality.
- i. Guidance.
- j. Irresponsible.
- k. Supervision/ opportunity.
- l. Support services/ social workers.

CATEGORY 9: SEXUALITY AND SEXUAL NEEDS- Professional views
 PROPERTIES: Same as CATEGORY 8, plus the following:

- m. Attitudes of Parents (according to Professionals).
- n. Hidden competence.
- o. Attitudes.

- p. Passivity.
- q. Professional responsibility.

CATEGORY 10: RELATIONSHIPS- Parental views

PROPERTIES:

- a. Unable to cope.
- b. Having sex.
- c. Marriage.
- d. Against relationships.
- e. For relationships.
- f. Homosexuality.
- g. Support.

CATEGORY 11: RELATIONSHIPS- Professional views

PROPERTIES: Same as CATEGORY 10, plus the following:

- h. Casual relationships.

CATEGORY 12: REPRODUCTION: Parental views

PROPERTIES:

- a. Inability to cope.
- b. Should not have children.
- c. People with learning disabilities wanting children.
- d. External support.
- e. People with learning disabilities- their children into care.
- f. Parents' responsibility for their grandchild.
- g. Opportunity/ rights.
- h. Right not to have parents with learning disabilities.
- i. Genetics.

CATEGORY 13: REPRODUCTION: Professional views

PROPERTIES: With the exception of f,g,h,i, same as CATEGORY 12, plus the following:

- j. People with learning disabilities being able to cope.

CATEGORY 14: CONTRACEPTION- Parental views

CATEGORY 15: CONTRACEPTION- Professional views

PROPERTIES:

- a. Oral contraception.
- b. Against contraception.
- c. Other forms of contraception.

CATEGORY 16: STERILISATION- Parental views

CATEGORY 17: STERILISATION- Professional views

PROPERTIES:

- a. Not in favour.
- b. Motivation.
- c. Desirable.
- d. Understanding.
- e. Decision-making.

Additional property for Professionals:

- f. Facts.

CATEGORY 18: VIGNETTE- By Parents

PROPERTIES:

- a. Negative views regarding sexuality.
- b. Concern for the child.
- c. Concern for the grandparents.
- d. Against reproducing.
- e. Concern for the people with learning disabilities.
- f. Decision-making.

CATEGORY 19: VIGNETTE- By Professionals

PROPERTIES: With the exception of a and b, same as above,
plus:

- g. Against sterilisation.
- h. Positive views.

CATEGORY 20: CONCERNING PROFESSIONALS

PROPERTIES:

- a. Professional ideology.
- b. Control.
- c. Allowing freedom.
- d. Judgemental stance.
- e. Anomolies.
- f. Criticism of system.

- g. Language.
- h. Staff training.
- i. Superseding ideology.
- j. Quasi-religious fervour.
- k. Sexuality.

CATEGORY 21: PARENTAL VIEWS OF SCOTS LAW

PROPERTIES:

- a. Knowledge of tutor-dative system.
- b. Does son/ daughter have a tutor-dative?
- c. Multiple-choice answer to question of hypothetical situation.
- d. Sterilisation made easier to obtain.
- e. Sterilisation made more difficult to obtain.
- f. Decision-making.
- g. Parental involvement.
- h. Views of tutor-dative system.
- i. Should there be any laws/ legal intervention regarding sterilisation?

CATEGORY 22: PROFESSIONALS' VIEWS OF SCOTS LAW

PROPERTIES:

- a. No knowledge of tutor-dative system.
- b. Knowledge of tutor-dative system.
- c. Multiple-choice answer to question of hypothetical situation.
- d. Sterilisation made more difficult to obtain.
- e. Decision-making.
- f. Views of tutor-dative system.
- g. Should there be any laws at all?

The open coding was unrestricted and involved, as Strauss (1987) advised, "scrutinizing the fieldnote, interview, or other document very closely: line by line,...(and) word by word". The data were then axial coded by means of connecting the categories with each other. This was done "by utilizing a coding paradigm involving conditions, context, action/ interactional strategies and consequences" (Strauss and Corbin, 1990). Subsequently,

different views of sexuality, involving issues such as relationships or contraception, were found to be due to causal conditions. These were divided as either belonging to the parents or to the professionals. Paradigm models of their respective ideologies of care were developed therefore, using the concept of a conditional matrix. This, according to Strauss and Corbin (1990) is "useful for considering the wide range of conditions and consequences related to the phenomenon under study". On one matrix level, for example, the historical process is evident in the data. This is seen when the prevailing ideology of the professionals conflicts with the superseded orthodoxy which originates from institutional care. Using the techniques delineated by Glaser and Strauss (1967), Strauss (1987) and Strauss and Corbin (1990), prevalent themes became clear and a grounded theory emerged.

3.vii. Conclusion

The Generation of a Grounded Theory

The data when coded, in addition to all pieces of relevant information, such as fieldnotes and other memoranda, were collated to provide exploration of the contents of each category. From these categories emerged the "major themes of the theory" (Glaser and Strauss, 1967), with the actual data providing the illustrations. Strauss and Corbin (1990) clarify this saying, that by "developing a grounded theory we are trying to capture as much of complexity and movement in the real world that is possible, while knowing we are never able to grasp all of it".

One of the major themes that arose from the data concerned the disparate ideologies that are held by the parents and the professionals. These ideologies, although by no means indisputable, reflect attitudes towards and expectations of the abilities of people with learning

disabilities. This, in turn, affects parental and professional perceptions of the sexuality of people with learning disabilities. As a result, their views are prejudiced regarding matters of decision-making in the areas of marriage, parenthood, contraception and sterilisation and the perceived abilities of people with learning disabilities to cope adequately with them.

Evidence of the disparate ideologies is explored in Chapter 4. On a basic level, the language used to describe learning disabilities is indicative of different attitudes. On a more abstract level, the interaction of professionals with parents reveals their incompatible viewpoints. This was observed during their meetings together, in addition to their comments. Although it is possible that these types of interactions are idiosyncratic, they occurred consistently throughout the study as an integral part of the relationship between parents and professionals.

Although the starting point for this research involved the socio-legal issues surrounding the sexuality of people with learning disabilities, insight was gained into the problematic relationship which exists between parents and professionals. The study reveals that sexuality polarises these two groups, but the data suggests that there were also other factors which indicated that the views and interactions of the two groups were due to different ideologies. Examples of these are given in Chapter 4 and relate to parental protectiveness. Professionals commented on this on numerous occasions, complaining for example, that parents unnecessarily helped their adult son or daughter to dress themselves. Other examples included parents not allowing their son or daughter to use electricity, either by switching on the television or by making a cup of tea. Similarly, parents did not trust them to go out alone or to travel independently, thus 'hindering' the attempts by professionals to encourage people with learning disabilities to become more independent in accordance with the prevailing

orthodoxy. Professionals regard people with learning disabilities as having "hidden competence" or as having the ability to acquire skills in daily living which are denied by parents. Parents were sceptical about their son or daughter being able to achieve the aims set by the professionals. In one example, a carer disputed the claim by the professionals that her brother was able to swim.

It is clear that the attitudes of parents towards the ability of respective individuals were in direct contrast to those of professionals. The latter always expressed higher expectations of people with learning disabilities than did the parents, both in a conversational way and more systematically when they had to specify the level of disability, from mild to profound (see Chapter 4). This phenomenon suggests that the differences between parents and professionals are not solely in relation to issues surrounding sexuality. In addition, it reinforces the concept of two separate and disparate ideologies belonging to parents and to professionals.

These discrepancies permeated the data, but it was the topic of sexuality which accentuated them. Thus, the ideologies created and developed from their different experiences affect not only their attitudes towards each other, but also towards people with learning disabilities. This fundamental dissonance is due to conflicting ideologies and has serious implications for social work-family relations as discussed later in Chapter 8. The nature of this difficult relationship therefore forms a major part of the substantive and informal theory. This theoretical model could perhaps be applied in other situations involving a similar relationship between 'professionals' and 'lay' people and thus be developed into a formal theory.

As Strauss and Corbin (1990) state, the "discovery and specification of differences among and within categories, as well as similarities, is crucially important and at the heart of grounded theory". Bearing this in

mind, another theme which emerges from the data is that the ideology of the professionals is more complex than is initially perceived. The dividing factor between professionals is the era in which they joined the profession. The influence lies with the ideology which was most prevalent at the time. Invariably, this is the ideology which the professionals adopt. Therefore, as ideologies become refined or change more dramatically, there remain professionals who still adhere to ideas that they originally were imbued with. Such views of learning disabilities have been subjected to change (see Chapter 1). Conflicting attitudes presently exist, although normalisation is accepted by the professionals as the "prevailing orthodoxy". This has superseded a paternalist ideology illustrated in institutional care. The link between this latter ideology, held by some professionals, is made to a parental ideology (see Chapter 6). The differences between parents and professionals are complex and are obfuscated by the latent disparities between the professionals themselves. This has ramifications for people with learning disabilities, their sexuality and decisions regarding sterilisation. Both parental and professional groups influence, indeed have power and control, over people with learning disabilities. Problems can be exacerbated therefore if there are disagreements between the two groups.

What is clear from the data however is that much of the behaviour and views of each group can be predicted according to each of their ideologies. This study emphasises that the issues arising from sexuality serve to magnify the discrepancies between them (see Chapter 6).

Summary

This Chapter has described the methods used in this research, from data collection to its analysis. This is not a study of verification, but one of exploration and discovery. The qualitative interviews were conducted using sexuality and the surrounding issues as a base. From

this source, other matters of importance, to the parents in particular, emerged. These matters were investigated further in subsequent interviews. The process of sequential analysis progressed to such an extent that a theory grounded on the data was formulated.

Clearly, there are limitations to this research. The numbers of respondents are few and are closely linked geographically. It is therefore a study which is parochial and time-specific. This latter issue, however, contributes to the grounded theory in that ideologies of care are subject to change through time. The data concerning a superseding 'orthodoxy' suggests this (see example given in Chapter 5).

Although the theory is based on the data collection, its analysis is interpretative. Its credibility is evident through the internal consistencies of the data collected from the respondents and through observations of their actions. The findings in this study are consistent with other studies and the literature pertaining to the professional-parental relationship (Mittler and McConnachie, 1983; Cunningham and Davis, 1985; Evans, Forder, Ward and Clarke, 1986; Brown, 1988; Twigg, 1989; Robinson, 1991). Questions remain as to the ramifications of this grounded theory. These range from specific issues, an example being the effects on decision-making in the lives of people with learning disabilities, to the broader issue of normalisation as an ideology of care.

PAGINATION AS IN ORIGINAL

Chapter 4

TENSION AND CONFLICT:

An Analysis of the Relationship Between
Professionals and Parents of Adults With
Learning Disabilities.

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4.i. Introduction

The main aim of this study is to examine socio-legal issues of adults with learning disabilities. The central concern is the decision-making process regarding contraceptive use, in particular male and female sterilisation.

Semi-structured interviews were held with parents and other carers, of men and women with mild learning disabilities. In total, the respondents included one father, two sisters and nine mothers. Their ages ranged from 30 to 70 years, and the group contained a range of social classes. The adults with learning disabilities consisted of six men and six women. Their ages ranged from 19 to 41 years; the average age was 27.5 years.

Similar semi-structured interviews were also held with twenty one professionals, some of whom were key workers with the adults with learning disabilities. This group consisted of twelve men and nine women. They also represented a range of ages and social classes.

The earlier interviews in the study were of an exploratory nature. From the beginning, however, it was clear that any decisions associated with sexuality of the adults with learning disabilities were made or, at least, greatly influenced by parents. As such, it was made clear by parents that interference with decision-making from outside agencies, including the law, would be met with indignation, resentment and even hostility. It was also apparent from the beginning of the study that sexuality, or the potential for sexual activity, of the adults with learning disabilities were sources of anxiety for parents. These included fears concerning the vulnerability of these adults to coercion, which could lead to their exploitation and abuse. Some parents consequently expressed their fears of the possibility of their adult children having unplanned and unwanted pregnancies. Mothers, especially, believed that

they would feel responsible for the care for any such offspring, which could also have a learning disability:

" I'm 48....I don't want to be saddled with another child, who's probably going to be mentally handicapped as well.....No, I really shudder to think, you know, if it did happen."

(7, 7, 18-25)

"It's the thought of having another handicapped child to bring up...."

(5,3,26-7)

From their own experiences, many parents felt that welfare agencies had done little, if anything, to alleviate their burden when their own child with a learning disability had been born. Not surprisingly, parents were sceptical that these same agencies would offer help if those same children became mothers themselves. Some parents felt uneasy about this predicament and felt that it could arise if staff at Adult Training Centres provided any kind of sex education or counselling on sexual matters. One mother said that there was a risk of

"ideas being put into heads that aren't already there."

(3,7,35-36)

She went on,

" I don't like the idea of maybe *en masse* having sex education in an Adult Training Centre.....I would never ever agree with an Adult Training Centre doing it without the parents being consulted on it. Never."

(3,12,29-31)

It was evident that this was a particular source of tension between parents and professionals. Careful analysis of the data obtained from these interviews and of data obtained from close observations of meetings between parents and professionals, suggest that the existing tensions are not due to isolated incidents or to particular isolated issues such as this. It is the very nature of the relationship between parents and professionals that is responsible for the tension between them. This tension is exacerbated when controversial issues, such as sexuality, are raised. The relationship was explored more openly in the later interviews of the study, using direct questioning:

"How d'you think parents feel about the staff ?"

(22,5,4)

and

"What do you think staff feel generally towards parents ?"

(18,4,31)

Difficulties in this relationship were expressed in various ways by both parental and professional groups. Observations of their interactions offered some insight into the difficulties of the relationship. It is relevant to note that this particular relationship exists solely because of each group's relationship with people who have learning disabilities: it brings them together, but paradoxically, it also divides them. People with learning disabilities are a third group who play a passive rôle in this relationship. This has serious ramifications for their development as self-advocates, in particular, for their abilities in exercising choice and in making personal decisions. In this study people with learning disabilities were described as,

"really submissive.....say you're trying to get a contract or a working agreement with someone, it's really difficult because they just agree with everything. They don't challenge you, you know, and you can really manipulate things and you've got to be aware of that. It's really... it's putting the onus back on them to make the decision."

(18,8,25-32)

The power in the triadic relationship lies between the professionals and the parents. They both have the potential to influence and control the adults with learning disabilities. This power, however, is not evenly distributed and it is this imbalance which causes some tension between the two parties. It is one of the basic underlying features of the nature of the relationship itself.

Major differences between the two groups are their expectations of the adults with learning disabilities and their understanding of learning disability itself. Data from observations of meetings between parents and professionals clarify the nature of their interactions. Such observations are useful because, according to Goode (1983), despite professional "rationales of action (which) are often supported by voluminous articulations.....these are, at best, partial understandings of our actions." It is possible, he says, "that persons generally do not know, other than in practical ways, what they are doing while they are doing it."

It is therefore the aims of this Chapter to examine and analyse the relationship between the parents and the professionals. This will be a prelude to providing insight into their different attitudes to sexuality in general and

to sterilisation in particular, of people with learning disabilities. Data from qualitative interviews with these two groups will be used extensively in order to generate a grounded substantive theory.

4.ii. The Relationship

The perceptions parents and professionals have of each other are interwoven with their self-perceptions and the status each group holds within the triadic relationship. This status differs fundamentally because of the relationship each group has with people with learning disabilities. For most parents, knowledge of learning disability comes from the experience of having their own son or daughter. Their interactions are therefore based on emotional and kinship obligations. By contrast, the professionals interact with numerous individuals with learning disabilities on the basis of their paid employment within a hierarchical organisation. The nature of these obligations are illustrated by comments made by parents about staff:

"They don't want to attend attend anything that we do. They don't want to attend it. You'd think they'd turnup to let parents see the staff are interested as well. I know it's outwith their hours and they'll not get paidfor it....**We've** got to do these things."

(26,6,19-22)

A further example is a stoical remark made by another carer, referring to the lack of choice in caring for dependent adult offspring:

"She's **had** to cope with her"

(6,9,2)

Parents were aware, however, that staff were controlled by their professional duties,

"I think staff's pushed by the higher up ones."

(20,9,20)

and

"They've got to do it, or they're out (of a job)."

(20,9,24)

Cunningham and Davis (1985) believe that professionals are generally more objective than parents about people with learning disabilities and their situation. They claim that this is a major difference between parents and professionals and say, "parents are more emotionally involved with the (son or daughter) than professionals. This means that parents will have more intense reactions and feelings to the total spectrum of (their) behaviour than professionals." Awareness of this close parental identification with their son or daughter affects the attitude of professionals. A member of staff admitted,

"I would see (parents) as clients now."

(18,7,4)

In the words of the professionals, parents can be "very positive" (21,4,5), but it must be remembered that "some parents are easier to deal with than others" (12,3,4-5). There is "such a difference in parents' opinions" (21,5,22-3) and ideas that "it's very difficult to categorise it, it really is" (21,6,22-3). In the study,

only one professional attempted a typology of parents. He claimed that there was "one extreme of parents" (21,5,31) who nurtured the independence of their son or daughter and suggested that elderly parents were more restrictive than others of their sons or daughters with learning disabilities. He believed that elderly parents,

"need the (person with learning disabilities) more nowadays than they ever did."

(21,5,35-6)

This view reflects Richardson's study (1989). In an interview with an elderly widow, she quotes, "I could see that I needed (my learning disabled son) more than he needed me". She added, "I needed someone to relate to" and explained that a son or daughter with learning disabilities is "somebody who loves you and it's a lovely form of love. There's no ifs or buts about it. It's a pure love and it's lovely, you know."

As far as sexuality of people with learning disabilities is concerned, the older a parent is, the more restrictive they are perceived to be, "certainly with the older generation" (12,4,5). One professional clarified this,

"I think most parents are (restrictive, and that it is) not specific to people with learning disabilities."

(12,4,5-8)

This is an interesting point and is reminiscent of a study by Reiss (1973). In her study, Reiss claims that social rôle has paramount influence in shaping attitudes and values to sexuality and sexual behaviour. Being married and having children, as examples, have more effect in shaping people's

views than does their age. If transference of this phenomenon is valid, then it is possible that being a parent of a learning disabled person also shapes attitudes and values to a particular degree not shared by other parents. This study certainly suggests this could be the case, especially in the light of the wide parental age range of the respondents.

Several members of staff empathised with the parents because they were parents themselves. Several comments illustrate this:

"I can appreciate how parents feel...the majority of the parents, I can see a lot of their reasoning and I can understand that....It's very difficult, I mean like, not being in their position."

(14,7,4-14)

"They've been through it all before."

(12,8,8)

"It must be difficult for parents and carers."

(15,6,21-2)

"I understand that the parents don't look possibly at things the way I do....I can understand that from their point of view."

(16,4,36; 16,5,20)

They understand that parents "want the best" and show a "keen interest" (16,6,19 and 23) in their adult offspring:

"Some parents are totally caring and are really committed to their son or daughter."

(16,5,11-12)

"There are a lot of parents who will be looking for the better or what they think their son or daughter would want."

(14,17,25-7)

Nevertheless, the empathy shown by professionals is limited. This is perhaps due to their lack of understanding of the emotional implications arising from giving birth to a baby with a learning disability. Mittler, P. and H. (1983) warn that "we should...beware of drawing too sharp a distinction between parents of handicapped and non-handicapped people" but this view negates the phenomenon of "chronic sorrow", which can occur with parents of people with learning disabilities. This was first recognised by Olshansky (1962) and later studied by Wikler, Wasow and Hatfield (1981). The findings from their study contradict the accepted professional understanding that parents go through stages of "shock, guilt and rejection to the promised land of acceptance and adjustment" to their learning disabled son or daughter. Wikler et al (1981) claim that adjustment to learning disability is not time-bound, but that "over time, there are numerous occasions on which the intense grieving feelings are re-evoked and experienced" and that they are, in fact, an integral part of the parental emotional life which may never be resolved. They found that "Social workers tended to overestimate how upsetting the parents' early experiences were. They *underestimated** how upsetting the later experiences were", examples being entering puberty and the 21st birthday (* Own italics). Issues of sexuality and reproduction are also examples which could evoke chronic sorrow. It is interesting to note that they also say, "the mildest empathetic probing

of parents' feelings inevitably reactivates an intense but transient grief". Intense emotion was observable in many of the interviews with parents in this study. For some, it was almost a cathartic experience.

a. Parental Protectiveness

Parents are naturally fearful and anxious for their offspring regardless of their age or ability, as illustrated by a member of staff,

"There's a lot of apprehensions about life
for all parents."

(14,6,34-5)

These emotions are magnified and compounded by the offspring having a learning disability, which was acknowledged by a member of staff,

"As my oldest son is getting older, I realise I've got to let go of him. If he had learning difficulties maybe I'd be in the exact same place as they are and not want to let go, you know, you want to keep that protective rôle."

(13,5,28-32)

Professionals are less sympathetic to what they see as the parents' coddling of their adult sons and daughters. One member of staff commented,

"Maybe mum's a bit O.T.T. with doing things for him."

(13,12,3)

Such actions can be habitual because,

"they've been sheltered most of their life."

(15,6,20)

"(Others) as soon as they get into the house, they're not allowed to take their coat off, there's someone there taking their coat off for them."

(13,5,12-13)

As a result, professionals commonly believe that

"Parents can be very over-protective"

(14,3,25)

and try to wrap "them up in cotton wool" (18,4,30). A view which is echoed by professionals throughout the study. One parent admitted her difficulty in "letting go" (5,12,26-8) of her adult daughter. The professionals were aware of this problem, as clearly illustrated by the comment,

"Parents are unwilling to let them go."

(16,5,19)

The emphasis on people with learning disabilities becoming more independent members of the local community induces much parental anxiety and increases their protectiveness. Travelling independently is one such source of this. Examples include a fear of them boarding the wrong bus or of them getting off at the wrong bus stop. One professional succinctly encapsulated the fundamental fear, that people with learning disabilities "are so easily led astray"

(21,7,17) in the "bad world out there" (21,7,3). There is the possibility of them being,

"abused in the community by other people in general, taking a lend of them....(being) mimicked, mocked."

(21,7,14-16)

This fear has been acknowledged by Fairbrother (1983). She explains that parents are "back fighting for them, protecting them from a hostile world which rejects them." As a reminder, Brown (1988) says "it is important that we do not discount the protectiveness which parents feel for their own children, who are faced with indifference or hostility, and instead of characterizing it as neurotic, see it as a well-grounded response to the rejections, both overt and covert, which they and their children have experienced." When the professionals attempt to persuade parents to allow their adult sons and daughters increased independence, they are met with resistance.

Most professionals in the study generally regarded parents as an impediment to progress towards greater independence of adults with learning disabilities because of their over-protectiveness. At home, for example, the professionals explained that people with learning disabilities were not allowed,

"even to make a cup of tea in case they get burnt."

(14,7,4-6)

Nor were they,

"allowed to switch on the telly in case

they might get electrocuted."

(13,5,10-11)

Due to her personal experience, a staff member recognised the difficulties that are involved in having a family member with a learning disability. She observed,

"(For some parents) it's easier to do things for their son or daughter....it makes life easier.....it's more of a bother to let them do (an activity and) supervise (them) than it is to do it theirselves."

(14,6,21-6)

The professionals' empathy for parents is not sustained. There is a limit to what they see as acceptable protective parental behaviour. Beyond this they perceive parents to be 'over-protective'. This fundamental difference causes a great deal of tension between the two groups and leads the professionals to believe that parents are an impediment to progress. Most staff claimed that parents were the main hindrance to their work. Examples of their comments illustrate this,

"Parents are a major hindrance."

(21,4,5)

"Main hindrance....parents, I would think, if I'm truthful."

(14,3,20)

"(I) can see some parents as a hindrance."

(21,4,5)

Fundamentally, the hindrance is based on conflict between parents and professionals. It concerns each group's expectations of and attitudes to the people with learning disabilities because each group has its own ideology of learning disability. Although the people with learning disabilities connected with the study were adults, their parents referred to them as 'kids', 'boys and girls', 'children', or 'the wean'. Their view was of a dependent son or daughter who retained many child-like qualities, requiring parental guidance on a life-long basis. This is reminiscent of Wolfensberger's (1972) concept of the "eternal child" and Greengross' (1976) "Peter Pan syndrome" or the "infantilization process". A point made by a professional illustrates this,

"I think some parents might be used to speaking for their son or daughter....they might find it difficult that (he or she) is able to speak for themselves and maybe has a point of view that they didn't know they had."

(15,5,24-7)

Staff members were vehement about this issue, to such an extent that one professional claimed that people with learning disabilities were,

"abused at home, financially, you know, socially, not getting out..."

(18,13,21-2)

Professionals, however, saw these same adults as potentially able people with the rights for greater independence and self-determination. One mother revealed that the staff,

"tell you that (the daughter) I see is not
the (same person) that they see."

(19,3,10)

These views constitute a major division between parents and professionals. This division results in direct conflict between the two groups, as observations of meetings between them confirm. Each group sees the ideology of the other as threatening, with the possible loss of power and control their position holds for them. The issues of sexuality and sterilisation heighten this anxiety and serve to magnify the polarised views of parents and professionals.

In the light of their own experiences, parents view staff as impractical and unrealistic. This could be due partly to the nature of the professional relationship with people with learning disabilities. The quality of the parental relationship is essentially different to that of the professionals. Generally, the professionals do not experience the effects of living with a person with learning disabilities in the family, nor will they experience long-term responsibility for them. Cunningham and Davis (1985) state that "the parents will have more interactions with their (son or daughter) in a wider range of situations than the professional". They go on to say that "parents are more emotionally involved (and) will have more intense reactions and feelings to the total spectrum of (his or her) behaviour than professionals." Parental pragmatism is a result of this holistic experience. Commenting on professional ideology, one mother said,

"I think that it's not practical...."

(19,8,36-7)

"I think some of (the staff) read far too
many books....."

(19,11,33-4)

Her opinion was echoed by another carer,

"The choices (the staff) are talking about is (sic) unrealistic."

(20,8,33-4)

In the words of a carer, the difference between parental and staff understandings of people with learning disabilities are clear,

"You've got to remember their mental age is eight or nine, or six, an age like that. (The staff say), 'Not at all, not at all, they're adults.' Okay, their body's an adult, but I mean, their mind isnae."

(20,8,35-8)

The carer in this instance referred to sexuality and, again, the differences of opinion between staff and parents are clear. A member of staff had suggested to her that her brother, who had a learning disability, might get married sometime in the future. To which she had replied,

"Och....away you go and don't be so stupid, (he) couldnae."

(20,9,4-5)

The different estimates of the capabilities of people with learning disabilities creates uneasiness in the parents. They have a choice to make: between what they believe to be true and what they are told by an 'expert'. It is a dilemma. The parents, in their low status of carers and often feeling vulnerable when confronted with authoritative claims, unsurprisingly doubt their own natural judgements. It is an unresolved tension and one which is usually accepted without critical analysis. One carer explained that at a review of her brother's progress, the staff,

"told me all the things that he's done. I says, 'He cannae do them.' 'Yes, he can.' I says, 'He can't. I've tried it.' They say he can go swimming. He's been once, but he cannae swim."

(22,7,22-5)

Disbelievingly, she said,

"They were telling me things that I knew (he) couldn't do, but they said he can do them."

(22,3,16-18)

This unresolved conflict can undermine parental confidence as well as reinforcing feelings of professional superiority. Evans, Forder, Ward and Clarke (1986) note: "The training of professional workers is deliberately designed to create or reinforce the belief in the superiority of the informed judgement of the professional worker over the intuitive or commonsense approach of the layman." One mother was resigned to this. Regarding her daughter with learning disabilities, she said,

"(She) seems to be a lot more capable than we give her credit for."

(19,2,24-5)

Staff expressed higher expectations of people with learning disabilities than parents. The parents in this study were given the following list of ability levels:

- a. Mild
- b. Moderate
- c. Severe
- d. Profound
- e. Don't know

These categories of learning disabilities were originally defined by the World Health Organisation (1977). They were considered to be more suitable to this study because they offered more choice than the categories of "mental impairment" and "severe mental impairment" (Mental Health (Scotland) Act, 1984). These categories are only an indication of the general level of functioning because it is accepted that "intellectual abilities, and also social competence, form graded continua, so that any dividing line must, in effect, be arbitrary" (Clarke and Clarke, 1985). Most parents were asked to assess their son's or daughter's ability level using the above list and their replies were compared to those given by the keyworkers. The following comments illustrate the disparity between parental and professional assessment. A parent described her son, saying,

"I would definitely say he was severely handicapped."

(10,2,13)

This contrasts with the keyworker's assessment of the disability being "mild" (16,6,26). Another parent described her son as "severely disabled" (3,1,28) in contrast to the assessment of the keyworker, who commented,

"I would say (he) was probably 'moderate'."

(13,11,33)

Interestingly, a similar phenomenon has been described in a study by Roy, Corbett, Newton and Roy (1993).

They went on to say however that not only did parents underestimate ability levels, but they also overestimated the risk of pregnancy of their daughters. Parents believe that professionals are "pushing them" (19,5,32) and therefore are dissatisfied with this situation. They believe that people with learning disabilities could be put at unnecessary risk. One mother questioned the aims of the professionals,

"Why put her in danger?"

(19,6,13)

and

"Why put them in that position?"

(19,9,8)

The differences in expectation and assessment between parents and professionals cause severe tension. Parental anxiety and fear of the possible adverse consequences for the person with learning disabilities is re-kindled and exacerbated by this conflict arising between staff and parents. A mother expressed her anxiety,

"(Parents) are worried in that I think Adult Training Centres now tend to be almost promoting (sexuality) and I've heard other mothers say how worried they are about this."

(3,9,21-3)

Where sexuality is concerned, the tension between parents and staff is at its acme. It is a complex area where personal feelings, fear of consequences and the power struggle between parents and staff, occur simultaneously. This power struggle is based on the conflict between parental pragmatism and professional expertise.

b. Professional Expertise

Many of the professionals in the study clearly saw themselves as 'experts'. This is apparent in their own words,

"Some of them see me as someone they can come and talk to and use."

(18,7,19-20)

"I would like to think that we're really approachable. If a parent or a carer has got any questions they could 'phone up and (I'd) be able to speak to them no problem."

(15,4,17-19)

"So I says, 'She's going through adolescence.' And I think...this woman thought...because her daughter had learning disabilities, she wasn't gonna go through the normal stages of development...a lot of them will (say), 'Oh, I didnae know'."

(15,5,31-5)

"The mystique which surrounds professionals in society" (Robinson, 1991) enables the staff to "maintain a view of themselves as doing something essentially different to and (because (they) are paid for it) of more value than parents" (Brown, 1988). Consequently, parental self-confidence is undermined:

"If they showed me, or told me, what they were doing with him..." (22,3,22)

but

"....they don't explain anything to you about them."

(22,6,37-8)

The carer in this example believed that she could learn from the staff, but at the same time was overwhelmed by their authority and therefore did not actively pursue explanations from them. Wistfully, she admitted she would be prepared to

"actually (see) what they're doing, know if you can, I've never asked."

(22,3,23-5)

It did not occur to her that their skills were perhaps no greater than her own. Instead, she placed a committed and unquestioning faith and trust in their expertise. In some instances, the professional expertise resulted in parents feeling inferior and worthless. Examples of this are:

"I think (staff) think we're an awful nuisance."

(19,8,10)

and

"Sometimes I think (staff) just push you out the road."

(22,6,36)

The powerful image of authority created by the staff resulted in parents seeing them as "unapproachable" (20,6,8) and the consequences were observable in most parent-staff interactions. Some parents waited passively until staff requested them to attend the Adult Training Centre for a review of their son's or daughter's progress. Alternatively, they waited until there was a behavioural or situational crisis when communication with staff would then

be inevitable. A carer was unsure of her position in her relationship with staff,

"I don't know whether you can 'phone these places (ie. Adult Training Centres) and complain."

(22,5,30)

Parental feelings of helplessness can result in passivity. Additionally, in allowing professionals to assume their rôle of 'expert' unchallenged, this inertia was misinterpreted by staff, who said,

"Parents just don't seem to give a monkeys"

(12,8,8)

and, according to staff, some parents,

"don't hold a great deal of interest in actually what their son or daughter's doing."

(16,5,15-16)

This view was also reflected in other comments made by staff,

"There are a number of parents who see it as a babysitting service, if I'm truthful.... (Because they want)...to get their son or daughter out of their hair for the day.... That's all they're looking for I feel."

(14,6,7-11)

and,

"We're more of a respite service."

(13,4,10)

Professional power was reinforced by the way in which they used authoritative and corrective tones of voice and language. An example of this was revealed when a carer confided (almost conspiratorily, as if fearing punishment),

"If this gets back to (the staff)..."

(20,5,16)

"...I get into trouble for calling (people with learning disabilities) 'boys and girls'. (A member of staff) gets me into trouble 'cos (*Speaks in a high-pitched 'posh' voice*) 'They're men and women, not children' (*Laughs*) I keep getting told."
(*Laughs*)

(20,14,27-30)

As noted earlier, there was a marked difference in the use of language between parents and professionals when referring to learning disability. This symbolises the different ideologies each group holds. During a meeting, a professional's irritation became apparent when a parent referred to adults with learning disabilities as "children".

"(She) snapped, 'You'll get thrown out' and then immediately laughed, as if joking, which only fractionally lessened the unease her remark had caused."

(02,6,37)

Most of the parents in the study described their sons and daughters as "mentally handicapped". By contrast, this label was avoided by most staff because it was regarded as being archaic terminology. It was also politically incorrect, being what Bogdan and Biklen (1977) term

"handicapism", which they claim is discrimination, not unlike racism and sexism. A member of staff incidentally used the term 'mentally handicapped' when he was not being audio-recorded. He said that he did not "dare" to use this label in the presence of his manager. Another member of staff, from a different establishment, said that a manager would, "haul you over the coals if you use that word, that phrase, 'mental handicap'" (12,7,31-2).

Most of the professionals in this study assumed the rôle of 'expert' model. A young member of staff with one year's experience of working in this field, referred to the future needs of people with learning disabilities and said patronisingly that one of his aims was to,

"try to allow parents to become more aware
of the future"

(16,6,1)

but not all staff members were convinced by their professional image. Other comments are revealing:

"I think there's a sort of tendency to be
false in the type of approach that we
have."

(13,10,29-30)

"(and that they should) just tell (the
parents) the whole thing straightforward
from the beginning, not hide anything."

(15,5,3-5)

Professional ideology governs the views of the staff, although variations of ideology exist. These will be explored in the following Chapter. Parents' ideology is grounded in their experiences of caring for and living with a learning disabled member of the family. Both groups believe that their views are correct, thus making the

differences between them irreconcilable. Several comments from carers illustrate their feelings about their special knowledge:

"Parents know best when it comes down to it."

(5,6,18-19)

"I think the person that lives with them knows them."

(20,14,7-8)

"(Parents) know them better than anybody else...(and) know actually what they can do."

(22,11,36-7)

There was some criticism of and cynicism towards professional 'expertise'. One mother expressed her view:

"I think sometimes they think they know more of our kids than we do."

(19,8,14-15)

Professionals were "seen as busybodies" (13,4,12-13) and were especially unwelcome if, for example, there was sudden interference after a lifetime of neglect:

"I have been left to bring up this child on my own for the past nineteen years without anybody's help, thank you very much, and now all this suddenly, the first important decision is to be taken, I need somebody's say so. No, I don't think so."

(5,11,29-33)

The mother regarded this intervention from professionals as a "terrible slight" on parents, and went on,

"It's like, 'oh, you've been good enough for all these years, but now, you know, you don't know what you're talking about.'"

(5,11,37-8)

Parents have had various experience in dealing with professionals. Their present reactions are often influenced by the result of the culmination of these, usually negative, experiences from the time they first learned that their baby had a learning disability. Several studies have shown that communication problems, or indeed, lack of communication, between doctors and parents have increased parental trauma on discovery of their child's disability. This has led to "parental dissatisfaction with the treatment they have received" at these emotional times (Nursesey, Rohde and Farmer, 1991).

There were other sources of annoyance to parents. The two following examples concern people with learning disabilities who were involved in 'incidents' at one of the Adult Training Centres. The feelings of the carers were similar, but their reactions were different. After one incident, the carer explained,

"I was angry about that. But I says,
'Well, I cannae do anything about it.'"

(22,5,29-30)

After an incident that had recurred, another mother said,

"After the second time I was really
annoyed."

(3,9,15)

She had made excuses for the staff the first time the incident had occurred,

"But not the second time. The second time wasn't acceptable."

(3,9,17)

She had

"ended up making an official complaint about it down at Headquarters."

(3,9,12)

This latter example shows that parental assertiveness towards professionals, however limited, does exist. In some instances, parents have been described by staff as aggressive, there being "some crackers, effing and blinding" (18,9,38) and others having "written threatening letters" (18,7,9). A member of staff said that,

"You can be challenged a lot on your approach"

(14,3,26)

A carer explained how she had challenged the staff on the use of the hairdressing salon at the Adult Training Centre.

"I think only once or twice I ever saw anybody in it. When I brought that up I was told it was used every day."

(20,3,37-8)

Such communication epitomises the professionals' authority. They hold power in the framework of their professionalism. Parents, by contrast, hold power because of their relationship with their adult sons and daughters.

c. Parental Power

A professional expressed his shock when he realised the "amount of control parents actually have" (13,8,14-15). It is clear that people with learning disabilities have "great loyalty to parents" (14,4,5-6) and, before commencing a new activity will usually say to professionals, "You'll have to speak to my mum and dad" (14,4,20). A member of staff described what he believed the situation was at home,

"If the parents' wishes are obeyed, basically then, they will pile on the pressure when they get home. It's a case of, 'You will NOT go out', 'You will NOT do this', 'You will NOT do that'."

(13,4,27-9)

What has "probably been instilled by family and extended family (and) relations" (12,9,35-6) has repercussions affecting people with learning disabilities. This is illustrated in the following:

"She's probably been led to believe that it's not possible for her (to have children).... as many of our clients have been told these sort of things."

(12,6,33-5)

"She's been well-primed by mum....that possibly relationships are not for her."

(12,4,25-7)

If a relationship exists,

"It's gonna have to develop with help from parents. They've got to be supportive."

(16,9,18-19)

Approval, and in some cases permission, from parents was often sought for specific teaching programmes, such as for independent travelling or sex education. Whatever the parents' wishes were, the professionals believed they must respect them, even to what they may have considered was "the detriment" of the person with learning disabilities (21,5,18). This particular view has serious ramifications for people with learning disabilities, as well as calling into question the aims of the service. The consequences of this also affect the process of decision-making regarding sterilisation and other issues of sexuality. It also exemplifies the importance and power of the parental rôle. A professional explained his position,

"If a parent says 'No' and I continue with it, then I'm breaking the rules. I could end up with my head on the chopping block....if anything should happen to that person."

(21,5,20-3)

He added,

"At the end of the day, the parents' wishes are always what we adhere to."

(21,6,35-6)

A member of staff also gave an example of this,

"It's a case of (the parents saying), 'Oh, no, (my son or daughter) can't do that' and that's the end of the story."

(12,3,36-7)

In the light of the staff views of parental power, it is not surprising to discover their consequent feelings of helplessness. They explained their predicament,

"It all depends if the parent or carer is really really against it, then you really can't (do anything about it)."

(15,5,8-10)

and so "we back off" (13,4,23). Another illustration of this is,

"You're maybe not totally comfortable with (the situation) but you end up having to go with (it) because that's the way parents would like."

(14,3,31-2)

The feelings of helplessness induced by parental power gave way to frustration (14,3,36-7; 14,7,10) and disillusionment (18,5,14). Other situations also induced feelings of helplessness in staff. Through lack of training, "(staff) were out of their depth" (18,5,36) dealing with people with learning disabilities who were bereaved. In addition, a professional referred to the inefficacy of staff should other emotional difficulties of people with learning disabilities arise, such as post-natal depression (18,12,1-2).

One member of staff freely admitted to his feelings of isolation and powerlessness. His comments also serve to illustrate the differences between staff and parents,

"I seem to be stuck in the middle somewhere because often the management dictate what I've to do, but it may be

completely different from what the parents would like, so I'm sort of in the middle and I've got to try and keep both sides happy."

(16,4,31-5)

This is an example of a professional concerned about the relationship which exists between the two groups. The main issue that he was concerned with was diplomatic peace-keeping. The effects of the tension between the parents and the professionals on the people with learning disabilities was of secondary importance.

Despite their professionalism, staff also experienced anxiety and fear, although the causes of these emotions differed both from parents and from one individual to another. They included meeting the emotional needs of people with learning disabilities and communicating with parents (18,6,4); job security (21,7,36); and sexuality of people and its legal implications (14,1,21).

On meeting parents, staff admitted to feelings of apprehension, "I was really nervous about it" and "it was my biggest fear, the day we had a parents' day" (18,6,1). This was also observed at two different meetings of staff with parents. While waiting for the arrival of the parents, one staff member walked restlessly around the room (01,2,22); another staff member appeared nervous, rushing into the room to tell her colleague in a low excited whisper that a particular parent had arrived (01,2,23-5); a staff member was very nervous speaking to the parents at another meeting (02,3,12); and after the close of one meeting, a staff member "exhaled heavily, saying that he was glad that it was all over. He admitted that he had not been looking forward to the meeting. Now that it was over he looked relieved and more relaxed" (01,12,24-7).

As far as sexuality is concerned, for example, professionals felt that "we cannae promote it, we cannae

promote anything" (13,12,10-11). When asked about their professional responsibility for the sexuality of people with learning disabilities, for example, offering information about contraception, many professionals were "unsure" of the legal boundaries and said it was a "grey area" (17,4,4-5). Some staff admitted to being "not sure about my own remit" (12,8,16). For others there were mixed feelings about whether it should be part of their responsibility:

"I would feel (responsible). I don't know how I would act upon it."

(14,11,33)

"Yes and no. Yes and no."

(13,16,11)

"I'm sure it is."

(16,9,12)

"If they'd came and asked me about it, yes."

(15,8,20-1)

It is clear that these professionals did not have any policy guidelines on this matter. As a result, no action was taken and the staff remained helpless and passive on this issue.

There are other factors in the relationship which produce tension and lead to conflict between professionals and parents. One of these is that parents have been disappointed with social workers:

"We've had two that didnae give a tuppenny damn."

(7,7,35)

Another parent's disappointment was clear,

"A social worker's supposed to come and see me, but I've never had any word yet."

(4,1,33-4)

d. Communication

Another factor negatively affecting the relationship is the communication between them. Comments made by professionals reveal their beliefs that communication is important:

"I think there's got to be a certain amount of communication."

(15,3,38)

"It's good to have as much contact with parents as possible."

(14,8,10-11)

Communication between them, however, varies considerably both qualitatively and quantitatively. The following examples demonstrate this:

"(We) didn't have a good relationship."

(12,3,8-9)

"(The relationship is) an example of kind of a wee clash."

(16,5,26-7)

"I haven't really had a great dealing with (or) direct contact with (parents)."

(16,5,1)

Some parents apparently,

"Don't actually come in and talk to staff....especially men....don't like to come in to theCentre at all"

(18,7,20-2)

but, likewise, staff can also sometimes avoid initiating contact with parents:

"We don't always 'phone parents....it's no' always the parents' business(ie. sexuality)...you don't want to tell them."

(13,6,24-7)

One carer offered to work in collaboration with the staff. She suggested to them that she could help in teaching her disabled brother how to put on his jacket by himself and how to fasten the jacket's zip. Resignedly, she explained,

"I says, 'Well, if you keep in contact with me with all these things', I say, 'I can help him in the house as much as I can.' But I've never, ever had the 'phone call to say, well, 'We're into another bit'."

(22,7,35-8)

There is

"definitely a lack of communication between parents and staff"

(18,4,38)

and therefore it is not surprising that "things can get confused" (18,4,34-5) and that the relationship is "tricky at times" (12,3,4). This lack of effective communication is

problematic, but it is a symptom of the gulf between parents and professionals rather than being its source. The situation is obviously more difficult for the parents if the person with learning disabilities is unable to communicate,

"So I don't know what he's doing at the Centre because he doesn't tell me what he's doing."

(22,8,1-2)

During the observations of meetings between staff and parents, the issue of the lack of communication was raised. Parents complained of the omission by staff to inform them of certain events, which had caused parents a degree of inconvenience. There were several examples of this. One mother had helped voluntarily with swimming events and had travelled a long distance to the pool. On more than one occasion she had not been informed that the event had been cancelled until she arrived at the pool and there had "discovered it was off" (01,6,8). She felt that the apparent lack of consideration for her was demeaning.

A man with learning disabilities, attending an Adult Training Centre, had epilepsy. His parents wished to know how frequently these seizures occurred but they received "no notification from the Centre" regarding them (01,11,33). There was also parental confusion about activities at the Centre through lack of communication from the professionals (02,8,16-19).

The staff realise that good communication with parents is advantageous for various reasons. In one example, such communication links had the effect of controlling the challenging behaviour of a particular individual with learning disabilities (11,2,22-3). Another positive aspect of good communication was seen by professionals as being able

"to continue to persevere with parents to help change their ideas and views."

(21,6,38)

Any controversial or sensitive issue would have to be "introduce(d) gently" (13,5,17) because,

"if you take too bombastic a view, then you're obviously going to get folks' back up."

(13,5,18-19)

To maximise the potential that good relationships can nurture, one Adult Training Centre in the study held informal meetings between parents and the staff. These were known as "Tea and Chat" meetings. As their name suggests, they were intended to be informal and friendly social encounters. Some professionals explained why the meetings were held. They were "to introduce ourselves" (14,7,28) and to get

"to know a bit about the home background....wee habits 'n' that."

(14,7,35-7)

"(and to) get the parents to know me a bit better, allow me to get to know the parents better."

(16,5,6-8)

The "Tea and Chat" meetings were, however, more than mere introductions and informal chats. There were hints at such with their aim being described as "just to sort of get everything out in the open...." (16,5,6) and "maybe to reassure or say 'Everything's gonna be okay'" (15,4,8). A more accurate description of these meetings was,

"You get the moans...the things that (parents) would like.....it gives you a chance to chat and put why these things are happening."

(14,8,5-8)

From these illustrations, the "Tea and Chat" meetings gave the impression of equality and partnership with parents. In practice, this was an illusion because the meetings serve to reinforce the 'expert' model of professionals, relegating parents to a lower status.

4.iii. Observations of Meetings Between Parents and Professionals

Observations were made of two "Tea and Chat" meetings held between professionals and parents. At one of these meetings, people with learning disabilities were also present. They contributed little to the substance of the meeting, but it was interesting to observe the behaviour of the two groups towards them.

The "Tea and Chat" meetings, in particular, emphasised communication problems between the two groups. This resulted in tension and occasional conflict. More importantly, however, the rôles of each party were clearly delineated and established by the professionals. It was they who had organised the meetings at the Adult Training Centre and who were in control of their own agenda. The parents attended the meetings after receiving formal written invitations.

Data from individual interviews with both professionals and parents were consistent with the observations of the verbal and non-verbal behaviour and communication between them at these meetings. The meetings emphasised the differences between passive and active

parents and they also revealed the "tribalism" (Dalley, 1989) as well as the teamwork of the professionals.

It was during the meetings that it became evident that professional and parental rôles assumed a major significance in their relationship. As the two groups interacted, insight was gained into the complexities of this relationship. Pragmatism, cynicism and anxiety were the salient features portrayed by the parents. These were revealed through their challenges and complaints to the staff. As a reaction to the subsequent conflict, professionals defended themselves through teamwork. They asserted their 'expert' authority in an attempt to retain control of the situation and their image of power over the parents. This type of behaviour is explained by Evans et al, (1986), who say that "professionally qualified workers react strongly to the 'amateur meddling' of lay people, and to anything that feels like a questioning of their professional judgement. Such things undermine the foundations of their professional self-image."

The name "Tea and Chat" suggested familiarity, warmth and friendliness. It is not surprising then that most parents were ill at ease when confronted by formal and business-like introductions at the meetings. The setting for one "Tea and Chat" was unwelcoming. The room

"was prepared for this meeting with...hard formica chairs arranged to form a large circle in the middle of the room...It looked bare but functional...It was cold."

(01,2,1-9)

Refreshments were set aside, but as there were no references to them, the parents took the initiative and helped themselves to tea and coffee (01,2,28).

The business-like manner of the meetings was set by the professionals. They were formally opened and then each person in turn was requested to introduce him or herself to the group (01,3,12; 02,3,5-6). This created a level of tension among the parents. It was exacerbated by one of the professionals pre-empting the parents from talking "specifically about (their) own case" until after the meeting when "referrals" would be taken (01,3,35-6).

Specific incidents within the meetings illustrate and emphasise particular characteristics of each group. Parents' pragmatism, for example, led them to state that people with learning disabilities "must be stimulated" (01,8,35). This is a source of conflict with some professionals who argue that people with learning disabilities should only be 'stimulated' if they wish to be. A mother firmly believed that if people with learning disabilities were given choices, the result would be that they would not make any decisions at all,

"I think we all have to do some things in life for our own benefit which we don't particularly enjoy doing and I think there might be a terrible danger in just lazy people becoming more lazy, being allowed to become more lazy."

(01,8,25-8)

Their abilities to make choices was also questioned by parents. A carer commented on this issue during an later interview,

"Just because he wants to do it, doesn't mean to say it's all right for him."

(20,9,14-15)

This is not to say that parents are totally opposed to people with learning disabilities having choices and making their own decisions. They are more cautious and hesitant than professionals in initiating opportunities to exercise choice. This is because parents hold the ultimate responsibility for them. This has particular significance in respect of the sexuality of adults with learning disabilities and for decision-making regarding their sterilisation or other contraceptive use.

The parents stated that their sons and daughters were vulnerable to coercion and so asked the professionals how they would distinguish 'real' choices from choices made to please others (01,9,1-3). An example of this was given by a mother who explained that her son would agree to travel independently, "but will then panic" (02,7,13). The aim of independent travelling became an issue of conflict at the meetings between staff and parents. One parent, who was opposed to the independent travelling scheme, argued against it saying that her daughter was "never used to buses because we don't use buses" (02,5,19-20): the family always travelled by car. This practicality dissipated the argument. Due to easy accessibility to family car transport, another parent in a later interview reiterated the same point,

"(my daughter) doesn't require to do it.
She doesn't need to do it. She'll never,
ever need to do it."

(19,6,9-10)

The professionals tried to alleviate the parents' anxiety by reassuring them that they did not "want to make people feel vulnerable" (01,7,25) and that "nobody (was) at risk", being given "maximum support" (02,6,1-3) at all times. Some parents were not convinced by these words of reassurance, and remained cynical.

Some parents said that their expectations for their sons and daughters had been raised in the past but the plans made for them by the professionals "in practice don't work" (01,5,12-13). This cynicism produced tension which resulted in the professionals being defensive and resorting to formal language and jargonised expressions. The professionals talked of a "structured programme" (01,4,27), "age-related activities" (01,4,35) and "previous recommendations" (01,9,18). They described further education tutors as "processing" and "identifying" individuals and how the "allocation of tutor-time" was "linked into tutor facilities" (01,10,15-22). Some situations, the professionals added, were "outwith (their) control" (01,10,31).

Most parents that attended meetings such as these were 'active' and assertive. One parent in particular had "loads of questions" for the professionals to answer (01,5,5). It is not surprising therefore that there were direct challenges to staff on various issues that caused them dissatisfaction. Regarding the future plans and timetable of activities for people with learning disabilities, one parent bluntly asked,

"How will this work and not fall apart?"

(01,5,11-12)

Cynically, she added,

"After the first week it all falls apart....it becomes a joke."

(01,5,11-12)

Further dissatisfactions and complaints ranged from lack of communication from professionals to their son or daughter having insufficient activities at the Adult

Training Centre. One father reported saying disbelievingly to his son,

"You didn't sit there and make tea all day."

(01,8,3)

Parents were disappointed that they had been "let down so many times" (01,11,23) by the "awful imbalance of service here" (01,10,30). Dismayed at the high number of key workers that her son had experienced, a parent asked staff, "Are you permanent?" (01,9,9).

Hostile conflict arose on several occasions during the meetings with both groups contradicting each other (01,5,20-1; 01,6,15; 02,6,11). Evans et al (1986) describe the "destructive effect of mutual suspicion between parents and professionals", saying that "face-to-face contact can sometimes produce bruising conflict." They explain that "parents may be over-zealous in putting their point of view, without realising that the professional workers, seeing themselves as caring people, may take this as personal criticism and become antagonised."

It was during these altercations that the staff displayed professional teamwork, using "presence of mind" (Goffman, 1959) to help their colleagues in difficult moments (01,4,29; 01,5,7/13; 01,6,9). The teamwork was apparent as the professionals 'closed ranks'. Occasionally, the professionals could not answer unexpected questions. Their embarrassment was prolonged if a colleague was unable to "cover up on the spur of the moment" for them (Goffman, 1959). Only one professional was openly disloyal. He told parents that what his absent colleagues had said was untrue. Generally, however, the members of each group supported one another. Their need for alliance was strongest at moments of antagonism. This was called for by one parent to another,

"...you've got to back me up on this..."

(01,6,3-4)

A professional rôle, however, allows individuals to "suppress his (or her) emotional response...to the audience when they induce untoward...hostility in him (or her)" (Goffman, 1959). After one meeting, a professional expressed concern about his 'performance' and whether he had been aggressive towards the parents. Another professional duly reassured him, quashing his fears (01,12,30-1). According to Goffman (1959), these are "shared staging problems; concern for the way things appear" to the audience of, in this case, parents.

Not all the players exhibited the same degree of professionalism. During a heated debate, a member of staff rudely told a parent to,

"wait a minute....you're not listening to
what I'm saying....you seem to forget..."

(02,6,25-34)

She also suggested that the protectiveness this parent felt towards her learning disabled son was "a problem".

At most times, the staff strove to maintain their authority and their images of power, control and expertise. In so doing, some of their remarks were patronising. The parents wanted to know what their sons and daughters actually did at the Adult Training Centre during the day. They were unable to discover this through communication with them. A member of staff told them that this was because the people with learning disabilities chose not to talk to their parents about their activities in the Centre. She warned the parents from pursuing their questions, saying,

"You've got to think of people's dignity and respect."

(01,6,16)

She clarified this by saying,

"I think it's striking a balance between respecting people's wishes of privacy and having ownership of what they've done during the day.....But you still must be able to respect their right not to want to share itwith you."

(01,8,4-10)

Conflict at one of the meetings manifested itself between professionals of different establishments. This was noted in an earlier interview with a professional (13,3,10f). Conflict of this nature affected not only an emphasis on the amount of technical language (01,9,13), but the professionals, in defending themselves, assumed more authoritative tones of voice and assertive body language (01,9,17).

The meetings ostensibly concerned people with learning disabilities, but their hidden agenda was the power struggle between professionals and parents. Several times parents made suggestions or offered to help on a voluntary basis, but were discouraged or refused. One parent who was willing to volunteer her help said,

"It's a pity we haven't been asked."

(01,6,26-7)

The professionals were successful in maintaining their position of 'expert', in controlling and making decisions. A carer suggested that a particular service in the community could be used by people with learning

disabilities to supplement the activities at the Adult Training Centre. The staff replied that the people with learning disabilities "might prefer elsewhere" or that there would be "difficulties in getting there" and then added, "we know about these facilities but we don't want to swamp them" (02,6,15-23). This carer later discovered that the staff had not known about the service she had suggested. Ironically, they were investigating the facility with a view to implementing her suggestion without due acknowledgement to her.

Professional jargon rarely ceased to be effective, but occasionally it was discarded and the professionals appealed to the parents,

"We do our best....we just do the best that we can."

(01,10,32-3)

"If (the programme) hasn't worked, please feel free to slag us off, but in the meantime offer us as much support as you can."

(01,11,15-17)

This abrupt change of style by the professionals seemed to be an effective tactic. Some parents appeared to be mollified by it and subsequently spoke in reconciliatory tones,

"I'm actually delighted, I'm over the moon that you invited us here today in a group setting."

(01,9,27-8)

and,

"I think it's wonderful to hear you being so enthusiastic. I just hope that you personally get the chance to see it all work."

(01,11,8-10)

Such words in fact heralded the imminent close of the meeting and were no more than a veneer for the underlying tension between them.

4.iv. Conclusion

From the data gathered in this study, the beginnings of a substantive, grounded theory of the relationship between parents and professionals has been formed. This will be expanded in the following Chapter. The relationship in question is characterised by tension, which can lead to conflict. The relationship is confined, however, within a framework and is dependent upon it for its existence. This framework is the product of the interaction of rôles rather than of individual personalities. Mittler's (1983) recommendations that professionals will "need to enlarge their own understanding of....the infinite range of personalities which they will encounter in parents" is misplaced in its comprehension of the nature of this relationship and its inherent conflict.

Within this framework are the key players: the professionals, the parents or other carers, and the adults with learning disabilities. It has been acknowledged that problems exist in this type of relationship (Mittler and McConachie, 1983; Cunningham and Davis, 1985; Evans et al, 1986; Brown, 1988; Twigg, 1989; Robinson, 1991). It has even been suggested (Lloyd-Bostock, 1976) that these

problems can appear greater than those arising from disability itself.

There have been various theoretical interpretations of this parent-professional relationship, resulting in the description of various models of rôle behaviour. Cunningham and Davis (1985) share the ideas of Mittler and McConachie (1983) by examining the relationship from a professional viewpoint. They describe various professional rôles: the "expert" model, the "transplant" model and the "consumer" model. Briefly, in the first example the professionals assume expertise and as such are "likely to increase parental dissatisfaction by failing to meet their expectations". The "transplant" model blends professional expertise with the view that parents are "resources" and that collaboration with them would be in the best interests of people with learning disabilities. Finally, the "consumer" model regards parents as consumers, thus being in control and making choices regarding the type of services their sons and daughters receive.

Using these interpretations, in this study all professionals assume the "expert" rôle model. The "Tea and Chat" meetings, *per se*, suggest however, that there could be some effort towards the "transplant" model. In terms of the "consumer" model, some of the professionals attempt to promote the people with learning disabilities as consumers (by giving them choices), rather than the parents. These expert and consumer models combined produce conflict between parents and professionals.

Twigg (1989) examines the relationship in terms of the parents or carers. She "outlines three models that provide frames of reference for this relationship: carers as resources; carers as co-workers; and carers as co-clients." In the study, it is interesting to note that one staff member explicitly stated that he "would see (parents) as clients" (18,7,4).

It is possible that this type of framework of relationships exists in other professions. Much depends on the concept of professionalism (Wilding, 1982). The increasing emphasis on consumerism and individual rights affects this general area of social policy (Rowley, Welsh and Reid, 1994) and concerning learning disability in particular (Scottish Human Services Trust, 1994). To be successful, the innovations produced by the latter would necessitate the 'expert' model of professionalism becoming obsolete. Some of the Adult Training Centres in the study are changing their aims to accommodate consumerism, which is adding to the extant tensions and conflict between parents and staff. The Social Work Department in Strathclyde (1994) omitted to acknowledge this problem. Instead it noted the "conflict which will necessarily arise from time to time between the interests and wishes of *service users* and *their carers*." This is in direct contradiction to the claims made earlier by Fairbrother (1983), who says, "parents' rights and the rights of mentally handicapped people do not conflict; they are in harmony". She adds that one of these parental rights "is their right to lead lives independent of their children once they have become adults."

As with earlier writers, Robinson (1991) recommends the relationship between parents and professionals be a partnership. His explanation regarding staff training does not go beyond a superficial level in solving the innate problems in achieving this. He says, "there is insufficient training of professionals to prepare them for a partnership rôle", so that even if they "think they are treating parents as equal partners, they may be controlling the encounters". Mittler (1983), by contrast, believes that a successful partnership depends on the family. He says that the "emotional reactions and practical realities of all the individual members of the family will determine the nature and degree of any possible partnership between the family and professionals". From the data collected in this study, it is clear that Robinson and

Mittler do not take into consideration the incompatibility of parental and professional ideologies of care.

One of the main barriers to success in this relationship is, as Brown (1988) indicates, the difference between "professional assumptions and parental reality" which produce "a mismatch of service and need". As demonstrated, this leads to controversy, hostility and the "polarization between professionals and parents (that) is so clearly marked and so pervasive" (Brown, 1988). Both parents and professionals commented on the poor quality of communication between them. Various tactics were used by the professionals to enhance their authority, as observed in meetings between them. Joking and laughter were also tactics used by some staff to relieve the tension in these meetings (01,3,16; 01,10,8; 02,7,30-1; 02,8,1). It is interesting to note that Goffman (1959) claims "a joking manner (is used) to remove...importance (of what is said)".

It is evident in this study that this relationship is characterised by tension and conflict. This is due to each group's status within the relationship. It is this status that presupposes its particular ideology and understanding of learning disability. These are fundamental differences and, as such, are irreconcilable. This is particularly relevant where sexual matters are concerned. Being emotive and controversial, the area of sexuality epitomises the differences which exist between parents and professionals. The examination of this relationship offers some insight into how the sexuality of people with learning disabilities and the decisions made about sterilisation, are dealt with by the two groups. This will be analysed in the later Chapters.

Chapter 5

PROFESSIONAL IDEOLOGY:

An Analysis of Internal Conflict

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5.i. Introduction

The ideological differences between parents and professionals were analysed in Chapter 4. This highlighted the complexity of the issues surrounding sexuality and people with learning disabilities. The data collected from the interviews of the professionals suggest, however, that their ideology is more complex than first perceived. In addition to those who espouse the prevailing orthodoxy, based on the principle of normalisation, there are those who deviate from it, subscribing instead to an earlier but now superseded orthodoxy. In many ways the views of this latter group are similar to those of the parents.

5.ii. The Prevailing Orthodoxy

Normalisation is the guiding principle for the ideology of care for people with learning disabilities in Britain. The changing terminology used by Nirje to describe learning disability indicates changing perspectives and affirms that normalisation is in a constant state of development. John O'Brien's work (1990) exemplifies this. His 'Five Accomplishments' endeavour to make normalisation more accessible in practical terms to professionals working in this area. This is apparent in a "Changeover" project which was initiated in the early 1990s using O'Brien's basic tenets. A professional interviewed for this study explained the project as follows:

"I'm involved in a thing called 'Changeover', which is based on John O'Brien's 'Five Principles' of five accomplishments, like a re-statement of normalisation. I'm involved, carers, staff, parents. We call them

'**stakeholders**', people who have a vested interest in the Centre."

(18,4,3-7)

He went on to describe "**action plans**" to enable the maximum "**client choice**" (18,4,13/14). Another professional described the effects of the 'Changeover' on people with learning disabilities. She said:

"Centre Members are now getting the chance to say (what)....they think, (they are) listened to a little bit more and they're speaking up, they're getting the opportunity and they're finding the courage."

(15,5,14-18)

The 'Changeover' involves the participation of selected establishments in Scotland, England and Portugal. The effects of this project on professionals' views and working practices highlights the inevitability of change and development in the philosophy of care of people with learning disabilities.

The effects of this developing practice within establishments has been to increase the personal autonomy of people with learning disabilities. This, according to Perrin and Nirje (1985) is at the heart of normalisation. It is the "freedom to live a life based on the same values and on the same terms as others in society". Organisations such as 'Enable' and 'People First' have encouraged the development of self-advocacy groups. Examples of allowing greater freedom of choice to people with learning disabilities were described by the professionals. An example of this was a woman with learning disabilities who lived in a Social Work hostel who frequently went out on her own. Her destination and whereabouts were usually unknown

to the staff, which consequently afforded her total privacy in this respect.

Wagner (1988) states that as "a general principle the more personal a matter is, the more free should be the choice". There are various levels of personal choice allowed by professionals. Tolerance of the sexuality of people with learning disabilities is an example of this. Sexual activity is often seen as conditional. For some professionals it is acceptable only

"providing it was appropriate and that it was with consent of both parties and that they were happy and were not causing any other people embarrassment or hurt or anger."

(34,12,27-30)

Similarly, Brown (1994) points out that "Living as a couple is seen to be conditional on independence skills and financial autonomy both of which are rarely attainable by people with learning disabilities."

By contrast, another professional in the study admitted that their establishment allowed more freedom than would be socially acceptable in the community. He said,

"there's more freedom of expression in here and there's more empathy towards the client group which allows certain types of behaviours."

(35,4,18-20)

He went on to explain,

"It's like a learning process, but again we accept now that some of that learning

process is not acceptable in the community."

(35,4,27-9)

Allowing greater freedom of choice contrasts strongly with past practices. Indeed, "In the past the inability of (people with learning disabilities) to choose and therefore to express their individuality has been one of the main criticisms of....care" (Wagner, 1988). Under the principle of normalisation, the concepts of freedom of choice and individual autonomy are main aims. For some of the professionals who are relatively new to the service this has become an emotional issue. Brown and Smith (1992) comment on this phenomenon, saying "The commitment which (normalisation) can engender in individuals has led to it being likened to an evangelical movement, with associated doctrinal squabbles and schisms." A professional interviewed for this study described his experience of returning to the service after a period of absence. He had previously worked in a large institution for people with learning disabilities. His present employment was in a modern establishment involved with the "Changeover". He expressed his view with quasi-religious fervour, saying that his present employment experiences had totally renewed his "faith" (13,7,38).

Professional orthodoxy promotes the independence of people with learning disabilities as far as is possible or feasible. It is believed that this can be most successfully achieved through making personal and individual choices about their own lives. It is clearly evident from the data that, although the orthodoxy is promoted, not every professional strictly adheres to it at all times. Indeed, this would be an unrealistic expectation. Many professionals deviate from the orthodoxy either in their personal beliefs, which can affect their practice, or in their practice alone, which they may or may not be aware of. These types of contradiction are revealed in the data and are of varying degrees. It is suggested that where there are some minor

discrepancies, it can still be asserted that professionals follow the prevailing orthodoxy. However, where there are major discrepancies, it is suggested that these professionals follow what is to be termed a superseded ideology. (*N.B. For discrimination purposes, professionals adhering to the prevailing orthodoxy will be referred to as 'normalisers'. Professionals following a superseded ideology will be referred to as 'paternalists'.*)

Some 'normalisers', who worked in a residential establishment, felt the need to be protective despite their adherence to the prevailing orthodoxy. One professional described the following situation,

"one or two (people with learning disabilities) here...are still chaperoned because they're young and attractive, they're very immature and they absolutely adore being kissed and cuddled and without a doubt, given the right circumstances they would be, I would have to say 'abused' in terms of the law, they would be abused by other people whether those people would see it as abuse or not is difficult, I'm not sure. But they're unable to give informed consent, so therefore it's our job to ensure that they're not abused."

(35,8,21-8)

This illustrates the dichotomy that exists between practice and ideology. The dilemma that is created is difficult for them to reconcile.

Discrepancies were also present at a terminological level. Despite the fact that professionals are trained to use the currently acceptable terminology, there were occasions when they lapsed. Examples of this

were 'unguarded' moments during interviews when the audio-tape was switched off. It involved the use of labels which had been in common use when they first entered the profession. Labels that were used prior to their entry, however, were not used. More fervent professionals reacted differently to labels. As an example, at one Adult Training Centre a member of staff was shown a list of labelling categories once used by the World Health Organisation (Clarke, Clarke and Berg, 1985). These were mild, moderate, severe and profound and represented various levels of disability. She was shocked that such a list was used in the light of the prevailing orthodoxy. "Ugh!" she exclaimed, "I'm offended. I don't like to use any labels" because, she explained, labels denigrated people (F.29.3.95). However, she used the term "Centre Members" to refer to the people with learning disabilities attending the Adult Training Centre. To discriminate them from the professionals, the latter were known as "Centre Staff". Ironically, in their attempt to equalise people with learning disabilities with other people, another divisive label had been created.

An example of a contradiction in the application of the prevailing orthodoxy concerned small groups of people with learning disabilities going out from an Adult Training Centre. "As opposed to taking groups of ten, we take two, three, four (people)" said one professional (21,5,1-2). In practice, however, there was an occasion when a large number of "Centre Members" went to an Exhibition *en masse*, driven in Social Work Department buses. Another example of taking large numbers of people with learning disabilities into the community was described by a professional as a situation which occurred with the superseded philosophy of care. He said:

"so basically you were a shepherd. You just had this huddle and you moved *en masse* and you were constantly counting heads"

(13,7,31-3)

Wolfensberger (1978) satirically remarks on this practice, "you should make the client group so large that it becomes impossible for the surrounding social systems and resources to relate to them in any way, and so large that even you cannot identify or relate to clients as individuals. And when your clients do occasionally go outside the facility, make sure they go in groups that are large enough so that everyone will notice how different they look." His aim is to emphasise the negative effects of such practice.

By promoting individual autonomy through choice, the prevailing orthodoxy requires the professionals to provide people with learning disabilities with information about the options available to them. By doing this, and through non-directive counselling, they can be allowed the maximum freedom to make informed choices.

Staff are aware that people with learning disabilities are vulnerable to others taking advantage of them. With their more powerful status, professionals could coerce or even control those in their care. Although this is contrary to the orthodoxy, extracts from the data reveal that professionals are aware of this potential which is made explicit by the comment, "we can persuade people to do things they wouldn't ordinarily do". This was stated by a professional who went on to explain that most people with learning disabilities had lives dominated by others more powerful than themselves and as a result were submissive and passive. Similarly, another professional made the observation,

"I find the women (with learning disabilities) very conditioned. They've obviously been told things like, 'You can only have a baby if you get married' because that's a safe thing."

(25,4,10-12)

The Swedish National Board of Health and Welfare (undated) utilised this common trait of people with learning disabilities and recommended that "preventative work" be undertaken with women who they considered to be unable to care for a child. "Preventative work" was interpreted as the avoidance of pregnancy through directive counselling. Although this is an example of past practice, it was a form of coercion deemed acceptable under this Swedish policy. Professionals in this study acknowledged how influential they can be. They also recognised the risk of their being presumptuous about what was in the best interests of people with learning disabilities. An example was cited of a man with learning disabilities who, despite not wanting to be sterilised, could be persuaded by the staff to undergo the operation. A professional reiterated the possibility of persuasion with a woman with a learning disability,

"I think if you said to her, 'Look, this is for your own good', she would be quite happy to go along with that."

(12,8,36-8)

The orthodoxy promotes non-directive counselling to enable people with learning disabilities to make their own choices, but one of the professional's statements contradicts this. She said,

"I certainly think that advice should be on the discouraging side rather than on the encouraging side."

(34,13,16-18)

In addition to coercion, professionals are also able to exercise subtle control over people with learning disabilities. This was revealed when a professional said that they would only encourage a person to have a relationship if he thought they were ready for it. During a

sexuality counselling group, it was clear that the professionals were in a position of control throughout the meeting. An example of this control was observed when a member of staff "abruptly and sharply corrected" a person with learning disabilities (03,3,7). Another member of staff "told them to 'Listen to (....) a wee minute'" (03,4,31-2). It is suggested that the relationship between them is not on equal terms, as the prevailing orthodoxy advocates.

People with learning disabilities are also aware of their position within the tripartite relationship between themselves, their parents and the professionals. This is because of the "communication link" between professionals and parents being "seen as authoritative" (11,2,23). This type of situation could have negative effects on the growth of assertiveness of people with learning disabilities, especially concerning the expression of personal choice.

Some professionals expressed their difficulties in translating ideology into successful practice. One residential establishment, for example, could not provide privacy for its residents. It was also "off-set from the community" (24,1,12) in that it was removed from real life situations. Additional problems were that it did not cater for shared accommodation between men and women and also there were no facilities for couples to live together. Some staff complained of the inappropriateness of the physical aspects of their establishment, in that it attracted negative attention. One building was painted bright green and situated on a hill outside the town. This, again, is reminiscent of Wolfensberger's satire (1978). He said that it is "essential that the appearance of our facility clash with all the other buildings in the neighborhood" and cites an example of "an orange fire escape down the front facade". In the study the large size of the building was also a negative feature,

"I've never liked the size of the building. I've never liked a hundred people in the building. I don't think it's a good idea....I think the Centre Members have lost their identity."

(21,2,14-17)

Another professional believed that a Centre for 100 people was unsuitable according to the orthodoxy. He went on to explain that an improvement would be

"more of a satellite-centre type idea, where you've got one...controlling body who is supervising"

(13,9,1-2)

Progress of the philosophy and the improvements of the practice, it was claimed, were hindered by the lack of support by and within the system. An example of this was the lack of collaboration between staff of different establishments. A professional explained that

"there was no...team-work or anything like that. We suffer here from not having a community-led team"

(18,11,30-1)

It was widely agreed that more support services were required for people with learning disabilities. The levels of support needed were unable to be given by the Social Work Department because of a lack of resources. An example of this was, prior to being seconded on a work-placement or securing permanent employment, people with learning disabilities did not receive education or training in appropriate socio-sexual behaviour. As noted in Chapter 4,

professional support is also lacking for parents. A member of staff held the belief that:

"it's something that we should be looking to removing that responsibility from the carer and say, 'Look, you're not responsible. If you want to be responsible, that's fair enough. If you want to give of yourself, that's okay, but you don't have to, you know, it's a voluntary thing.' It would be a voluntary thing on their part."

(28,27,1-6)

Such hindrances could be eliminated if there was a "stronger stance from the actual system itself" (13,5,38). It was believed by many of the professionals that policies and programmes should be clearly written down with a structure they could easily follow. One professional was adamant in his view that the system should be more directive. He believed that it should dictate the terms on which the service was provided. He said that

"the actual system (should) say, 'This is the control we have when they're here. These are the things that are to happen. (The parents) have no say in what happens when (the people with learning disabilities) are here or there is no service (*Laughs*). And that's the only way you'll actually see folk going to get any true benefit."

(13,6,3-7)

Professionals were clearly dissatisfied. One said:

"I'm at a disillusioned stage myself. I think we try and focus so much on the physical and on the social side of things...I think they just completely miss so much on meeting people's emotional needs, really. I really feel about that."

(18,5,14-18)

Although there are difficulties resulting from the practical administration within the Social Work Department, professionals believe there are other fundamental problems. One said:

"Care in the community's great on paper and from ideas, but the support, I feel, it's a let-down. In theory it's excellent, it works, in reality it sort of lets itself down somewhat."

(21,12,38/ 21,13,1-3)

A professional believed that more insight was needed, in addition to increased financial support, to ensure that community care was successful. She clarified this saying that there should be

"safety nets in place to be able to cope with their life, be it independently, partially independently or with a lot of support. I feel what people need should be provided. I realise that won't always be the case..."

(14,5,11-14)

5.iii. A Superseded Orthodoxy

The prevailing orthodoxy exists simultaneously with 'older' ideology, rather than eliminating it. It is

this situation which causes tension and can lead to conflict within the profession and, indeed, within professionals themselves.

Under the prevailing orthodoxy, professionals perceive people with learning disabilities as having hidden potential (see Chapter 6). This was not so apparent before normalisation. An examination of some of the past attitudes is helpful in understanding how present attitudes have developed and also how some co-exist with the orthodoxy. Theoretical ideas have developed faster than the attitudes of the professionals. This is illustrated by the following comment, that some staff

"are maybe due for retiring or whatever,
but still have the same old attitudes"

(23,5,1-3)

These "old attitudes" are not unlike those of parents as described in Chapter 4. An example of this is the attitude to adults with learning disabilities as being "eternal children" (28,12,35). A similar view is also held by some professionals:

"a lot of (people with learning disabilities) were seen as children and they still are, to a lot of the older staff, still are, still see them, you know, as children and their views are a wee bit different. It's attitudes of the staff we've got to be, gotten over."

(23,4,23-7)

In one particular establishment, staff were even called "house parents" (24,11,8-9), but this practice has changed with the superseding orthodoxy.

A 'normaliser' believed that some of the 'paternalists' viewed people with learning disabilities

"almost as subhuman species, to be honest with you...They're not seen as full human beings, as full adults,you know."

(28,13,10-15)

There is therefore a potentially tense relationship between professionals who adhere to different orthodoxies. Staff members joining the profession do so assimilating the prevailing philosophy. It is not surprising then that these 'normalisers' generally have a different outlook than those who began employment several years earlier. These differences are magnified the greater the time difference is between them. One professional believed that the differences between them were irreconcilable. He also believed that the contribution made by the 'paternalists' to the service was detrimental to people with learning disabilities. He clearly believed that,

"you get folk who are in the system who shouldn't be a part of the system"

(13,4,33-4)

He said that this was because the 'paternalists' based their work on outdated ideology rather than on the prevailing orthodoxy. This resulted in a misunderstanding of the aims and objectives of social care, which had since developed from industrial-type production to the teaching of social skills. To illustrate this he said,

"you still get the dinosaurs within the system who have to tramp out five hundred fruit scones a week before they actually think they've done something"

(13,7,11-13)

The prevailing orthodoxy is "person-centred" and regards the person with learning disabilities as the "client" or the "consumer". Such individualism necessitates self-advocacy and opportunity for choice. In some establishments the staff are providing the opportunities for people with learning disabilities to express their individuality and progress towards self-advocacy. A 'normaliser' explained that residents' meetings had recently started which gave them the opportunity to make rules for themselves. This allows them to live co-operatively on their own terms, rather than on those imposed by the professionals. At these meetings, the people with learning disabilities have had discussions independently of the staff and have decided that they want certain aspects of their lives changed. The results have been successful,

"And so they're getting control over their lives at the moment, more control over their environment"

(28,7,29-32)

This professional was a keen advocate of the prevailing orthodoxy. He said that people with learning disabilities

"certainly should have the opportunity to make their own decisions affecting their own lives. And obviously they should have choices, as far as I'm concerned, in any area of their life. We all have that choice, whether we think we have or not."

(28,7,29-32)

The orthodoxy recommends that professionals encourage people with learning disabilities to form opinions independently. An example of this is through using an open-question technique. Another example concerns people with learning disabilities being consulted about their training or instruction programmes,

"I've asked the residents first before I ask anyone else what they think about it"

(28,5,35-6)

He said this is because

"I don't really think there should be any limits or restrictions put on them"

(28,8,10-11)

He believed that this was realistic and progressive. It is clear that the orthodoxy not only affects the professionals, but it also affects individuals with learning disabilities. In a new establishment, "a lot of the clients brought parts of the old service with them" (18,6,28-30). They were, he explained, "institutionalised" and "cossetted" (23,2,22). Inevitably, there is some conflict for people with learning disabilities with the new philosophy signifying an increased freedom for them.

"There's a lot of things that they are able to do themselves they just, in the past or in other institutions, have not been able to do"

(23,2,11-13)

Unfortunately, this can cause problems because

"things have been done for them so much in the past and now it's a case of them having to do it themselves. Sometimes some of them don't agree with them having to do it themselves and especially the older residents, you get, they say it was much

better in the olden days when everything was done for them."

(23,2,27-32)

The outlook, however, is not altogether pessimistic, as one professional said,

"I saw them as just so set in their ways and I didn't know how they were going to make any changes, whether they'd be able to change. But I think they have, to a degree"

(25,2,18-31)

The 'paternalists' were sceptical about the prevailing orthodoxy and office-based social workers who were perceived as being its zealous advocates. A professional revealed her thoughts on the situation:

"I think mostly social work people sit at their desks from nine 'til five and they think up all these things and then they go away home at five and they don't think of the poor(person with learning disabilities) that's sitting here."

(30,8,2-5)

It was believed that, as a consequence, they did not have sufficient time to be involved in the practicalities and implications of the orthodoxy. Instead, it was believed that their time was spent in meetings.

It was noted in Chapter 4 that parents viewed guidance or help offered from outside sources as "interference" from experts whose experience was from book-based theory rather than from personal and direct daily

experience of people with learning disabilities. A comparative view was held by the 'paternalists' towards social workers:

"I feel sometimes the people, they've got it all through their books and through their 'what should be's and their Inspection Unit, other things and all the rest of it. What **should** be, but they don't have the experience."

(30,8,17-20)

"the people who dictate all these things, they're not dealing with the (people with learning disabilities)"

(29,12,18-19)

It was the credibility of the social workers which was questioned by the 'paternalists'. Their view towards the orthodoxy reflects those held by parents towards professionals in general.

"I mean, where do Social Work get these views? (*Laughs*) Where do they get them? Is it one person that says, 'This is my view'?"

(30,13,36-8)

"I think Social Workers that I have come, me personally, have come into contact with, I kind of question their common sense sometimes. They're maybe very good at what **should** happen and very good at what **could** happen, but sometimes when it comes to things not just working out,

common sense is not very good, and that takes experience."

(30,8,6-11)

The frustration felt by the professionals was directed at the social workers because they were regarded as the embodiment of the prevailing orthodoxy. A professional believed that the aim of independent living for people with learning disabilities was not always in their best interests. She described the situation as,

"Social Work setting them up in a nice wee flat and showing them how to do things and they get on fine with it for the first month or so and then they don't have the help, you know, they ease off their help and I think they get a bit (isolated)And as the isolation will be different from what they used to have when they were in an institution....it can be just as bad."

(30,5,10-17)

The comments made by the professionals provide illustrations of dissatisfaction and cynicism. Some of them are hesitant in articulating their doubts about the realism and sensibility of the orthodoxy. This is because they are "frightened to shout out and be the minority" (30,14,8-10). A major doubt experienced by the 'paternalists' concerned allowing people with learning disabilities freedom of choice. Although in theory this emphasises and protects their human rights, in practice it creates difficulties because there are individuals with learning disabilities who have problems coping with unlimited freedom. For some, their lack of experience and knowledge inhibits their use of such freedom.

The implications of this have been evident within Adult Training Centres. Centre Members were taught social skills and were given instruction in handcrafts. More recently, they have been expected to choose their daily activities, but some individuals find this exercise difficult. A 'normaliser' expressed doubt as to whether this was the most effective approach in the orthodoxy. He explained that although ideas had changed they had not necessarily improved. It was, he said,

"going from the idea where it's totally 'hands-on', making things, you've got to produce. to a point of questioning why this has been....to another point you could actually say they're throwing the baby out with the bath water."

(13,6,24-8)

He admitted that "a life without a product can be a very empty one" (13,6,30). He also explained that it was no longer acceptable to **instruct** people with learning disabilities. Instead the new ideology required staff only to **counsel** and **advise** people with learning disabilities. Despite finding this acceptable, he disagreed with other professionals who took this notion to its extreme. The result, he believed, could create a situation where an individual with learning disabilities refused to participate in any activity at all, even though it might be of benefit to him or her.

With regard to preparing people with learning disabilities for employment a 'normaliser' was realistic, highlighting the lack of direction in the prevailing orthodoxy. He said:

"we do really have to look at what we're actually training people for, you know, are we training people to do voluntary work, unpaid, or to sort of train them to

do manual repetitive boring tasks that nobody else wants to do..or do we train people in the life-skills, in the leisure skills, where they find leisure activities to fill their time."

(13,10,21-7)

He added,

"I think there's a sort of tendency to be false in the type of approach that we have.....There's three million other folk out there trying to (get a job as well)...who don't have a label (of learning disability)."

(13,10,29-30/ 34-5)

A 'paternalist' highlighted the difficulties that could ensue if people with learning disabilities were encouraged to have children. He believed that support, in the form of children being taken into care, would be necessary. It would be a contradictory situation, he believed, where the Social Work Department would be taking an increasing number of children into care while at the same time attempting to place more people out into the community. He stated that this would result in the Social Work Department's philosophy going full circle (29,16,27-8).

Many of the professionals in this study acknowledged that the orthodoxy was not fully adhered to. It was unclear whether they believed this was because its aims were inappropriate, or whether the methods to achieve those ideals were inappropriate, or whether it was a combination of both of these. In terms of attitudes, the ideal of the general public being aware that disabled people are not a threat to society is important to the

'normalisers'. Another issue of concern in the orthodoxy is the empowerment of women with learning disabilities.

The professionals remained realistic, believing that the service could be improved. Although there are individual professionals who have great enthusiasm for the prevailing orthodoxy, there are others who tend to be more cautious. This is illustrated by the comment:

"I think you've got to come to get where it mixes. What you do in supportive care and how far the support involves like taking their own risks and letting them do what they can do"

(23,2,32-5)

A 'paternalist' believed:

"A wee bit more freedom and a little more choice doesn't do them any harm at all, but I think you need to do it very slowly and you still have to have guidelines, you still have to have, you know, you have to have a dividing line between what you can do and what you can't do....it's difficult teaching that because in your own home life you can't do what you want all the time (*Laughs*) and suddenly you're telling people, 'It's your choice, you can do what you like'."

(30,6,3-11)

The prevailing orthodoxy can be interpreted in a manner whereupon unrealistic goals are set for people with learning disabilities. Most of the professionals in this study recognised this. Many of them referred to 'realistic choices' and 'realistic achievements', being mindful of the

limitations of the individual. They recognised that, although it was difficult to 'find the happy medium', a 'middle ground' was necessary in order to achieve a balanced growth and development. Some professionals felt that to negate all the past philosophy was erroneous.

"I think there's room for things that have happened in the past. I don't think everything about the past is bad. I think there's room for changes, yes, to go on, I don't agree with all of them."

(34,3,32-5)

This professional added that she did not believe that all the changes were an improvement, because

"there are people who are being given too much, too many decisions...about their own lives where they really need guidance and help."

(34,4,4-7)

Problems arise with the orthodoxy. One of these entails the issue of confidentiality owed to the person with learning disability, rather than to their parents or carer. A professional illustrated this type of dilemma. A woman with learning disabilities decided to use oral contraception but did not want her parents to know this. The professional said,

"do we show confidentiality to the client, who was able to make decisions for herself, or do we go through, or go behind their backs, so to speak, you know, to work the system and tell the family?"

(24,4,26-9)

In this predicament, the professional did not, in fact, inform the family. They later discovered for themselves that their daughter was using contraception.

Other problems concerning the orthodoxy were also highlighted in this study. Local public reaction to the opening of a home for people with learning disabilities was reported as being negative and as a consequence its opening was prevented. A 'normaliser' believed that society was "greedy" and "very commercially-orientated" and, consequently, was not supportive of people with learning disabilities. He considered the major problem to be the

"forcing of a move into the community, through the Community Care legislation, where we're being told that community is ready to take these people. Now, personally, I'm not convinced that's true..."

(35,11,12-15)

He believed that such policies, resulting from the orthodoxy, were futuristic. He was, however, keenly aware of the changing nature of the orthodoxy. As a result he recognised that

"in five years' time my views might be completely outdated....probably more ten to fifteen years' time"

(35,10,12-14/ 35,11,36-8)

5.iv. 'Normalisers' and 'Paternalists' in Conflict: A Case Study

It is clear from the data that different professional views regarding the ideology of care of people with learning disabilities exists simultaneously. It has

also been suggested that the 'paternalist' philosophy is reminiscent of parental ideology rather than representing the current and prevailing 'normalisers'' ideology.

In this study it was apparent that at one particular establishment the staff were deeply divided between the prevailing and the superseded philosophies of care. Changes within the establishment were being instigated by the Social Work Department and the Inspection Unit in order to modernise the service. This process was taking place at the time of the data collection and it exemplifies the problems surrounding a superseded ideology within an establishment. The tension and conflict which results from the juxtaposition of the 'old' and 'new' ideologies are also illustrated by this case study.

A 'paternalist', who had been employed for several years at this establishment, explained that the Social Work Department had only been involved for the previous two years, but within this time the change had been radical. He said,

"before the Social Work became so much involved, the residents were happy. We looked after them more as a family. We were sort of, my wife and I were mother and father to them and they were semi-independent. They could go away at weekends, do what they wanted but they had a base to come back to (*Respondent bangs his forefinger on the table several times*) and they were happy, they knew they had that base. Since the Social Work became involved three year (sic) ago or more, we don't have as much say in that respect. We have to treat them as ourselves, as it were, they have to make their own choices, not like a family. We are here to provide

a service to them because of their disabilities."

(29,7,1-11)

Another colleague claimed that they could be "classed as parents to quite a lot of the (residents)" (30,8,37-8). Another suggested that the establishment was like a family home. She was told by senior social workers " 'They are not your family'...so...that was the end of that" (34,9,8-9). She explained how, in the past, they

"would listen to what they wanted to do or wanted to buy or whatever and encourage them to save and do. I mean it was always just the same as I would have done with my own family"

(34,9,37-8/ 34,10,1-2)

Adherents to the superseded orthodoxy were reluctant to change their views because they believed that their approach to learning disability was appropriate. As one explained,

" Everybody (with learning disabilities) who was here was very proud to be (here). They **worked**....they got their **wages**...at the end of a week and they could go up the town. They could be as good as anybody else. There was nobody emphasised to them that they were handicapped."

(30,3,38f/ 30,4,1-4)

She said that the residents did not feel stigmatised by the label of 'mental handicap' because they did not consider themselves disabled, but "that's getting beaten out of them very much" (30,4,11-12). She was sensitive to some of the

possible consequences of the changing practices and their effect on the residents. Being given free choice, for example, she said,

"can make them even more confused. That suddenly you're supposed to be doing different things. You're supposed to have different rights. (*Imitating a resident*) 'What do I do with them? (*Laughs*) You know, you know, 'I have always done such-and-such.' "

(30,4,19-24)

Staff holding these views expressed resentment at what they considered to be the Social Work Department's intrusion. It is interesting to note that this type of reaction is reminiscent of parental feelings as described in Chapter 4. One of the 'paternalists' encapsulated what he believed to be at the heart of the conflict. He said:

"Well, it's all down to our practical sort of experience and the Social Work philosophy. That sums it up."

(29,6,8-9)

He explained further, that

"some of the Social Work envisage things that are not practical or feasible...(that) people (with learning disabilities were) being allowed (to make) choices that are not practical or suitable for that person"

(29,6,15-19)

He acceded that people with learning disabilities would be able to choose for themselves, but he remained doubtful that they would be able to make reasonable decisions (29,4,37-8). He said,

"Well, I think maybe one or two experiences where the Social Work philosophy is everyone should be out in the community, out on their own basically, with some back-up. Certainly is, but the Social Work don't have the back-up and they're inclined to push people out into the community when they're not capable of surviving in the community and that's it in a nutshell. And the people (with learning disabilities), if they're not capable of surviving because they don't have the guidance or the back-up, then they fall into traps and trouble and you have a lot of people locally who know that has happened."

(29,6,27-36)

In this particular establishment the professionals were in a caring and protective role, not unlike parents. Their knowledge and experience of the particular residents gained from daily living and working with them, led the professionals to believe that they ought to try and advise them. This highlights the problem underlying interpretation of generalised ideology into practical terms for individual people with learning disabilities. A 'paternalist' illustrated this dilemma:

"a senior officer has intimated that when (the residents) leave (they) are responsible for themselves. And I've battled with him and I've said, 'That's

not true. If anything was happening to them, first person they would come to is us (here). He said, 'But they're over eighteen.' I says, 'You can't look at it that way.' But that's Social Work philosophy and to me it's...it can't work."

(29,7,18-24)

Giving a specific example of the difficulties facing the professionals in this situation, he said that one of the residents within the establishment had problems of inappropriate sexual behaviour when he was out in the community. If this person were to go out unsupervised and an incident occurred involving such behaviour,

"we'd be the first to be hauled over the coals and yet a senior person (in the Social Work Department) says, 'No, they're responsible'."

(29,7,32-5)

This difference of opinion regarding personal responsibility is a source of tension between professionals. It reveals a major difference in attitude towards allowing people with learning disabilities freedom of choice and action. It also highlights professionals' expectations of ability.

It is evident that there is a serious conflict in the basic ideology of care. The terminological use reveals the depth of feeling of a professional when he said, "I've had this **battle** with the Social Work" (29,7,15-16). The 'paternalists' at the establishment in question were very sensitive to this situation and were clearly aware of the conflict. Traditional practices of the professionals were queried and criticised by both the Social Work Department in general and the Inspection Unit in particular. They were

described as being "very sore on staff" (34,7,11). A 'paternalist' expressed her view:

"It's very demoralising and it's very...it...(Exhales)...it would make you say well, why should I care? (Laughs) But I do, but I try as best I can to...take the Social Work's ideas and fit them in.....But it's when people come in and...you know...(Exhales) they're only in ten minutes and they've never been here before and yet they'll tell you that everything you're doing is wrong."

(34,7,21-30)

The staff felt that their work, both ideologically and methodologically, was being disparaged. A professional said, "some people would look down on us for doing that" (29,5,26). The 'paternalists' did not feel that criticism of their work was justified. One said:

"it's just a conflict of opinion. It's the people maybe outside (here) who don't really know the residents and they feel you shouldn't have advised them, but they don't really know them. We advised them for their own benefit really, if it is a bad choice or if it was liable to lead them into a bad area or that. So it all comes down to sort of practical experience...helps in that case. And I prefer to think that we have a right to try and advise them."

(29,5,33-8/ 29,6,1-2)

This protectiveness towards the residents at the establishment was also felt by other members of staff. A

'paternalist' believed that staff should be protective like parents. She said,

"Well, yes, that's what I feel and that's what I've tried to do and I know it's wrong, well, at least it's wrong in today's way of thinking, so there you are, yes."

(34,7,6)

She admitted to this despite knowing that it was a contradiction of the orthodoxy. All who had visited the establishment, from the Social Work Department to the Inspection Unit, had expressed their disapproval of the traditional methods of care. Being required to assimilate the new philosophy created a high level of tension among the 'paternalists'. Some of them retained their own personal views while simultaneously trying to adapt to the orthodoxy.

A professional admitted that her views were inconsistent with the modern philosophy. She said,

"I know I've got to change my views or I'm supposed to change my views in this day and age. My children tell me I have to change my views."

(30,12,36-8)

Such an attitude led her to confrontation even with her own adult children, but she added assertively,

"It is my view and I'm quite entitled to my own view.....(although)....I'm getting more and more quiet about it publicly....because there is peer pressure and just pressure to conform."

(30,13,9/ 13)

Exacerbating the conflict at this establishment was the presence of 'normalisers' among the staff. From an ideological viewpoint, comparing the same events from different perspectives is revealing. The practice at the establishment was first described by a 'normaliser',

"I mean, it was all unbelievable, they were about thirty years behind the times...."

(31,4,16-17)

"(although) they thought this was the modern thing"

(31,8,35-6)

"It's almost Dickensian, it's a disgrace"

(31,9,12)

He explained that the Inspectorate had threatened to close the establishment when they discovered how disparate the care practices were with the orthodoxy. He said that the establishment had received a "shocking report" (31,12,35). There were several reasons for this, some of which included basic health and hygiene regulations. In-service training for the staff was started in an attempt "to try to enlighten the staff as to what care was all about" (31,3,37-8). Unfortunately, this exercise increased the tension within the staff group.

"The difficulty was staff, were a bit suspicious of meintroducing all these new rules, new regulations and various other things and it was making it complicated for them."

(31,3,30-3)

The basis of conflict between the professionals was ideological. The 'paternalists' identified themselves in a parental role which was in direct contrast to the prevailing emphasis on independence and self-advocacy. The 'normalisers' explained this as trying to:

"maintain the person's optimal independence and increase their independence levels and things like that, which (the staff) didn't understand. They just saw it as cossetting them and the staff indoors thought 'the poor wee souls' and called them 'boys' and treated them as children and they wouldn't give them any independence whatsoever. They'd to book in, book out. They got fined for foul language or if they were to put a step in the wrong direction they'd be fined or they were kept in. They were just treated as children. It was unreal."

(31,4,1-9)

How the residents had been treated during the last fourteen years was illustrated in a description of Christmas parties that had been held. These had

"been (like) a children's party, buns and soda and things like this and 'Musical Chairs' and 'Pass the Parcel'...it's unbelievable....It's just like they were small children"

(31,19,25-9)

The 'normaliser' remembered how he had felt "mortified" at the sight of adult men being subjected to childish entertainment. Although the 'paternalists' claimed to treat the residents as a family, their behaviour towards them was

not filial. Their reactions to the residents' behaviour, however, were taken on a personal rather than on a professional level.

"everything the (residents do) is taken as a personal slight. If the residents don't shave and (then) go up to (the town), they take it as a personal slight on them and the residents will pay absolute hell for them because they didn't shave."

(31,8,5-10)

Although the 'paternalists' described the establishment as a family home, there were many ways in which it was similar to an institution. For example, the Manager was called the "Superintendent". Meal times were also examples of institutionalisation, with the serving of tea in particular. It was made in two teapots, one with milk previously added and the other already containing milk and sugar. To identify the different drinks, a piece of string was tied round the handle of one of the teapots. This mass catering is a typical example of institutionalisation.

There were also reports of residents being exploited. An example of this is that one resident was required to assist in the kitchen every day on an involuntary basis and without payment. A 'normaliser' described how the residents had been expected to work on the land,

"first when I came here...it was a disgrace what (the residents) were doing. Potatoes, they were harvested by hand. Turnips, carrots, cabbages, potatoes and fields and fields of potatoes, and there's older people there with rheumatism....(As a consequence)...the state of their feet,

in wellingtons, theirfeet were absolutely
dreadful...."

(31,22,23-31)

He believed that the residents were used in this way because they were regarded as less than fully human.

"Some of them would treat their animals with more respect...they do things...with the best of intentions, but I think most of their intentions are suspect."

(28,13,12-13/ 15-20)

The same informant reported to have heard a 'paternalist' colleague claim,

"I'm the (professional) and they're just residents and they're mentally impaired, they can't be my equal."

(31,16,21-4)

A statement such as this is in direct conflict with the prevailing orthodoxy. It arose because he disagreed with the proposal that the residents should call the staff by their first names, rather than address them by the title of "Mr." or "Mrs."

The attitude of one of the 'paternalists' to the residents was considered by a member of the 'normalisers' to be unprofessional and inappropriate. He said that she "shouted" and "bawled" at them and

"if she's in a bad mood she takes it out on residents and staff, it's really dreadful, (the) things that's she's actually said to residents"

(31,5,23-5)

Nevertheless, the changes in the establishment led a 'normaliser' to believe that

"it's a lot better now than it was eighteen months ago and certainly from the residents' point of view it's a lot freer"

(31,22,23-4)

This was mainly because a residents' group had been formed. They had meetings and discussed their problems, as noted earlier. At these meetings, the residents expressed their wishes to go to bed later in the evenings and have showers at any time of the week, rather than on a specified 'shower night'. Progress, however, was slow.

One of the 'normalisers' was optimistic that beneficial changes were occurring and that the other 'normalisers' were, as a consequence, more enthusiastic about their work. He said:

"they have a future now, they see a future, they see something beyond (here). (The residents) freely speak to us now, they openly discuss things...they would never have done that, they were terrified to say anything...the staff were the same. The staff used to be closed-mouthed..."

(31,13,4-12)

Establishments such as these are slowly being eradicated, for example, Humble Village (The Guardian, 1996a; The Herald, 1996; BBC TV, 1996). Others are changing in their outlook to accommodate the new philosophy (Hansel Village, F. 6.2.95).

This case study is an example of the difficulties experienced in achieving change in establishments. It also serves to highlight a parallel between the parent-professional relationship and the 'paternalist'-'normaliser' relationship. Comparisons can be made linking the two different types of relationship. Both the parent group and the 'paternalist' group perceive their role towards people with learning disabilities as one of protection. A 'paternalist' justified this,

"when you've lived, where there's four people living and working with these people, with the residents, over these years, you come to think, I mean, you are the one that sorts the cuts and the bruises and treats the 'down' times and the 'up' times and the sick times"

(34,9,11-15)

The protectiveness can also be seen with the view that:

"you could save that person an awful lot of distress and suffering...but I know that's, it's not the modern day thinking, I mean, in many ways I feel we're being told to treat these people, our residents, as normal people"

(34,4,17-21)

Generally, the 'paternalists' and parents express the wish to protect people with learning disabilities from unpleasant experiences, but it is these experiences which help towards human growth. Without negative experiences it could be more difficult to appreciate positive ones, to "love the unevenness of...life; even become grateful for its uneven texture, its seamlessness, its problematic unpredictability..." (The Guardian, 1996b).

It is the change in philosophy that has allowed the notion of 'normalisers' to emerge. Professionals believe that there is a similar tendency occurring among some parents but these tend to be parents of younger adults, or of children, with learning disabilities. A professional reiterated this typology. He believed that these parents were saying,

"we need more, we need these people (with learning disabilities) to go out into the community and independent travelling. We want them living on their own, in a joint tenancy-type thing."

(21,6,5-8)

He added that some parents were very keen and had progressive ideas. Another professional agreed saying that generally,

"Parents are becoming more liberated in that service-users across the country are having more say in a sense proving to people given the opportunities that they take much more control over what happens."

(35,9,24-8)

He also believed that this was only relevant to younger parents.

"Oh, more certainly younger parents, most certainly. There's no doubt in my mind the integrated system's set up by younger parents, segregated systems by older parents."

(35,9,32-4)

The change in philosophy therefore affects parents as well as professionals, although at a slower rate. Because of this, professionals can foresee change occurring both with parents and people with learning disabilities themselves. The following statement made by a professional illustrates this view:

"I think with the new set of younger parents coming in and they've got the younger attitudes, and the day-attenders are bringing in a whole lot of different attitudes as well."

(23,7,6-8)

It is clear that the prevailing orthodoxy creates tension and conflict between professionals. Tension also arises within individual professionals if they experience difficulties in assimilating the orthodoxy with their personal views. This is evident, particularly with the 'paternalists'. Although it has been shown that the 'normalisers' do not always fully adhere to the orthodoxy, their stance is generally in conformity with it. The issue of sexuality and the orthodoxy introduces further tensions for both the 'paternalists' and the 'normalisers'. The complexities of this are considered below.

5.v. The Prevailing Orthodoxy and the Issue of Sexuality

The prevailing orthodoxy, in advocating opportunities for personal development, promotes sexuality as an integral part of life. Although the Social Work Department has recently been involved in a 'Sexuality Awareness' Course for both professionals and parents, sexuality has generally not been an area of priority treatment either for policy-making or for staff training. This was confirmed by a professional:

"It's one of those subjects that the Department's never fully investigated. It's one of those sort of, 'Oho, you don't want to get involved in that', because I think there are a lot of political issues are involved in it as well."

(21,12,9-13)

As a result of this situation, staff complained of there being no guidelines nor policies to follow. This view was also held by other staff who said that sexuality and people with learning disabilities was a "grey area" where there "should be clear guidelines" (17,4,5-6). Any presentations of sexual guidelines that had been made in the past had been found to be unhelpful. This was because the Social Work Department was essentially reticent about sexuality.

It is also in this area of sexuality that there are some inconsistencies between the attitudes of a number of the professionals and the orthodoxy. Their personal views deviate from those of the 'professional model'. This incongruity is exemplified by a professional admitting that in some areas of sexuality counselling she was uncomfortable with the orthodoxy,

"it's so difficult, my own personal views on things and what (people with learning disabilities are) doing, you know, sometimes it doesn't quite meet....and it's really hard, you know, you've got to go against what your own beliefs are and say, 'Well, this is what you could do....but, you know, in the background you've got 'I don't really believe what I'm saying here', but I've got to tell them, you know, and it's really quite difficult at times."

(23,9,35-8/ 23,10,1-4)

Sebba (1983) comments on how higher moral standards are expected from people with learning disabilities than from other members of the population. Although one professional acknowledged that sexuality was important, he believed that society was

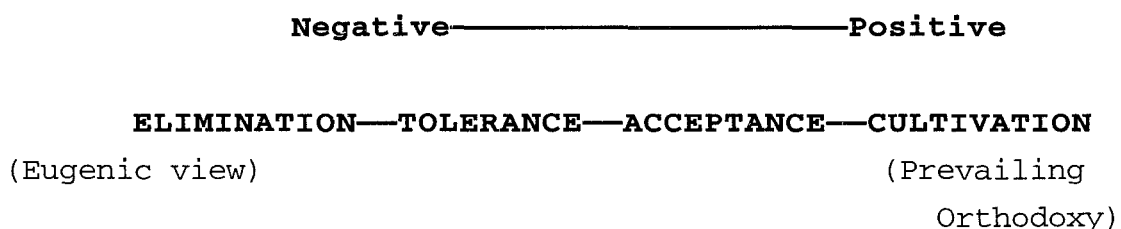
"very Edwardian when it comes to sex with learning difficulties. With the sexual revolution in the sixties only for certain people"

(13,18,3-5)

Kempton and Caparulo's (1983) description of four general types of attitude that exist towards the sexuality of people with learning disabilities is a useful guide in clarifying the professionals' statements (see *Figure 1* below).

Figure 1.

Scale of Attitudes towards the Sexuality of People with Learning Disabilities



The most negative attitude in their scale is that of "elimination". This is interpreted as a denial of the sexual needs of people with learning disabilities and, therefore, any manifestation of sexual expression is regarded as unnatural. This is reminiscent of the

eugenists' view, as described in Chapter 1. There are examples of this denial of sexuality in the professionals' comments,

"A lot of people don't think they have the same possibility of sexual development as the mainstream public..."

(28,13,10-11)

"I mean, many people still deny that they have sexual feelings. I mean, just like the old thing, 'They don't feel pain', you know... (*Laughs*) "

(28,19,2-4)

This type of attitude also influenced the practice in some establishments. As an illustration, an establishment was described as

"a family kind of place. It was high moral standards and I'm not saying that's wrong, but...rather than go into reasons I think they looked for nice little neat answers like, you know, marriage, sex is for marriage and sex is so frowned upon...."

(25,4,23-8)

A professional stated that at one particular establishment several years ago, people with learning disabilities were punished if they had a relationship with a member of the opposite sex. The punishment was

"two weeks in bed with pyjamas on and you weren't allowed to get out of bed unless it was to go to the toilet. Full stop."

(35,7,10-12)

In one establishment the subject of sexuality was broached only if there was an incident involving inappropriate sexual behaviour. A professional described the shocked reactions of staff members when they witnessed relationships developing between people with learning disabilities. He said,

"a lot of staff go, 'Oh, they're kissing come in (and look)'. Two members of staff say, 'The two of them are at in there', you know, you still get that attitude."

(18,10,10-12)

This professional perceived the staff's negative attitude to sexuality through his experience of "a wee negative vibe" (18,17,3) from them. He explained:

"I think it's shifted from....eh...when I first started...from 'As long as it doesn't happen in (this) Centre, ah, don't bother' to a certain amount of fear talking about it and not looking too deeply into it. That's the general view."

(18,18,4-8)

Other professionals were also clearly negative about sexuality and people with learning disability, perceiving it as a problem. Their views can be interpreted as a denial of their responsibility in providing information, support and counselling:

"No, I don't see that."

(14,11,19)

"We don't promote anything like that."

(16,3,31)

"I wouldn't help promote that."

(21,11,31-2)

"Well, what I'm saying is, we were never taught. So I won't teach it."

(29,10,16-17)

Another professional added,

"I'm not in favour of...eh..encouraging homosexuality because I don't think even with handicapped people it would be a natural thing."

(30,16,20-2)

Her comments also illustrate the "elimination" category described by Kempton and Caparulo:

"I think we're using enough resources looking after the handicapped people, looking after them if they're married, somebody helping them and all the rest of it, without bringing other poor wee handicapped people almost semi-intentionally..."

(30,18,20-4)

She believed that contraception should be compulsory for people with learning disabilities. Such negativity is in

contrast with the pro-active stance of the prevailing orthodoxy. It is not an isolated viewpoint, but one that is reiterated by other professionals,

"it's not the way we were brought up. I'm one of the oldies, you know (Smiles)...er...it's a different world now...er...from what it was when we were younger."

(29,9,8-10)

He later added, "I think it's going too far" (29,9,16), saying that he believed

"It's the whole philosophy, as I say, you would only discuss (sexuality) if they asked you questions about it. But if they start educating people...eh...they become more aware of the sexual side of life where maybe previously they were not interested."

(29,9,20-3)

The language used by some of the professionals also reveals a negative attitude. An example of this is the use of the term "promiscuous" to describe women with learning disabilities who had had several boyfriends. Contrary to the orthodoxy, this is judgemental and sexist. It is clear that some of the professionals assessed individuals with learning disabilities in their care by their own moral standards. A 'paternalist' expressed her view that such a sexual relationship should be actively discouraged and qualified it by saying,

"it would depend on whether it was a relationship which had progressed from friendship through the stages or whether

it was something that was being done for sexual satisfaction"

(34,11,20-3)

She later continued,

"I would discourage it, I don't think, I mean, now we can't stop anything, but I think discourage it and try to find some other way for the one person or both parties to control their sexual feelings other than just making use of somebody."

(34,11,31-4)

The second type of attitude described by Kempton and Caparulo is that of "tolerance" of sexuality. Most parents, they claim, are likely to belong to this category although evidence is not given to support this.

They believe that the third category of "acceptance" is to be commended. This is because of its egalitarian stance, accepting that people with learning disabilities have the "normal emotional needs to love and be loved, to show affection, to establish relationships, and to express their sexuality." It is also based on the recognition of the 'rights' of people with learning disabilities not to be denied 'normal' experiences as decreed by the United Nations (1971).

There are some difficulties in discriminating between "acceptance" and "tolerance" within the statements made by the professionals in this study. There are also some professionals who are hesitant in expressing clearly defined opinions. As a consequence, their responses are non-committal. An example of this is the comment, "I wouldn't encourage (sexuality), but I wouldn't discourage it" (16,3,18). Another professional said,

"whether it happens here or outside, if they two people are consenting adults there's no really a lot I can do about it."

(21,11,35-7)

Several other professionals said that they would be willing to counsel on the subject of sexuality and sexual relationships, but only if their help was requested by people with learning disabilities:

"I think maybe even they have to make the first steps"

(15,8,24)

"if (he) approached me...wanting help about a problem...(then) I'd be willing to tell him."

(16,7,15-17)

"unless a student or client came to me and asked me specifically what I felt about such and such a thing then..."

(21,10,1-3)

"it's only if they come and ask us questions about it, then we can discuss it with them."

(29,9,1-2)

The fourth category depicted by Kempton and Caparulo is that of "cultivation" of the sexuality of people with learning disabilities and the one with which the orthodoxy is most compatible. Despite Kempton and Caparulo believing that this attitude "is not readily or widely accepted and seldom seriously considered", they acknowledge that it is with this viewpoint that people with learning disabilities "can be encouraged and helped to enrich their lives through sexual expression". They believe this can be achieved through policies, training, sex education and counselling. Not all the professionals in this study revealed adherence to the orthodoxy with regard to sexuality. For some it was a source of internal conflict. As noted earlier, a professional explained that sexuality was a subject rarely spoken about,

"It was something in the past, sexual relations were swept under the carpet. If something happened that was the way it was and I'm going back not a long time. Some staff bring their own personal views into it."

(24,9,20-3)

Consequently, people with learning disabilities

"were very embarrassed about the body, the words, just everything to do with sex"

(25,3,25-7)

It was the 'normalisers' who expressed the "cultivation" viewpoint and who nurtured the sexuality of people with learning disabilities, for example,

"I would like to feel that my own views are quite pro-active in encouraging all

people, encouraging all people to have the same opportunities for relationships."

(35,10,5-9)

This professional went on to explain that a

"number of staff (were) specifically trained in issues of sexuality so people have access to condoms, people have access to contraception. We are not going to turn round to anybody and say, 'We think you should be on the pill.' This is not an issue. We did five or six years ago, we don't now."

(35,12,11-15)

It is salient that this 'normaliser' described how the philosophy and practice have changed during the past "five or six years". The issue of sexuality magnifies, not only the differences between parents and professionals as outlined in Chapter 6, but also the differences within the professional philosophy. The professional concerned in this example explained that whenever they witnessed a relationship developing between people who were in their care, they offered support and counselling by

"(working) with the person in organising a visit to a Well-Woman clinic and then they go there and get advice there and have family planning advice and where they need support for that, that is really given."

(35,12,20-3)

The orthodox view of "cultivation" is illustrated by another 'normaliser', as quoted earlier, who said,

"we should not be protecting people with learning difficulties from taking reasonable risks. And I think a reasonable risk is any emotional risk and we should be allowing them to have that experience and to hopefully learn from it."

(28,22,32-6)

This is because, he explained,

"we can learn more from the practical experience than we do from any amount of theorising."

(28,23,1-2)

A nurturing attitude is in accordance with the prevailing orthodoxy, but not all professionals held such progressive views. Some of them, the 'paternalists', were closer to the parents in their outlook regarding sexuality. A professional encapsulated a typical parental reaction to the orthodoxy,

"But mum's initial (shocked) reaction was 'What are (the professionals) doing? Allowing free sex and the rest of it?' And the answer to that in many ways has to be, 'Yes', in that people have urges or do anything with them. It's our job to make sure they're as responsible as possible."

(35,13,1-5)

Sexuality is not openly discussed, however, in many establishments. This is unhelpful to people with learning disabilities because they are then unaware that advice is available to them. Moreover, many of them are also unaware that they require instruction, and possibly counselling, on sexual matters. Despite this, a professional

believed that it would be reasonable to ask a person with learning disabilities,

"'Do you know about safe sex?' They may not wish to, for me to counsel in that way. I may have to ask them, 'Do you wish counselling?'"

(21,10,36-8)

Many people with learning disabilities remain in "ignorant bliss" regarding sexuality (30,14,29). As mentioned earlier, this lack of sexual knowledge is a typical phenomenon with people who have learning disabilities (Deeley, 1990). An example of this was a sixty-two year person who believed that both men and women could have babies (30,14,20-1). A professional stated that information would not be given unless the individual specifically requested it. To reinforce this view, another said that she did not believe in telling somebody about sex if they really did not want to know about it.

The differences in professional attitudes account for some of the practices which are incongruent with the orthodoxy. In particular, personal differences are revealed where sexuality is concerned. An additional factor relating to this incongruity, is the training given to the professionals. The general consensus among them is that training is a source of dissatisfaction. Training opportunities vary between establishments because of the lacuna in national guidelines or policies. This is illustrated by the following comments,

"some of the training has been pretty irrelevant"

(13,2,12-13)

"I haven't been given a great deal of training"

(14,2,15)

"there's a lot of fear about (sexuality because of the lack of training)"

(18,6,4)

"There is very little training, education for staff"

(28,10,6-7)

5.v. Conclusion

Chapter 4 examined the relationship between parents and professionals. Also examined were the effects of this relationship and the different ideologies of care involving major issues for people with learning disabilities. Although the prevailing orthodoxy suggests a consistency, in reality professionals represent a more heterogeneous approach. From their responses, it is evident that subtle anomalies exist which require further investigation. These irregularities could be due to individual differences between the professionals and the prevailing orthodoxy. On closer analysis, however, it is clear there is an ideological link between the 'paternalists' and parents of people with learning disabilities.

Many of the differences between professionals involve their understanding and expectations of people with learning disabilities. The issue of hidden competence, which is explored further in the following Chapter, is

significant in this respect. The 'paternalists' do not believe in the concept of hidden competence and in this they are closer to parents of people with learning disabilities than to their professional colleagues.

Most professionals base their work on the prevailing orthodoxy. However, the orthodoxy changes over time. Many of the professionals in this study adhered to, or assimilated, the orthodoxy, but there were some professionals who did not. Their practices and views are gradually being superseded by what they consider to be unrealistic and impractical. The newer entrants to the profession are unsympathetic to such individuals who hold these views. This creates antipathy between them.

The orthodoxy is a result of developing ideas. It is therefore to be expected that this continuum will effect changes in the future. Moreover, the present 'normalisers' will be required to assimilate the future views or risk becoming 'paternalists' themselves. In contrast to parents, professionals begin and cease contact with people with learning disabilities at a quicker rate. It is not surprising then, that parental ideology evolves at a slower pace than that of the professionals.

The credibility of the orthodoxy is called into question by parents and the 'paternalists' who share a similar ideology. It is also criticised by the 'normalisers' who, at times, regard the orthodoxy as idealism. The comparative views of professionals and parents on the issue of consent to sterilisation of people with learning disabilities also questions the viability of the orthodoxy.

The data in this Chapter has illustrated that the differences between parents and professionals are not always absolutely definable, although there are major differences in the area of sexuality. It is in the light of this that the issues surrounding sexuality and the legal issues of

decision-making concerning sterilisation of people with learning disabilities will be examined in the following Chapters. It will then be possible to ascertain the level of influence of the prevailing orthodoxy and if indeed a more integrated approach is necessary to an understanding of the complexity of the various influences on people with learning disabilities.

Chapter 6

SEXUALITY AND LEARNING DISABILITY: An Analysis of Professionals' and Parents' Views

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6.i. Introduction

Tension and conflict within the relationship between parents and professionals were explored in Chapter 4. The differences between their views of people with learning disabilities are magnified with the subject of sexuality. During the qualitative interviews, referred to in Chapter 4, the parents and professionals expressed their attitudes to various issues of sexuality and adults with learning disabilities. These issues ranged from their emotional and physical needs to sterilisation. They included other topics such as relationships, parenthood and contraception.

The respondents were requested to give their views on a vignette which was presented to them at the end of the interview. It depicted a hypothetical sexual relationship between a man and a woman, both of whom have mild learning disabilities. They were asked to specify at which point in this developing relationship they considered contraceptive use to be the most appropriate and, if at any point, where they considered sterilisation would be in the best interests of the couple. This exercise served to highlight the complexities of decision-making in this controversial area.

The differences between parents and professionals provides a basic framework of each of their ideologies of care. Their views on sexuality and people with learning disabilities reinforces this basic framework. However, as in all human relations, the differences between the two groups and within the groups are complex. The subtle differences which can be found within the professional group have been explored further in Chapter 5.

The views of sexuality and people with learning disabilities expressed by parents and professionals reflect their respective ideologies of care as described in Chapter 4. For parents of adults with learning disabilities, sexuality is a major source of anxiety. One of the reasons

for this is the inexorable association which exists between sexual activity and procreation, despite the existence of reliable contraception. Because of their kinship obligations to their adult children, parents expressed feelings of responsibility for any resulting offspring. Parental anxieties also concerned the vulnerability and possible exploitation of their sons and daughters, issues of concern which were also found in a study by Bambrick and Roberts (1991). Professionals, who do not have such kinship obligations, present more liberal and objective attitudes to the sexuality of people with learning disabilities.

6.ii. Sexuality

The widespread lack of sex education for adults with learning disabilities has resulted in the lack of accurate sexual knowledge in this section of the population (Johnson, 1973; Elwood, 1981). In a study by Johnson (1984), it was discovered that out of a group of thirty one women with learning disabilities "only 6...could identify female masturbation and orgasm". This lack of knowledge leads Johnson to believe that "sexual pleasure may be unknown to a large number of handicapped women". This situation can be interpreted as an example of sexual oppression which exists "by being deprived of knowledge about sexuality itself" (Elwood, 1981). This problem is now being addressed through the general process of change in policy initiated by the Community Care Act of 1990. Specifically, this is evident through the "Changeover" programme which has been introduced in establishments for people with learning disabilities in parts of Scotland, England and Portugal.

At present the general dearth of sex education for this section of the population (Deeley, 1990) has not been completely remedied. Both parents and professionals acknowledge that many people with learning disabilities lack

accurate sexual knowledge. The degree of information that they have varies from virtual ignorance to full knowledge of "how to do it and what to do" (23,5,15). Some adults with learning disabilities, however, remain without basic sexual knowledge and both parents and professionals are aware of this:

"She doesn't know the facts of life"

(1,2,33-34)

"I don't really think (he knows)...er...no, he doesn't know"

(20,10,38)

"I don't think he does, no."

(22,10,11)

Other adults lack understanding:

"this sixty-two year old person thought that both men and women could have babies"

(30,14,20-21)

"He knows. I don't know if he fully understands, but he does know."

(7,1,32-33)

"She had absolutely no thought that periods and babies went together."

(23,7,7-8)

Some parents claimed to have imparted selected aspects of sexual knowledge to their sons and daughters in an effort to

protect them from exploitation and the possible consequences of sexual activity.

"She knows that she's not supposed to let boys touch her body"

(5,6,25)

"I've said to her not to allow anyone to kiss her or all the rest of it and she is able to protect herself"

(8,2,32-35)

Gordon (1972) acknowledges that people with learning disabilities "are by far the most vulnerable segment of our youth in regard to exploitation". Sexual knowledge can serve as a protective device, even to men:

"If they're out somewhere and some woman was drunk or something like that, they got them up a back street or something like that, they ought to know, "I shouldn't do this" or "I shouldn't do that" or "If I am, oh boy, I should know what to do."

(30,11,33-36)

There are other adults with learning disabilities whose sexual knowledge is accurate but limited:

"She seems quite knowledgeable about...giving birth...but I'm not sure that she's got a great deal of knowledge about the conception, or whatever, and, you know, I'm not sure she's a hundred per cent about that one."

(12,3,23-27)

Parents and professionals differ in their attitudes to this issue of sexual knowledge. The latter are

more concerned with the "rights" of people with learning disabilities to have knowledge and understanding. A professional said that if such education is not provided then "(we are) taking some of their rights away" (24,7,11) so that "definitely, some form of education is needed" (24,7,1). Many parents, however, have reservations about unlimited sexual knowledge being given to their sons and daughters. One parent had these doubts:

"I don't really know if it's a good thing. I wouldn't like to think it would give him the idea that it was a free-for-all."

(10,7,16-17/ 27-28)

Another parent said:

"I still say you don't give sex education to people who aren't aware of their sexual...side of life, until they show some signs of starting to be aware of it."

(3,10,16-18)

Some of the parents denied that their son or daughter had any sexual interest at all:

"She really has no interest. She shows no interest, in fact, she doesn't have any friends really. She doesn't take any real interest in anyone or anything else"

(1,2,9-11)

"he doesn't have particular friends"

(3,2,14-15)

Despite these comments, interviews with professionals revealed different situations to those described by the parents. The people with learning disabilities associated with this study had all shown some sexual interest in the past or were currently involved in a relationship, according to the professionals. In contrast to the denial of sexuality by some parents, there was evidence of the perpetration of myths concerning their sexuality. Comments made by parents illustrate this:

"Some of these people are very sexually orientated"

(7,7,5-6)

"She's very affectionate. This is the danger with Down's syndrome, they can be very affectionate."

(8,4,7-9)

Stewart (1979) explains this, saying, "Popular opinion tends to be divided as to whether the mentally retarded are perpetual innocent children with neither desire for, nor capability of, sexual expression, or whether they are human satyrs with an overload of dangerous sexuality."

Being in the daily company of mixed gender groups of people with learning disabilities affords professionals a realistic view of the situation. "I can see there's that awareness of sexuality" (18,18 24-25), said one professional and referring to its inevitability, said, "the place is bursting with it" (18,29,10). Moreover, people with learning disabilities can

"go out socially and they can pass themselves very well out socially, talk away quite well to the opposite sex."

(30,11,3-5)

Physical and Emotional Needs

A fundamental and crucial issue is whether people with learning disabilities experience sexual physical and emotional needs. The attitudes of professionals are objective and positive:

"You can't put restrictions on it. I mean, that their needs are, these (people) have got the same needs as you or I, physically, emotionally, sexually"

(21,11,18-20)

"I would have to say that, yeah, they have the same drive as anybody else. I take that view... obviously have sexual feelings same as anyone."

(24,12,9-11)

Further comments illustrate this belief:

"They still have their needs"

(29,8,25)

"Oh, yes, aha, they're all human, just the same as us....They'll all have the same sexual desires."

(30,11,17-20)

"Oh, no doubt, I've got no doubt at all"

(25,6,17)

One professional had a strong empathy with their needs. She said,

"I see sexuality and sex as so much part of us all....you (can't) smack it and tell it to go away....it's just not that easy, it doesn't go away. It's there, it's part of us, we've all got it. We like feeling, we like to be loved, we like to be touched."

(25,8,21-27)

Other professionals recognised that "many people still deny that (people with learning disabilities) have sexual feelings" (28,19,2-3). Parents discussed the sexuality of their adult sons and daughters from a different perspective. Their adulthood was generally acknowledged, "he's a normal male in that respect, we've had the wet dreams" (3,8,15-16), but parents were more concerned about appropriate social behaviour. Referring to masturbation, a mother said,

"we explained to (him) if he had these feelings, that was where he went, he went to his room and he dealt with them how he felt that men did."

(10,4,16-18)

Although parents were sensitive to their sons' and daughters' learning disabilities, they accepted that they had bodies of adults and not children. However, this was more often expressed through positive comments on their emotional, rather than their physical, needs. An example of this is a parent's recognition of her daughter's growing need for independence and adult status. She explained,

"if we're going away and she really doesn't want to come with us, I mean, she's got that part of adult in her... I mean, "I want to go myself" sort of thing..."

(6,5,21-23)

Another parent believed that her son wanted to emulate her other sons,

"his brothers was (sic) bringing girls to the house,....so he wanted the same thing."

(10,4,30-32)

When a serious relationship finished, her son was "devastated". She said,

"I can't tell you how ill he was. He lost stones in weight. He was really, really ill with it because he absolutely adored her, absolutely adored her."

(10,3,38/ 10,4,1-3)

Significantly, other parents recognised both maternal and paternal needs in their adult offspring. Their comments illustrate this:

"She is awful fond of wee kids and she would like to think....the idea of having a baby would appeal to her....not the actual pregnancy but the looking after a young baby, that would appeal to her."

(5,3,2-5)

"I think he would be really upset (if he had a vasectomy) because he really likes children. He seems to relate quite well with children."

(7,5,8-9)

Societal expectations of 'normal' adult behaviour, for which adult status is subtly confirmed, centres around child-bearing. "A lot of people might like to think they're going to have a family at some (time)" (14,14,6-7). People with learning disabilities have similar aspirations, "we had people here saying that they want a child" (23,7,22-23). Other comments made by professionals confirm this:

"she certainly has great affection for (children) and I think maybe deep down inside she'd maybe think it'd be nice to have a child of her own."

(12,6,30-32)

"he'd be quite chuffed and happy about (becoming a father)"

(16,8,26-27)

It is recognised by parents and professionals that adults with learning disabilities have these feelings. It is the prospect of the realisation of such feelings however that produces polarised reactions from these two groups. The professionals' estimation of competence, as discussed in the previous Chapter, is again at a higher level than that of the parents. Issues such as the responsibilities of child-rearing, combined with the perceived immaturity of people with learning disabilities, leads parents to have negative views in this area (see section iv. of this Chapter).

Professionals believe that people with learning disabilities have both physical and emotional needs in the area of sexuality. A professional expressed her view:

"I think they still have this feeling of wanting to care or wanting to have

something, someone who belongs and loves them."

(25,6,29-31)

This need for love, "could become sexual" (25,6,23-25). This is a source of anxiety among parents, with the recurrent fears of their being taken advantage of, being abused or coerced into sexual activities. This does not appear to perturb professionals. As recalled from the previous Chapter, an objective view is maintained by them:

"We should not be protecting people with learning difficulties from taking reasonable risks. And I think a reasonable risk in any emotional risk is a fairly reasonable risk and we should be allowing them to have that experience and to hopefully learn from it. As sometimes we can learn more from the practical experience than we do from any amount of theorising."

(28,22,32-36/ 28,23,1-2)

Incidents

Anecdotal evidence of incidents relating to sexual behaviour were given by both parents and professionals. Most of these situations described public socially unacceptable sexual behaviour, for example, "incidents of masturbation in the building" (21,10,26). Other examples included, "exposing himself down the street" (3,10,4-5) and a report of a man who "goes up to little girls and kisses them and their parents report it to the police" (29,7,38f). There are instances where women have been in "compromising situations" (5,4,21-22),

"There was a boy annoying her, kissing her and she said, "Stop it", and he didn't."

(8,2,36-37)

One parents described how her daughter had been raped,

"the father had heard (her) screaming....and told them to get dressed and get out"

(4,4,35-36)

There are problems when they are out in the community when

"they've actually been touched up or in one case sex had actually taken place and they had done nothing about it"

(25,19,12-14)

Such reports affirm the lack of socio-sexual skills, knowledge and experience in dealing with sexuality in socially acceptable and appropriate ways. An example of this is their being "over-friendly with strangers" (28,15,28).

Problems

As one professional reported, "some folks see (sexuality) as a (problem)" (18,18,13). It is less to do with sexuality per se than with the implications or consequences of their behaviour, because "it's the families that end up with the problems" (3,8,6). Parents tend to view the situation in a more holistic way and consider the possible effects on the family unit. With these anxieties, it is not surprising that some parents fear their son or

daughter having sexual knowledge. This is because of their belief in ignorance being equated with innocence. Conversely, they express the belief that sexual knowledge could encourage sexual activity.

"You don't start putting ideas into people's heads. I really don't like that."

(3,7,30-31)

"...ideas being put into heads that aren't already there"

(3,7,35-36)

"(he) hadn't any problem until this started to get mentionedit was because of what was put into his head by other people."

(3,10,5-7)

These beliefs are refuted by various studies. Craft and Craft (1983) claim that sexual knowledge "does not stimulate or motivate students into sexual activity". Demetral (1981) also claims that people with learning disabilities did "not emit more sexually undesirable behaviour after exposure to sex education and counselling than those same students did prior to exposure." Mihill (1995) states that it is a "myth that sex education leads to (early) sexual experimentation - the evidence is that the opposite is true."

One of the professionals explained that the problems regarding sexuality of people with learning disabilities are

"aggravated by the views of society, views of their parents, where a lot of parents

still see them as eternal children and a lot of society still see them as eternal children."

(28,12,34-38)

He continued,

"But I think that's the main problem, is the fact they are viewed very much as eternal children. A lot of people don't think they have the same possibility of sexual development as the mainstream public either....they view them almost as subhuman species, to be honest with you.....They're not seen a full human beings, as full adults."

(28,13,9-15)

This is reminiscent of Greengross' notion of the "Peter Pan syndrome" (1976) where people are denied adult status. Some parents "won't see them as adults" (23,7,5-6).

Professionals also see the lack of communication about sexual matters as a problem for people with learning disabilities. It is the "feeling that it's been shunned, it's never talked about" (18,9,12-13). Another problem, according to professionals, is "getting somebody to react with them" (30,11,25). Failure in this respect could lead to feelings of rejection or inadequacy. This could be the reason why

"a lot of them think they have to (have sex), because they want to be friends. They want to be nice to that person so they have to do whatever.....especially on the female side."

(23,8,22-24)

This leads to further problems concerning "consent and no consent and the assertiveness of one partner over the other" (23,8,17-18). Some of the professionals were actively involved in counselling in this area. They explained that it was a matter of

"trying to get through that they have the same rights as a man has and they are worth just as much as what the man is and because it takes two to tango, if you like, and if they don't want it, they don't have to."

(23,9,24-27)

Promoting Sexuality

With the differences in attitude to sexuality so far explored, it is not surprising that professionals and parents react differently to the issue of promoting sexuality. Parents, for example, expressed negative views about how "very nervous" and "worried they are" (3,9,23/33) at such a prospect. Their situation is contradictory because parents acknowledge the needs of their adult sons and daughters, but are fearful that sexual openness will lead to sexual activity. One parent encapsulated this difficult situation by saying,

"they probably have the right to know all about it, but it's the nervousness of triggering something off."

(3,9,38f)

Many parents felt, however, that if their sons or daughters were showing sexual interest or actually having a sexual relationship, then sexual knowledge should be given to them.

Before this point, it was generally felt that giving information would be encouraging sexual activity.

"I don't think you should suggest to them to have relationships if there's not already (an) inclination"

(3,11,25-26)

Using Harris' terminology (1968), one of the parents took an etic view of her son. This was based on her own perceptions and not from direct evidence from him. She said,

"as far as he's concerned, he's quite happy with his life and to bring sexual relationships into it, I feel, would be very complicated for him"

(10,7,19-22)

This denial of sexuality has been apparent within the professions and their comments illustrate this, as mentioned earlier:

"It was something in the past, sexual relations were swept under the carpet..."

(24,9,20-21)

"(It was not) recognised as happening. It was kind of 'Sh! Sh!' "

(25,9,32-33)

Some women with learning disabilities have

"obviously been told things like, "You can only have a baby if you get married",

because that's a safe thing. Nobody gets married here, so that's no problem about them having babies, you know." (Laughs)

(25,4,10-14)

This has affected the attitudes of people with learning disabilities in this particular establishment, as the professional explained,

"sex is so frowned upon because you feel, they feel it's naughty. You definitely get the feeling that when they're answering your questions that it's a bit naughty."

(25,4,26-29)

Guidance

When confronted with the possibility of their son or daughter developing a sexual relationship, parents expressed their wish to retain an element of control over the relationship:

"you should give them guidance if a relationship starts, to try to direct them in the right direction"

(3,11,23-24)

One parent believed that she would be in contact with the parent of her son's girlfriend should the relationship become 'serious', or if the girlfriend in question became pregnant,

"I think the two of us would get together and decide what we were going to do with them."

(7,4,30-31)

The opportunities for people with learning disabilities to develop personal relationships are generally restricted and there are "limitations to where (sex) can take place" (21,12,4). Many residential facilities do not, for example, "cater for shared accommodation between sexes" (24,6,26). On a more personal level, a professional spoke about a particular man with learning disabilities who lived in his parents' home. He said,

"I don't know whether there is ever a situation when (he) is on his own and has some, like, private time."

(16,8,38f)

The reasons for this lie with the parents, because they "get over-protective, especially in subjects like that" (16,9,20-21). Other comments made by professionals reinforce this view,

"I think she's been well-primed by mum on that side of things, that possibly relationships are not for her....."

(12,4,25-27)

".....she's probably been led to believe that it's not possible for her to go down that road."

(12,6,33-34)

Parents admit to their feelings of protectiveness (see Chapter 4) and this is particularly salient with regard to sexuality. They said,

"She's never out unless she is with us. I mean, I don't let her go out"

(4,5,23-24)

"I was very protective towards (him), maybe I was too much that way"

(10,3,31-32)

A mother's comment illustrates the altruistic element of the parental philosophy regarding protection. She said,

"they're people and they've got the right to experience every experience in life, but then, would we want that for ourselves? Because there's a lot of things that happen in our lives that we don't want to happen. So, if we can prevent that happening in their lives, well, I would say that was all to the good"

(19,9,12-17)

She believed that an unwanted pregnancy would be disastrous for her daughter with learning disabilities. If her careful supervision ceased to be feasible, this mother said that she would not hesitate to request that her daughter be sterilised.

Vulnerability

One mother explained why she felt protective towards her daughter. It was because

"she couldnae be trusted on her own...she would go away with anyone....she'd talk to anybody"

(4,2,14-15)

Professionals were aware of this predicament in several instances. One professional said of a woman with learning disabilities,

"she could be so easily used and abused because she's so loving and guileless"

(25,8,2-3)

It is interesting to note that one professional commented that sexual problems could also affect people who were not recognised as having learning disabilities and that unplanned and unwanted pregnancies occurred throughout the population:

"But let's say if somebody gets into that situation and the hormones dae kick and get carried away, then that's....the mistake could happen"

(13,15,29-31)

Another major problem, according to parents, is the lack of ability of people with learning disabilities to make decisions. They claimed,

"(she) can't make simple decisions about things"

(1,3,14)

"from my point of view (he) couldn't make a decision"

(22,7,11-12)

By contrast, the professionals believe that any deficits in this area are a result of the lack of opportunity to make decisions. Having led sheltered lives under the protection of their parents, adults with learning disabilities have learned to be dependent upon them for decision-making. A professional explained that they

"have never been allowed to make decisions before so it's difficult for them to actually make a decision.....(they are) really submissive....they just agree with everything, they don't challenge you....you can really manipulate things and you've got to be aware of that."

(18,8,23-30)

Another professional added,

"it's all right saying, "I'm an adult and I can make my own choice", but when it comes to the bottom line, what their mum and dad's saying....they, you know, they're very receptive"

(23,6,7-10)

It is interesting to note that this is the case even where the person with learning disabilities is no longer living in the parental home and has, as a result, reduced contact with parents and other relatives. Other professionals' comments reiterate this,

"she always says, "I'll need to ask my mum and dad"...Everything is, "I'll need to ask my mum and dad...they must ask their parents' permission to do things"

(25,7,28-29)

Professionals believe that adults with learning disabilities should be given the widest possible range of choices in order to make their own decisions. They

"certainly should have the opportunity to make their own decisions affecting their own lives. And obviously they should have choices, as far as I'm concerned, in any area of their life. We all have that choice, whether we think we have or not."

(28,7,29-32)

The polarisation of professional philosophy and parental reality is encapsulated with a comment made by a professional:

"I don't really think there should be any limits or restrictions put on them even if they're not capable of making choices."

(28,8,10-12)

Professionals are aware that parents are reticent about the sexuality of their sons and daughters with learning disabilities. From their viewpoint, most parents

"tend to be very narrow-minded about the whole thing. It's a case of "Oh, no, they can't do that" and that's the end of the story."

(12,3,35-37)

"it's a dirty subject as far as parents are concerned. In theory it's a dirty subject, it's a taboo subject, it doesn't

happen with these people. It does. It does happen...."

(21,11,9-12)

Sexuality, according to the professional philosophy, is a "part of life" and that parents have "got to accept it" (24,5,31-32), no matter how "totally terrified" (23,5,36) they are at the prospect. There is, however, "a certain amount of fear talking about it and not looking too deeply into it" (18,18,5-7) by the professionals themselves. It is particularly within the controversial area of sexuality that professionals can experience internal conflict. This involves a difference between their personal beliefs and those of the orthodox philosophy of their profession, which was explored in the previous Chapter.

Professional Responsibility

There remain "a lot of grey areas" (21,15,18) regarding sexuality and people with learning disabilities. Most professionals in this study agreed, however, that they have a responsibility to ensure that information, advice and guidance are available to people with learning disabilities so they know "just how to keep themselves safe" (25,2,16) and to be aware of the responsibilities that accompany decisions regarding sex (23,7,1-2). Another issue involves "empowering the women (which) is one of the major things we need to do" (25,3,22-23). Further comments made by professionals clarify their position,

"I would try to put in place as much information as I could to let them make (their) choice. Yeah, I think it's part and parcel of my remit in that respect."

(14,11,26-28)

"I think it is my responsibility"

(21,10,33)

A member of staff explained that sexuality is

"treated in a very irrational way (by parents) so somebody's got to be rational about it and I suppose that's where we come in."

(13,16,14-16)

Although professionals predict that

"as time goes on the parents will be brought in even more and it'll be more or less a kinda open thing, it won't be sort of shut and closed in."

(23,6,23-25)

One professional raised a pertinent question regarding the provision of contraception for people with learning disabilities following the teaching of sex education. Anxiously she said,

"you may be opening a can of worms. The fact that what are you going to do if, at the end of the day, these people say, "Yes, I do wish to have a sex life"? But are we going to keep them safe contraceptively? Or are we going to keep them safe from sexually transmitted diseases?"

(25,9,9-13)

She went on,

"Are we then going to take it further and counsel these individuals on contraception? And are we going to have condoms available?...What are we going to do to enable these people to live up to the lesson you're...teaching them of safe sex?"

(25,9,34-38)

Hidden Competence

The influences that govern parents evolve from their expectations of the ability and competence of people with learning disabilities. These are based on their holistic experiences of their sons and daughters since birth. By contrast, professionals are governed by orthodox philosophy based on normalisation (see Chapter 4). Inherent in this, is the view that people with learning disabilities have potential that is not always apparent. This "hidden competence" has been the subject of research (Goode, 1983). In his study, Goode discovered their level of functioning and communication was at a more complex level than previously assumed. His findings reinforce the idea that disability is, in part, a socially constructed phenomenon. It also highlights the difficulties in distinguishing between emic and etic descriptions of people with learning disabilities (Harris, 1968). This is illustrated by a comment made by a professional,

"I don't think they view themselves as people with learning difficulties."

(24,12,3-4)

Most of the professionals in this study expressed a belief in the hidden competence of people with learning disabilities. It is this belief which forms the foundation of many of their attitudes. Their apparent helplessness and vulnerability is believed to be learned behaviour and not inherent in learning disability. Studies have shown that such behaviour is learned (Floor and Rosen, 1975; Abramson, Garber, Seligman, 1980). Through training, however, new skills can be acquired:

"There's a lot of things that they are able to do themselves they just, in the past or in other institutions, have not been able to do."

(23,2,11-13)

"We have a misconception of the ability of people with learning difficulties. They are slow to pick up...but once you've gone over something sufficiently..after a while they will understand it...It may be a bit painstaking"

(28,21,10-16)

Some professionals believe that, although their expectations of people with learning disabilities are higher than those of parents, they still tend to underestimate their actual potential. Some professionals are aware of this as illustrated by the following comments:

"(he's) got the capabilities to be more independent"

(16,9,37)

"he's very much an unknown quantity...he's selectively quiet....."

(13,11,36)

"he's sort of unknown that way. But you see glimmers of...there's a smart man in there."

(13,12,6-8)

"...there's a lot in there.."

(25,20,16)

Another professional summarised this idea,

"most of them are quite cunning and quite devious as wellThey've got a hidden intelligence ... I've come across people who've been given an I.Q. as low as 15 or 20 and Down's syndrome and they're acting with a social skill performance level of about 70 or 80 I.Q."

(28,16,9-14)

He added,

"I would agree there is a hidden competence in most of them. Not all of them, but in most of them. And it's a matter of finding that and developing that."

(28,16,9-21)

The idea, therefore, that people with learning disabilities have hidden competence influences the views of professionals, especially concerning sexuality. This is apparent in the estimations of their ability to cope with events and responsibilities associated with sexuality. These issues are explored below.

6.iii. Relationships

All the people with learning disabilities in this study either currently were involved in a relationship with a member of the opposite or the same sex, or had had such a relationship in the past. The professionals were the source of this information. Although most of the parents acknowledged that their adult sons or daughters had such relationships, some denied this to be the case. Some of the parents also denied that their sons or daughters would be able to cope with such a relationship whereas the professionals all believed that they would be able to cope (see Figures 6.1. and 6.2.).

Figures 6.1. and 6.2.
Comparison of agreement between parents and professionals on
the potentiality of people with learning disabilities to
cope with relationships, marriage and parenthood.

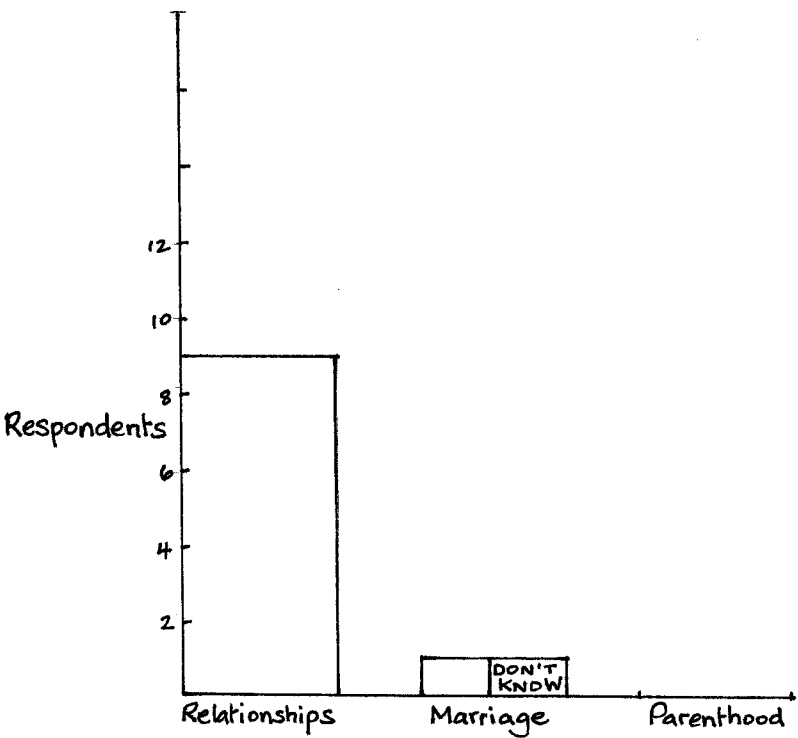


Figure 6.1.
Parents' Views

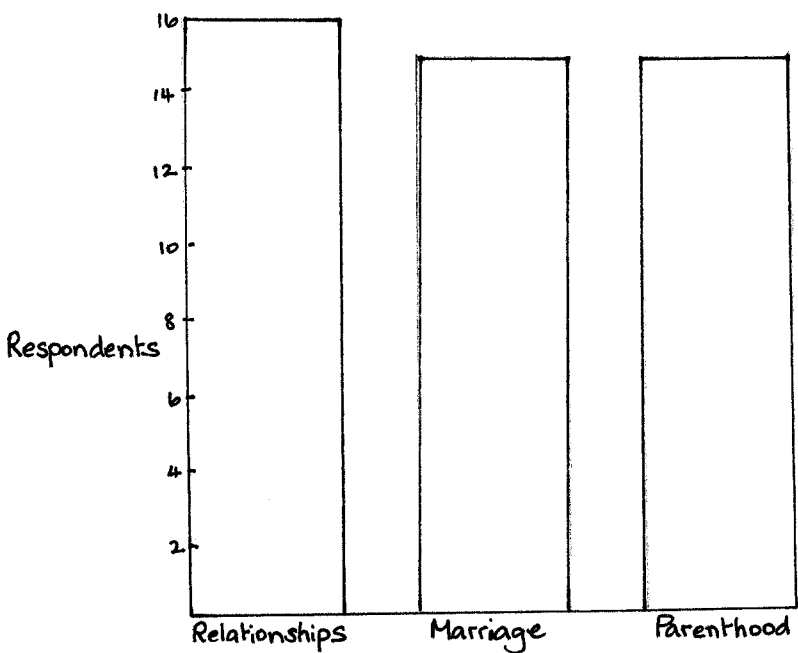


Figure 6.2.
Professionals' Views

Statements made by parents were negative:

" if she had such a relationship, she
would just get into trouble"

(1,3,7-8)

"No, I don't actually, no, I don't
actually, no, no, no."

(3,3,32)

"No, not really, no. She couldn't cope

(4,2,38)

"she just couldn't cope with the
situation."

(6,3,23)

"too much of a responsibility for him"

(20,11,27)

There is no evidence to suggest that their sexual preferences are not as diversified as the rest of the population. However, the opportunities to explore these preferences are limited. For one particular person with learning disabilities, sex was not confined within a steady relationship.

"This is because (he) wants it like that.
It's not any depth. It's just, I think
that's what I mean, it's sort of like

convenient. It's because that person happens to be there."

(13,13,18-21)

This comment raises the problematic moral aspect of sexuality and people with learning disabilities. It is possible that a person may have the competence to cope with a sexual relationship, be it casual or long term, while not being competent to sustain a committed relationship. Also, they may not want to commit themselves exclusively to a long term relationship. Within Social Work establishments, in particular, this could cause adverse publicity. It is salient to emphasise that Sebba (1983) believes the risk of scandal leads professionals to expect higher moral standards of behaviour from people with learning disabilities than they would from the general population. In one residential establishment, for example, a professional stated that they "would do their utmost to prevent a pregnancy" (F:6,2,95). Nevertheless, the professionals are more positive than parents in their views on relationships:

"personally, I feel that somebody is capable of sustaining a relationship, whether it be a physical relationship, or an emotional, or both, whatever, then they should be allowed to, whether it be with someone who is termed a 'normal' or whatever."

(13,14,15-19)

Other professionals expressed similar views,

"I'm all for it"

(21,12,26)

"outside or in, within marriage, I don't see a problem at all"

(28,13,24-25)

"if the pair of them are happier and can help each other that's....then why should they not help each other and be very comfortable sex-wise as well?"

(30,12,26-28)

One professional held strong views on this issue. He said,

"I think everybody has the potential to sustain a long-term relationship. I don't think learning disabilities comes into it. We have people who are quite heavily disabled who are involved with another person with the same sex or whatever sex and they have formed a relationship.....Everybody has the ability to form long-term relationships, but there are very diverse forms of relationships."

(35,6,19-23/ 31-33)

Parents are less liberal and have more restricted views on the matter. One parent felt anxious about her adult son having a relationship with a woman. She said,

"I thought it's not fair of me saying 'no'. I didn't feel as if I was being fair if I said 'no' but I could foresee ahead...I could look ahead and foresee trouble..."

(10,3,13-15)

She went on to explain that "it can cause awful problems" (10,5,5). Another parental comment emphasises the negative feeling in this area:

"relationships, I don't believe in it....I believe in companionship....but marriage, no, and that sort of thing...it shouldn't go that far. There shouldnae be any chance."

(19,12,16-22)

Homosexuality

Despite a professional stating that homosexuality and bisexuality were topics not generally freely discussed in the context of learning disability, they were less reticent about these issues than parents. However, a professional explained that they did not have the "full confidence to handle that yet" (18,15,17) but "hopefully" he added, "it'll become an issue soon" (18,11,14-15). The professional viewpoint can be summarised by the comment that "what they do in privacy is up to them....if that's what they want to do" (23,9,32/36). A major problem, however, is their having access to privacy. There are limitations, therefore, on their behaviour. A professional gave his view on the matter,

"If that's what they wish to do then...I've no qualms about that...as long as these things are done in the right places at the right time and it's not going to encroach on anyone else's lifestyle."

(21,13,6-10)

Another professional was positive in outlook,

"(if) that's the person's choice, I wouldn't bring my own opinions into that. From a professional point of view, if that's what the person so desires, they would be supported in their own choice."

(24,7,35-38)

Sexual Activity

With regard to sexual activity of people with learning disabilities, professionals are more realistic than parents. This is because they are more willing to acknowledge that sexual intercourse or other sexual activity could take place. This is illustrated by their comments,

"Let's put it this way, if the need or want is there, be it in the woods or in the gardens or whatever, they'll find a way."

(23,12,4-5)

"Just because the accommodation's not there, doesn't mean sexuality doesn't happen. It does happen. It is going to happen."

(24,6,36-38)

"I think you will always find a place or something you can do to satisfy these needs."

(25,8,27-29)

These views are not confined in their application, but are relevant to all the population,

"I think people will always find a way of satisfying what is, in my view, a basic human need...I think the feelings are there....I think they would always find somewhere to meet or somewhere to satisfy whatever craving they happen to have at the time."

(25,8,12-19)

In contrast to these comments, many parents denied that sexual activity would take place:

"I don't see the situation ever arising"

(1,5,6)

This parent clearly did not wish the situation to occur, saying,

"I'd be more concerned about (trying) to reassure that nothing like that happened."

(1,5,2-4)

"(and) whoever's in charge of looking after, should be ensuring authority and responsibility, ensuring these things don't happen."

(1,5,25-26)

For other parents, these concerns are not an overwhelming issue because they hold low expectations of the sexual needs of their adult sons and daughters.

"I don't think it's even crossed his mind"

(20,13,30-31)

"I think (his) level is like kissin'.....it's just kissing and holding hands and cuddling"

(20,11,9/17-18)

"(I asked) "What do you do with your girlfriend?"....."Cuddling up"....and, he says, "That's sex.""

(22,10,14-16)

Marriage

During the qualitative interviews parents and professionals were asked to consider the abilities of people with learning disabilities to sustain a long term relationship either with or without being married (see Figures 1 and 2). The parents' views were decisively negative in their estimations:

"No, not really, no. She couldn't cope."

(4,2,38)

"No, because she would never be able to look after herself, let alone anybody else."

(19,11,38f)

"No...He wouldnae want all that...I don't think he would think o' it at all....I don't think he'd want to. I don't think he's interested in that."

(20,13,11-12)

Although the professionals held some reservations regarding the desirability of marriage for people with learning disabilities, they did not negate its possibility. They said,

"Well, it's a possibility, why not?"

(16,7,23)

"They have a right to get married if they so desire"

(24,7,22-23)

"I think if they're functioning, people who can care for themselves and each other with degrees of support....I don't see anything wrong with at all."

(25,14,24-27)

"if a couple were married then they could possibly cope with the pressures of life"

(29,12,34-35)

Both parents and professionals agreed that some people with learning disabilities would benefit from an external support system in order to cope with problems arising from relationships and sexuality.

"Oh, I think you'd need to have some sort of support..."

(8,6,2-3)

"They need support"

(18,11,1)

"there's got to be back-up. There's got to be support...the support has to be given"

(21,12,28/33)

6.iv. Parenthood

Llewellyn (1990) states that people with learning disabilities "are disadvantaged in many ways by low incomes, unskilled jobs, inadequate housing and poor health and may therefore experience social isolation, increased stress, and poor self esteem". These factors are likely to negatively affect their parenting abilities.

There are studies concerning parenthood and people with learning disabilities (Shaw and Wright, 1960; Mattinson, 1975; Greenspan and Budd, 1986). Sirota and Hoffman (1987) claim that the "results of empirical research evaluating the parental abilities of mentally retarded people are equivocal due to sampling problems and biases." There are also no satisfactory methods of measuring the qualitative element of good parenting: "exactly what constitutes adequate parenting has yet to be determined" (Sirota and Hoffman, 1987).

Regarding the ability to cope with parenthood, the opinions of professionals and parents seem at first to be

pessimistic. On closer analysis, however, it is clear that the professionals take into consideration the potential competence of people with learning disabilities to cope with child rearing. They felt that at present parenthood would be too "stressful" (11,3,9) and they would not be "responsible enough to cater for the needs of a baby" (2,1,26-27). This was because of their "immaturity" (12,6,7). They believed that their maturity could develop to allow them to cope with the demands of parenthood. It would be a "possible future option" because of their "potential" (17,3,33/36).

In opposition to this view, parents believed that their sons and daughters had reached the limit of their potential. Parenthood, therefore, would be beyond their capabilities (see Figures 1 and 2). Their comments illustrate this:

"Cope? No way, never. She'd never be able to look after a child on her own."

(1,3,32-34)

"I know that she couldn't cope with a kid."

(4,7,1)

"there is no way that he could look after or bring up a baby....he definitely doesn't have the capabilities."

(7,3,10-13/ 7,5,10)

"It would be a terrible ordeal for her....the responsibility, I feel, would be a bit too much."

(10,7,1-7)

Even with the possibility of external support, parents tended to disapprove of their sons and daughters having children of their own. They stressed that they "would need an awful lot of help" (6,4,8). Such help would not be "a normal way of bringing up a child" (3,11,3). As one parent pointed out,

"you can't have somebody supervising this child 24 hours a day"

(3,11,17-18)

The kinship obligations of parents is a major influencing factor on their views. These, ofcourse, do not affect professional views. As parents, and as potential grandparents, they felt a responsibility towards any possible offspring. Their comments illustrate these feelings and their consequent anxiety.

"I'd be responsible for that baby"

(6,5,29)

"it would fall on the family. I think that's where the anxiety comes in. And you've got to remember it's their grandchild."

(9,3,34-36)

"who's gonna be left? Parents again, like myself. I'm 48...I don't want to be saddled with another child"

(7,7,17-18)

"I...would be...left to look after it"

(5,3,19-20)

"I think the outcome...It's the parents that's got the heartbreak and the responsibility, isn't it?"

(5,12,4-5)

The prospect of having to look after a grandchild in these circumstances was regarded with aversion by most parents. This is not surprising because it would be an addition to the continuing responsibility they feel towards their son or daughter. Some parents held strong views on the matter,

"But personally speaking, from a selfish point of view, I've brought (her) up, no thank you, I don't want to do it again."

(5,3,11-13)

"I really shudder to think, you know, if it did happen...I certainly wouldn't be able to cope... I would do what I could, but I really don't think I could go back through this again."

(7,7,24-25/ 7,6,30-33)

From a parental viewpoint, sterilisation offers a solution to this problem. Furthermore, if parents are to be responsible for rearing a child in such circumstances, then they could be morally justified in assuming the responsibility for the prevention of a child's conception. As one parent said,

"if they want to have sex, well, that's it, as long as there's no baby"

(3,7,8-9)

Exacerbating their anxieties is the fear that the baby could also "be mentally handicapped as well" (7,7,19-20). This is reminiscent of Macklin and Gaylin's idea of the 'child's right not to be mentally handicapped' (1981).

There was also the undesirability of the stigma the child would carry knowing "its mother or its father as mentally handicapped" (9,3,12-14). In particular it could be

"very difficult for the child when it grew up....very, very difficult for the child to cope with that when it went to school"

(8,6,8-10)

One parent commented,

"My feelings are too much for the baby, rather than for the parents really. I think everybody's entitled to a better upbringing than that."

(3,11,10-12)

The following statement reveals parental pragmatism,

"You have to be realistic about it, apart from the sentimental part of it. You have got to be realistic about the child, haven't you?"

(8,5,31-34)

In the context of professional philosophy, these views are not considered relevant. A professional explained,

"I don't think that a child who is being brought up by parents with learning difficulties is going to look down on them because they've had learning difficulties. I'm quite sure there's many children who are extremely bright who have been brought up by parents of lower intellect and they're still their parents at the end of the day. They still have love for their parents."

(28,14,18-24)

Professionals believe that the option of parenthood must remain open as a future possibility for people with learning disabilities and therefore sterilisation at present would be unjustifiable and inappropriate. The overriding feature influencing professionals is the notion of reproductive freedom for people with learning disabilities and the principle of choice. Parents disagree,

"That's not the point. I mean, it's the question of, are they capable of giving the child a good life?"

(3,10,38f)

The professional philosophy, however, remains in support of the 'rights' of people with learning disabilities to have children. It is emphasised that, being adult, they have the same choices and decisions to make as any adult who does not have a learning disability. "If that is what they want from life" then professionals do not see "any reason why it should be denied" (16,8,8-10). There are adults with learning disabilities who want to have children of their own (23,7,22-23). This creates a dilemma which increases the tension between parents and professionals. A professional

described how a woman with learning disabilities wanted a child against the advice of all who knew her. She said,

"She definitely has a desperate...need to hold something that's hers...(she) goes on a lot about having a baby and loving a baby and she could look after it and even, if you point that her living situation's perhaps not ideally suited to her having a baby she still doesn't see that as a barrier."

(25,7,10-15)

6.v. Contraception

Because of its reversibility, contraception is not regarded as problematic and, according to professionals, should be easily available (28,18,21-23).

"I think if they're able tae take or to have a sexual relationship wi' somebody and if they want tae use contraception, I think they should, with counselling, so they know the ins and the outs, just the same as like you or I, if we wanted to (use contraception)"

(15,7,34-37)

The professionals emphasised, however, that contraception should always be a matter of individual choice for the person with learning disabilities concerned. They also stressed that their consent was a vital issue.

On the topic of contraception, most parents said that they would only consider its use if their son or daughter developed a 'serious' relationship. This suggests

that they would only take action to ensure the prevention of an unplanned pregnancy if they felt there was some tangible evidence of its possible occurrence. Close supervision of their son or daughter leads some parents to believe that contraception is unnecessary.

"I've never really bothered (about contraception) because she's never out unless she is with us."

(4,5,22-23)

Other parents

"wouldn't consider it. I feel that she's got enough to cope with."

(6,6,10-11)

6.vi. Sterilisation

From their objective viewpoint, professionals regard the sterilisation of people with learning disabilities as an infringement on their freedom to reproduce. It is seen as a matter of principle and one of choice for each individual adult. It is interesting to note that none of the professionals regarded sterilisation as a means to an increased freedom. From this perspective, sterilisation could serve to enhance sexual activity because it would be freed from fears of an unwanted pregnancy. These fears are a reality for women with learning disabilities as they are for other women. At the time of one of the interviews, a woman with learning disabilities was awaiting the result of a pregnancy test and who "was extremely worried....because she did not want to become pregnant" (2,3,16-17).

Another woman with learning disabilities had been sterilised at her own request. She explained,

"I've been sterilised. I'm not against it. If I did have (a partner) I'd be worried...(about a pregnancy)....I don't want kids. I wouldn't hurt them, but the risk they might be mentally handicapped- no offence - you know, I'd be upset if something like that happened."

(27,3,4-8)

Professional philosophy regards people with learning disabilities as adults with responsibility for themselves. Sterilisation would therefore be "infringing on (their) rights" (15,11,5). Because of this professionals did not "believe in it" (17,4,17) but disagreed with it "totally" (28,20,20). Other professionals, while also disapproving of sterilisation, expressed an understanding of the difficult situations that could ensue:

"I can't say that I agree with it, but I know it leaves an awful lot of work for maybe an awful lot of people and we don't maybe have the resources to deal with that."

(14,14,34-37)

In some instances, professionals felt that sterilisation would be acceptable if a person with learning disabilities "elected" this form of contraception for themselves and

"if they understood it. I mean, if it was an informed decision."

(28,21,1-2)

A professional added,

"I don't think it's something you can press upon anybody without (their) agreeing what's happening."

(16,10,16-18)

Another professional agreed with this view,

"I don't think it should be done unless they want it."

(23,10,21)

One parent was not in favour of sterilisation because of her own personal experiences. Her regret of being sterilised offers insight into how women with learning disabilities might also feel. She had been given advice in favour of sterilisation from friends, relations and her doctor and, as a consequence, had consented to the operation. She confided that she had since "regretted it, very much so" (10,9,37), explaining,

"I felt very guilty after it...not only that, I still longed for more children. Oh, I was sad. I mean, they were saying to me, that is the best thing for you and I went ahead with it. I really regretted it."

(10,10,8-11)

Most parents, however, were in favour of sterilisation, especially if their son or daughter had a "steady relationship" (5,2,14) or if they anticipated what they euphemistically referred to as a 'problem'. One mother said,

"I would like to get her sterilised rather than have the problem crop up."

(5,2,7-8)

It is of interest that parents of sons do not differ in their outlook,

"I've said this for years, that if by any chance we ever started to have problems in that direction, I'd have him sterilised....if we ever started to have any sort of problem I would be straightaway asking for him to be done."

(3,4,9-11/ 18-19)

Although professionals generally thought that sterilisation would be too complex a concept for some people with learning disabilities to comprehend at present, this situation could change with their increased maturity. Parents did not foresee this as a possibility and were adamant in their beliefs that the present understanding in their sons and daughters had reached its ultimate level. Despite their belief in the lack of understanding, parents were of the opinion that their adult children would be compliant in consenting to sterilisation.

"Oh, I think she would consent but she really wouldn't know what it is."

(4,3,33-34)

"If you gave her a form and told her to sign it, yes, she would sign it. I don't suppose for a minute she would know what she was signing."

(5,5,2-4)

These comments reveal potential legal problems with the issue of the validity of consent (see Chapter 2). Most of the parents also had no doubt that their sons and daughters did not have the capacity to make such a decision regarding sterilisation.

"as far as handicapped persons (are) concerned, I don't think they have the capability of making a decision like that."

(10,12,1-2)

This is because it is

"too important a decision for them and I feel it's too....that would be a very, very difficult decision for a handicapped person to make on their own..."

(10,11,31-33)

Other parents did not think that people with learning disabilities should even be asked to make that type of decision and were prepared to take that responsibility themselves.

"I would probably have to make that decision with the likes of him. He couldn't do it himself. He really wouldn't know what you were talking about....."

(22,11,18-19)

The subject of sterilisation and its incumbent decision-making is a matter of great seriousness for parents, as one mother explained,

"it's not a decision you're going to take lightly. It's going to be a long-thought-out (one)...."

(5,12,10-11)

This parent felt strongly about outside 'interference' from Social Work agencies who might take such a decision "out of your hands" (5,12,9-10). She described her feelings about the possibility of this situation occurring.

"I have been left to bring up this child on my own for the past nineteen years without anybody's help, thank you very much, and now all this suddenly, the first important decision is to be taken, I need somebody's say-so. No, I don't think so....I think it's a terrible slight on parents to do that. I mean, it's a much as a case as well, "Oh, you've been good enough for all these years, but now, you know, you don't know what you're talking about", you know? No, I don't think, I think it's a terrible slight on the parents, I really do."

(5,11,29-38/ 5,12,1-2)

By contrast, professionals believed that they, themselves, had no rôle to play in making this type of decision unless they were part of a review committee (24,6,17-19). Apart from this situation, there were no other circumstances in which the professionals would feel justified in being involved in such a 'permanent' decision.

"I don't think we have the right to say whether people should be sterilised or not."

(12,9,15-16)

According to the professional ideal, this type of personal decision should be "entirely up to the own individual's feelings" (16,10,27-28) which would then be acceptable "if the person so desires" (24,8,31).

6.vii. A Controlled Comparison of Professional and Parental Attitudes towards Contraception and Sterilisation

A vignette was devised. It portrayed a man and a woman, called Paul and Jane, both of whom had mild learning disabilities. The couple were described as having a sexual relationship which becomes more intimate as the vignette progresses from Situation 1 to Situation 6 (see Appendix A at the end of this Chapter).

The vignette was presented to each respondent near the end of each interview. They were asked to identify at which Situation they felt it was most appropriate for the couple to use contraception. They were then asked to identify at which Situation, if any, they felt that sterilisation would be appropriate. They were asked to qualify their response by stating whether they thought the man or the woman, or both, should be sterilised. There were no significant gender differences in the replies.

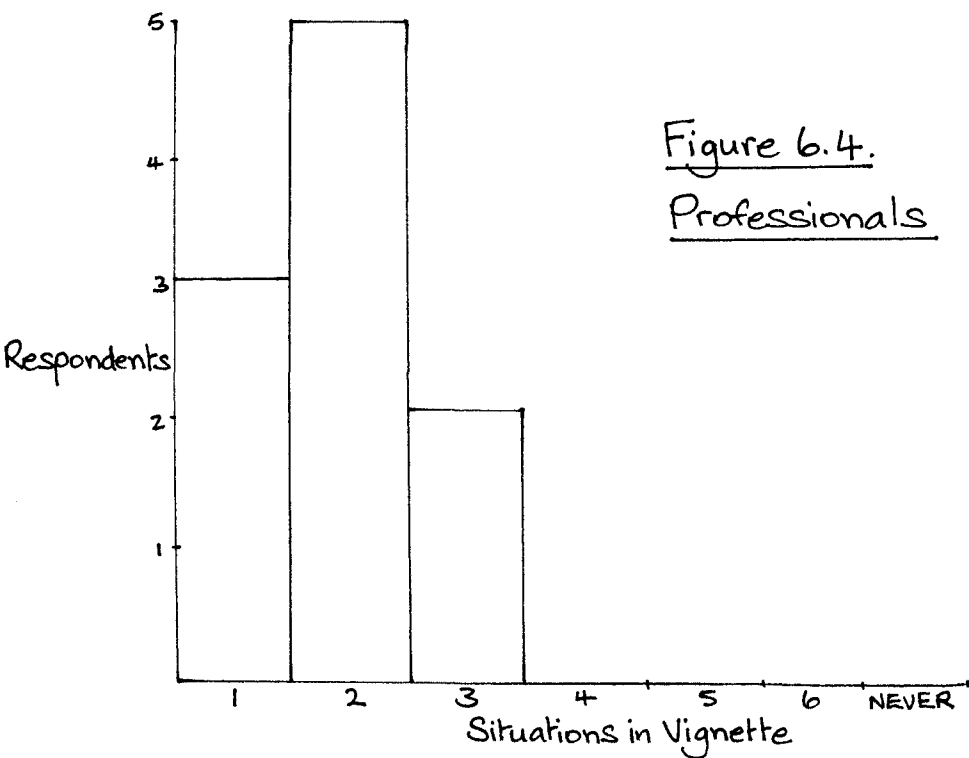
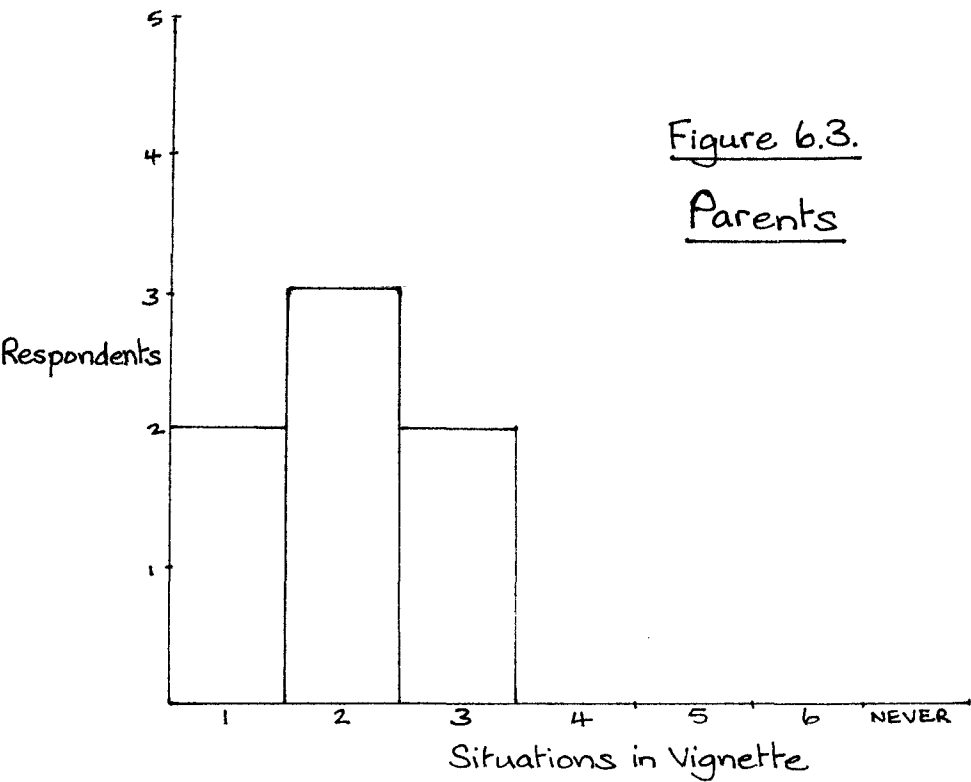
The purpose of the vignette was to examine the decision-making process in order to identify the point at which the decision to sterilise was made in each instance. Using this hypothetical scenario clarified and reinforced the respondents' earlier statements. This is because they are consistent with their views regarding people with learning disabilities to whom they are related or with whom they work. The vignette therefore offers a modest quantitative element to the study. More importantly it

substantiates the grounded theory which has been generated by the data from the qualitative interviews.

There are no clear indications in Situations 1, 2 or 3 that sexual intercourse takes place between the characters. All the respondents indicated one of these Situations as the point at which they felt contraception should be first introduced. There is therefore no significant difference between the responses of the parents and those of the professionals in this part of the exercise (see Figures 6.3. and 6.4.). The generally accepted irreversibility of sterilisation produced a distinct difference between the responses of parents and professionals (see Figures 6.5 and 6.6.).

Figures 6.3. and 6.4.

Question: "At which situation should contraception first be introduced?" A Comparison of Parents' and Professionals' Views.



Figures 6.5. and 6.6.

Question: "At which situation should Jane or Paul be sterilised?" A Comparison of Parents' and Professionals' Views.

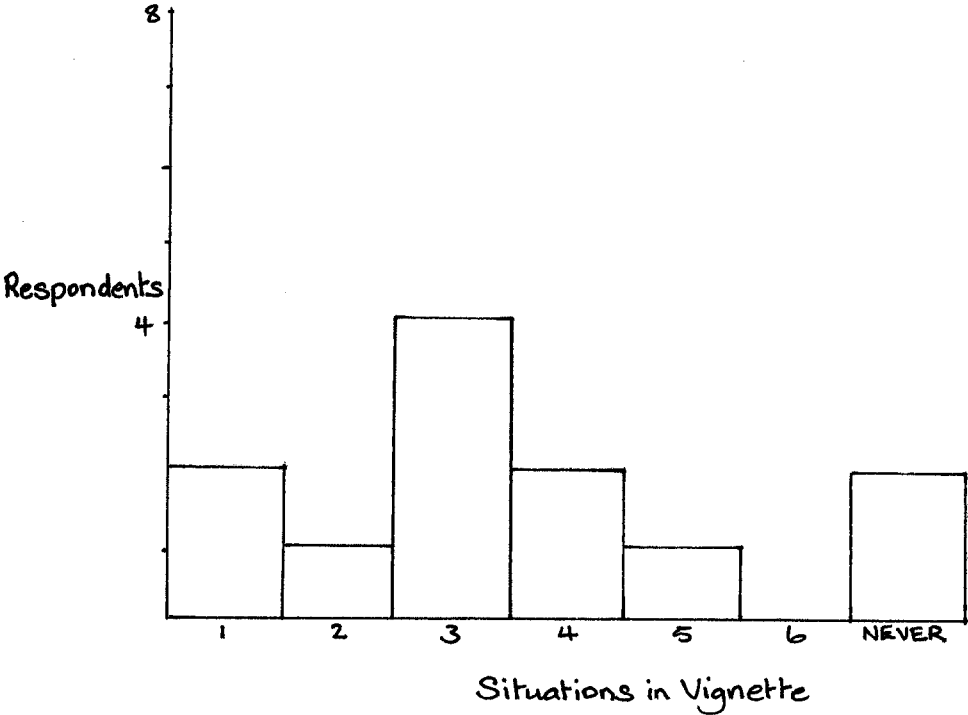


Figure 6.5.
Parents

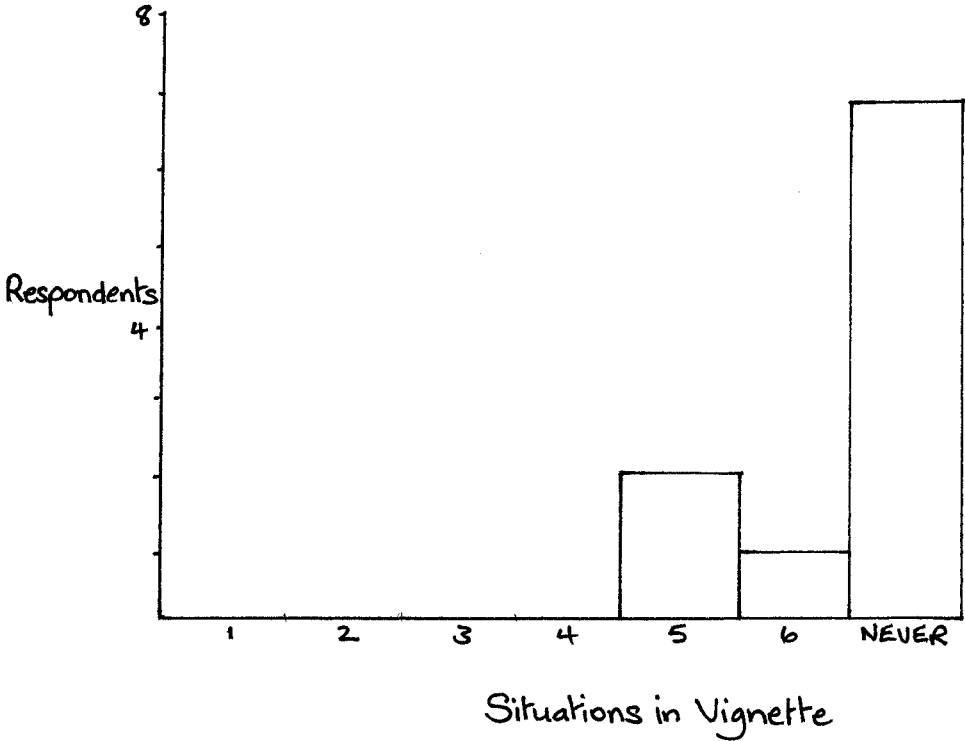


Figure 6.6.
Professionals

In accordance with their personal beliefs, only two parents chose the option of "Never" regarding sterilisation. The other parents' responses were spread between Situations 1 and Situation 6. For some parents, sterilisation was immediately preferable to any other form of contraception.

Only one professional said that he did not know under which circumstances sterilisation would be most appropriate. Some professionals chose the later Situations (5 and 6), with the majority choosing the option of "Never" as the most appropriate response. This is consistent with their earlier comments regarding people with learning disabilities having the 'right' to choose whether or not to procreate.

"(sterilisation would) solve a lot of problems, but to be sterilised is taking away a right."

(24,13,11-12)

Referring to the vignette, the professionals also revealed their philosophy.

"I don't think it's up to me to make a decision for them like that. I think it's up to me to support them with a decision, not to make it."

(16,12,28-30)

They said that Jane and Paul had a "shared responsibility" (17,5,4) in the decision-making. Their feelings about sterilisation were clear:

"Sterilisation is too final"

(10,13,17)

"Jane and Paul should never be sterilised"

(17,5,9)

"Sterilisation, I wouldn't consider"

(18,4,4)

"But definitely again, no sterilisation"

(23,14,36)

"I don't think there's any need for
sterilisation"

(25,16,35-36)

"I don't see any need for it at all"

(28,27,35)

Similarly, the vignette accurately reflected the parents' earlier comments. There was a tolerance of Jane and Paul's sexual relationship, on condition that babies did not "materialise" as a result of their union (3,5,34). They felt that the couple would not be able to cope with a baby (9,6,26-27) and there would be a risk that they would treat a baby like a "doll" (20,17,20), emphasising that "sterilisation should have been done" (19,15,4) in one of the Situations before Jane became pregnant.

The vignette stirred parental emotions. One parent commented,

"I don't think they should be allowed to
be together like this"

(1,7,26-27)

and went on,

"I'm not in favour of anything that leads to making it easier, or leaving them free to do these things on their own.....(because) they are not able to make these decisions for themselves, they are not mentally able to decide for themselves."

(1,8,8-10/ 1,7,38f)

It is interesting to note that parents discussed further issues than the professionals. They expressed concern, for example, for the resulting offspring depicted in the vignette. Their views were similar to those described earlier,

"I don't think it's fair on the child"
(3,6,5) "children are not considered in lots of cases. It's just what the couple want rather than bringing a human being into the world. They don't consider that at all...my point is for the child"

(8,11,3-6)

Another parental concern was for the grandparents, reflecting earlier statements,

"I think it's very unfair...for the grandparents....because nine times out of ten it'd be them that would end up with the responsibility of the child."

(3,5,38/ 3,6,2-3)

Finally, the parents empathised with the couple, Jane and Paul, in the vignette. They described their situation as

one of "turmoil" (5,7,32) and a "very traumatic experience" (8,11,17). One parent queried,

"They allowed (Jane) to have (the baby), so why, so if they're not allowed to keep it, why did they not sterilise her in the first place? It would have saved an awful lot of heartbreak. What will that girl be going through, knowing that she's got a wee girl, a wee baby, out there somewhere?"

(5,8,25-30)

In answer to this, another parent summarised the consequences, Jane would be "broken-hearted" (20,17,18).

6.viii. Conclusion

By examining the attitudes of parents and professionals towards the sexuality of adults with learning disabilities it is clear that this issue magnifies the differences between them. Undeniably, there are some similarities, but these are superficial because closer analysis reveals points of major divergence. Examples of these are the reasons given against sterilisation. Unlike professionals, parents do not propound the 'rights' of people with learning disabilities to bear children. Another apparent similarity is that both parents and professionals are dubious about the competence of people with learning disabilities to care for a child, or children. Nevertheless, there is here again a major difference between the two groups. Parents deem this situation permanent, but professionals view it as temporary. They believe that their hidden potential will become evident with their maturation, which, because of their learning disabilities, is delayed.

Parents, in their kinship rôle with its inherent obligations, felt that a lack of competence and responsibility in child-rearing rendered any 'rights' to reproduce as obsolete. This is particularly salient because in their parental reality, it is they who would have the responsibility for any offspring of their sons and daughters with learning disabilities. The themes of tension and conflict within the relationship between parents and professionals is exacerbated by these respective views on sexuality. As a consequence, the irreconcilable nature of the relationship is emphasised.

The focus on sexuality also reveals some of the aims of the orthodox professional philosophy. This is "person-centred" and places people with learning disabilities in the 'consumer model', rather than their parents. Again, this serves to widen the distance between parents and professionals, especially when parents suspect the professionals of promoting sexuality. This is perceived by parents as creating unnecessary problems and difficulties for the individuals and families concerned.

The results of the vignette reveal in diagram form the similarity of responses of parents and professionals to the question of contraception. This is due to its reversibility. There is a distinct contrast, however, between their responses to sterilisation and reflect their earlier opinions. Studies involving children with learning disabilities have shown that many parents approve of sterilisation (Bass, 1967; Alcorn, 1974; Turchin, 1974; Whitcraft and Jones, 1974; Wolf and Zarfes, 1982; Pueschel and Scola, 1988; Bambrick and Roberts, 1991 (involving children and young adults)). The latter two of these studies found that the gender of the person with learning disabilities was "not significantly associated with parents' views on sterilization" (Bambrick and Roberts, 1991), which is similar to the views of parents in this study.

The examination of the different views of parents and professionals offers insight into the complexities of the decision-making process regarding sterilisation. It also emphasises the different philosophical and ideological perspectives analysed in the previous Chapters. It also confirms the significance of their rôles within the framework of their relationship.

The situation is, however, more complex, with some professionals experiencing personal internal conflict. This does not appear to occur with the parents. In some instances the issue of sexuality reveals differences between their own personal views and those of the professional ideology. Under closer scrutiny, it appears that this is not an extension, or a further dimension of the professional ideology, but rather it is a tendency to adhere closer to the parental philosophy.

Appendix A

VIGNETTE

SITUATION 1

Jane and Paul are both 25 and have mild learning disabilities. They are very friendly with each other. At a dance they spend the whole evening together, dancing closely and kissing.

SITUATION 2

Jane now says that Paul is her steady boyfriend and they want to spend some time alone together. A holiday has been arranged for a small group of people and a few members of staff. Jane and Paul will both be going.

SITUATION 3

Jane and Paul now talk about being in love with each other and they want to get married.

SITUATION 4

Jane and Paul do not get married but Jane becomes pregnant. Early in the pregnancy she has a miscarriage.

SITUATION 5

Jane becomes pregnant again. It has been arranged for the baby to be taken into foster care after the birth.

SITUATION 6

Jane has a second child who is also taken into care.

Chapter 7

STERILISATION AND DECISION-MAKING

WITHIN SCOTS LAW:

An Analysis of Parents' and Professionals' Views

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7.i. Introduction

The aim of this Chapter is to describe the views of parents and professionals on decision-making regarding sterilisation of people with learning disabilities. Reference is made to the legal framework in Scotland which, in this particular instance, involves the tutor-dative procedure. When a person with learning disabilities is deemed incapable of giving valid consent, it is this procedure which allows consent to sterilisation to be given on their behalf. The respondents were asked to consider whether this type of legal provision or any other legal intervention in this matter was necessary.

Both groups of parents and professionals were presented with a hypothetical situation and asked to choose from a multiple-choice list of responses. This hypothetical situation concerned a person with learning disabilities for whom sterilisation was considered to be in their best interests, but who was also deemed incompetent to give valid consent to the operation.

From the multiple-choice responses, they were asked to indicate whom they considered the most suitable person, or occupation, to make that decision on behalf of the individual with learning disabilities. As with the vignette, (see Chapter 6), this adds a further quantitative element to the study. As in Chapter 5, the professionals will be referred to as either 'normalisers' or 'paternalists'.

7.ii. The Tutor-Dative Procedure

There are no general sets of legal rules which apply to people with disabilities (Ward, 1984). According to Ward (1984), the law will "define whether a particular individual has legal capacity for one particular purpose, at

one particular time, and in one particular set of circumstances". If an adult with learning disabilities has full legal capacity, then only that individual can legally give consent to a sterilisation operation (see Chapter 2). Inevitably, problems arise if a person with learning disabilities is considered to have only partial legal capacity or no legal capacity at all. In the latter circumstances a curator bonis can be appointed to manage their financial or other business affairs, but these do not include personal decisions such as consent to medical treatment.

In Scotland, valid consent, on behalf of a person with learning disabilities, can be given by a tutor-dative if such power is granted by the court. This can include the power to consent to sterilisation. In modern Scots law, a tutor-dative is a personal guardian who is usually appointed for a particular purpose and for a stated period of time. Any number of tutors-dative, who may or may not be related to the person with learning disabilities, can be appointed for the individual.

In Old Scots law, the management of affairs and personal guardianship could be under the auspices of a curator-dative, which was later renamed as tutor-dative. Ward (1992) explains that "the office originates from the practice of the sovereign of delegating guardianship of those cognosced as 'insane' to a team of kinsmen selected as being 'men of judgement and discretion'."

It was in 1924 that this old common law procedure was altered when a tutor-dative was appointed to act only as a personal guardian (*Dick v Douglas*). In 1986 further change was made to this procedure by the *Morris* case. The tutor-dative was given limited and specific powers in the role of personal guardian and the position was for a limited duration. It was clear however that this case "did not introduce a full modern personal guardianship code into

Scots law. It refined and updated the existing tutor-dative procedure, without fundamentally altering it" (Ward, 1990).

One of the powers that can be given to a tutor-dative is "the right to consent to any health care that is in the best interests of the dependent adult" (Ward, 1990). The issue of sterilisation raises a particular dilemma because of the controversy surrounding what constitutes the "best interests" of a person with learning disabilities. If it is not in the best interests of the individual, the consent given by the tutor-dative could then be invalid or wrongful. In these circumstances, the tutor-dative could be sued for compensation and his or her appointment as tutor terminated. Therefore, in order to safeguard everyone concerned, which includes the person with learning disabilities, the tutor-dative and the medical team, it is advisable that prior authorisation to consent to this operation is sought from the court. If the tutor has been appointed for the purpose of giving consent, it is advisable that as a safety measure, additional approval of the proposed sterilisation operation be sought from the court.

There have been several cases where the power to consent to medical treatment has been conferred on to the tutor-dative. These have included surgical operations that have been considered to be in the best interests of the person with learning disabilities. Ward (1992) cites two cases (D., Petr., 1991 and G., Petr) where "the court has in addition granted, without prejudice to the generality of the right to give medical consent, power and authority to consent to surgical sterilisation of a mentally disabled woman." It was considered in both these cases that the women with learning disabilities involved would have had their best interests served if they did not experience pregnancy and parenthood. In one case there were additional eugenic grounds for preventing pregnancy because, as Ward (1992) claims, "there was a 50 per cent risk of any child inheriting the genetic deficiency giving rise to the mental disability."

It is notable that both of these cases, permission to perform the operation was granted "without any hearing or discussion". There was a hearing, however in the more recent case (L Petr, 1996). An appointment of tutor-dative with power to consent to sterilisation was made. This action was opposed on the grounds that it was "unjustified and inappropriate". The woman with learning disabilities was thirty two years old and had been using the contraceptive pill for approximately twenty years. Although she had a sexual interest in her boyfriend, there was no evidence to suggest that sexual intercourse had, or indeed would, take place. No tests for her fertility were carried out. It was claimed that a pregnancy "would have a devastating effect upon her" and she would not be able to cope with it. Moreover, other forms of long-term contraception had been rejected on the grounds that they would not prevent her from menstruating. Although menstruation had not been raised as an issue of concern prior to the case, it was claimed that it would be "very difficult to cope with because she was so fastidious". Lord MacLean concluded that she "should not be allowed to menstruate in the future" and sterilisation was therefore considered to be in her best interests.

McLean (1996) comments, "Decisions of this gravity need to be taken with the most stringent adherence to human rights and, in my view, only as a last resort." McLean admits, however, that sterilisation is not always a denial of the rights of an individual. The need for legal accountability, she believes, is still necessary, particularly to protect "the vulnerable from invasion". Ward (1987) reinforces this view, saying that "any diminution in status which is necessary should be authorised by law, and carefully controlled". McLean adds, "If there is a real concern about rights, then one might be forgiven for thinking that all such cases should be heard by an independent tribunal, fully appraised of the empirical evidence and alerted to the fundamental issues. It is not

sufficient that either parents, guardians or doctors think they are acting in the best interests of the individual."

This case raises the issue of the appropriateness of legal intervention. Although the tutor-dative procedure provides an element of accountability in the process of decision-making on behalf of another person, the court retains ultimate power. Ward (1990) says that the tutor-dative procedure "will tend to reinforce the parental role in a rather discriminate way". This, he continues, could "strengthen home regimes in which the role of parents is unduly dominant, or over-protective". He affirms, however, that "many parents who consider appointment as tutor-dative are motivated by a feeling, or a fear, that professionals ignore them and make unsuitable decisions over their heads. They will tend to see some professionals as domineering, and in need of restraint."

Ward expresses his belief that the tutor-dative procedure is useful in meeting certain needs where there is no other provision in Scots law. He acknowledges however that it is not entirely satisfactory and that "an integrated statutory code" is needed. This is a matter presently being addressed by the Scottish Law Commission.

7.iii. Parents' and Professionals' Views of the Tutor-Dative Procedure.

The parents in this study did not have any knowledge of the tutor-dative procedure. Most of them were bemused by its existence. Typical responses consisted of

"A what?" (1,6,6)

"Never heard of it" (3,4,28)

As a consequence, none of their sons and daughters with learning disabilities had a tutor-dative. However, when the system was explained and they were asked for their views on it, the parents generally gave positive responses. One parent, for example, said,

"I think that's quite a good idea. It would need to be somebody that you felt would be right..I think you really need somebody to be there, you know, for help with big decisions."

(10,11,4-5/ 7-8)

Other parents also considered it to be a good idea,

"Aye, aye, I think so" (19,13,18)

especially with

"The likes of something we're talking about (for example) sterilisation"

(7,5,29-30)

Most of the parents thought of themselves as being the most suitable person to be appointed tutor-dative if necessary. Their views on this issue contrast with those of the professionals. The latter were reticent about the amount of information they had regarding the law and were hesitant in discussing it. This was perhaps because they felt they had insufficient knowledge. Despite being unsure of the implications, one professional stated that he

"was aware that legislation exists concerning sterilisation and people with learning disabilities"

(11,4,1-2)

A professional in a managerial position admitted that she was unaware of the existence and function of the tutor-dative procedure. Other professionals also made similar confessions,

"To be honest, I'm not very clear on the law"

(12,10,1)

"I'm not all that sure of the legalities of sexuality of a person with learning disabilities"

(15,11,9-10)

The views of those who had heard of the tutor-dative system were generally divided along the lines described in Chapter 5. Those who adhered to the superseded orthodoxy, or the 'paternalists', approved of the tutor-dative procedure, that is, their views were more similar to the parents than to their professional colleagues. One 'paternalist' believed that this legal provision was beneficial. Another said that

"if it was somebody who was living at home and that person was in sole charge all then I think that (person) would have to be considered (to be appointed as tutor-dative)"

(34,14,33-35)

There is no doubt that a parent in the position of tutor-dative role increases their power, not only in their relationship with their son or daughter, but also with professionals. A 'normaliser' was aware of this. He said,

"I have real problems with (the) tutor-dative (procedure) because it gives too

much power to a person who is already potentially over-protective to that person and therefore one of the things a tutor-dative can do is continue to stunt somebody's development as long as the tutor-dative survives"

(35,14,27-31)

As a result, he added that the tutor-dative procedure

"doesn't appear to offer the actual person any more freedom or any more scope to develop within their lives"

(35,15,13-15)

The 'normalisers'' adherence to the fundamental right of people with learning disabilities making personal choices brought them into direct opposition to a procedure which is based on the assumption that valid consent cannot be given by such a person. This removal of personal choice meant that the 'normalisers'' opposition was unequivocal:

"I think (it) is quite sick actually, that other people are allowed to make that decision for someone"

(12,10,6-8)

"No, I definitely wouldn't (agree with that), no. No, I think it's infringing on (an individual's) rights as a person really.....Oh, no, definitely not, no."

(15,11,5-6/ 22)

"I would tend not to agree with that"

(18,16,4)

"No, never"

(23,11,1)

"I would disagree with it....oh, totally,
yeah, totally"

(28,21,25-7)

They disagreed with the idea of a person being responsible for making such a decision for someone else.

"No, I don't think just one person should take that on board."

(30,20,3)

"I do have reservations, great reservations about that, about someone consenting. Only because you can't always be sure that they're doing it for the benefit of the person (with learning disabilities)"

(14,16,4-6)

To safeguard against this, one professional believed that if absolutely necessary, it would be preferable for such a decision to be made by a number of people through

"a group meeting with that person (with learning disabilities) involved"

(24,9,9)

There were some professionals who were non-committal. The following comments illustrate a reluctance to state their personal views,

"I think it's going to depend on the circumstances. I think it's got to."

(13,8,31-2)

"I would be too scared to be dogmatic on that one I think. Every situation needs individual...needs to be looked at closely."

(25,12,35-7)

"in some cases, certain circumstances can be different and it might be acceptable...I think it (should be) an individual's decision, but there might be (circumstances which) arise where action or that has to be taken for the benefit of the client"

(16,10,35-8/ 16,11,1-2)

7.iv. Parents' and Professionals' Views on Decision-Making

The differences between parental and professional views examined in Chapter 4 are also evident in the analysis of their views on decision-making. Parents were firm in their views and expressed their doubts and reservations clearly.

"That's too important a decision and I feel it's too....that (it) would be a very, very difficult decision for a handicapped person to make on their own.... as far as handicapped persons (are) concerned, I don't think they have

the capability of making a decision like that"

(10,11,31-2/ 10,12,1-2)

"there's an awful lot of things he doesn't understand....as I say, the likes of sterilisation...no, he doesn't understand that"

(7,6,11-13)

"He couldn't do it hisself (sic). He really wouldn't know what you were talking about if you actually said to him (the reasons for sterilisation)"

(22,11,17-19)

Parents considered themselves to be the most appropriate to make any such decision on behalf of their son and daughter. Their vulnerability merely increased the parents' protectiveness. A parent gave an example of this. She said,

"If you gave her a form and told her to sign it, yes, she would sign it. I don't suppose for a minute she would know what she was signing"

(5,5,2-4)

Another parent described her feelings on the matter. She explained,

"you're not wanting the decision taken out of your hands. I mean, to me, it's not a decision you're going to take lightly. It's going to be a long thought out (one)"

(5,12,9-11)

In addition to personal knowledge of their son or daughter, there is no doubt that the parents felt strongly that their filial relationship enabled them to make a fair decision. They felt totally justified in this action, as their comments unanimously show,

"The parents know them more than anybody does...I think the final decision would need to be...the parents.....It would be easier for parents to say what they feel is right for their son or daughter"

(10,11,18-21/ 10,12,6-7)

"I would have to make that decision with the likes of him.....Well, I think the person who looks after them should (make the decision).....(because) they know them better than anybody else"

(22,11,17-19/ 25-6/ 36-7)

Another parent justified taking control of the decision-making, as follows:

"Well, I think the decision the parent makes is...out of knowing the person and knowing what's best for them.....I mean anybody would know what's best for their child and you have to remember their mental age as well, you know. Although they've got a body of a man or a woman, you've got to remember they're not really capable (of making that decision)."

(20,14,13-14/ 17-21)

These views are based on parental experience. It is the type of experience which has additional responsibilities to 'normal' parenthood because they are parents of people with learning disabilities. One explained,

"the parent knows the child...She's had to cope with her through these problems....they've reared them"

(7,7,14)

Reminiscent of the parental anxieties discussed in Chapter 4, reference was made to the responsibility of caring for an unwanted baby. Two mothers explained,

"There is (sic) a lot of these lassies who would be quite capable of bringing up a baby...but there's an awful lot of them wouldn't be, so who's going to be left? Parents, again, like myself"

(7,7,15-18)

"it's the parents that's got the heartbreak and the responsibility, isn't it?"

(5,12,4-5)

The realistic understanding of and insight into their own particular circumstances gives their argument credibility. Feeling that a child born to their adult daughter or son would ultimately be their responsibility, it was not considered to be unreasonable for them also to feel some responsibility for the choice of contraception for their offspring. One of the professionals was aware of this possibility. She believed that some of the parents

"may be doing it for their own peace of mind rather than for their daughter's benefit"

(25,13,10-12)

The parents' views are in direct contrast with the prevailing orthodoxy of the professionals. According to Ward (1990) the professionals "are often in practice more concerned about what rights, if any, they have to make decisions for handicapped people, and to exercise guidance and control".

The views of the professionals, as examined in Chapter 5, do not represent a consistent approach to the problem of such decision-making. The 'normalisers' stress the importance of people with learning disabilities having the opportunities for independent decision-making. This is exemplified by one professional who said,

"I think there should be great consultation with that person (and) I think there should be a lot of counselling (so that they are) as aware as they could be regarding sterilisation"

(14,16,18-25)

Nevertheless, there is the recognition that people with learning disabilities are vulnerable to being coerced into making a decision to be sterilised.

"They could be manipulated. That's a big danger"

(18,13,11)

However, another 'normaliser' felt that people with mild learning disabilities should always be encouraged and allowed to make such decisions for themselves, after being given advice and counselling. The only circumstances in which the 'normalisers' approved of sterilisation for people with learning disabilities was

"if that individual chose by themselves and they were able to sort of rationalise that decision....and know the pros and cons of it, then fine....if the individual's making that decision themselves in the full knowledge of all the facts"

(12,11,24-8)

Another 'normaliser' reiterated this,

If the reason were from their own point of that they wished to be sterilised, then I would tend to go along the lines of 'Yeah, well, that's your decision'"

(21,16,6-9)

It is clear that the 'normalisers' disagreed in principle with the tutor-dative procedure with particular regard to consent to sterilisation. A common response was

"No, not for something like that, no."

(12,10,11)

This was because they believed it did not allow for freedom of choice for people with learning disabilities. If they were unable to consent to sterilisation, they believed an alternative form of contraception would be preferable.

As stated earlier, however, not all of the professionals adhered to the prevailing orthodoxy. The 'paternalists' were closer in their views about learning disability to parents than to other professionals, or 'normalisers' (see Chapter 5). This claim is reinforced by their belief that parents know what is best for their own son or daughter. A 'paternalist' added,

"I would say the parents initially would be the main people (to make such a decision)...(they) should be the first choice...to decide, I mean, it's their family"

(29,14,18-20)

Following this exploration of the general views of parents and professionals, they were then asked to respond to a specific hypothetical situation which is described below.

7.v. A Hypothetical Situation: A Multiple-Choice Response to a Decision-Making Task.

The hypothetical situation was of a person with learning disabilities who was unable to give valid consent to sterilisation, but for whom the operation was deemed to be in their best interests. The respondents were asked which choice of person or group of people would be the most suitable to give consent on behalf of this individual. The choice was as follows:

1. Parents
2. Parents and Doctor
3. Parents and Independent Committee
4. Law Courts
5. Tutor-dative

Most of the parents chose the option of "Parents and Doctor" as the most appropriate. An example of one of the parent's responses was,

"in an ideal world it would be the parent
or the parent and the doctor"

(20,15,35-6)

This illustrates their belief that an important and personal decision, such as sterilisation, should not be within the public domain. Reminiscent of their statements referred to in Chapter 4, the parents resented what they considered to be interference from outside agencies.

Although some parents chose the option of "Tutor-dative" as the most appropriate, they also thought that this procedure was unnecessary because they thought they already had the right to consent to sterilisation on behalf of their son or daughter. By contrast, most of the professionals chose the option of "Parents and Independent Committee". Some of them hesitated, not wishing to make a commitment. Others experienced difficulties making a choice in the matter. One said,

"But again it depends on the
situation....It's a terrible question to
answer, this, a terrible question"

(21,18,5-6)

Figures 7.1. and 7.2. reveal the basic differences between parents and professionals. Figure 7.1. illustrates that parents regard consent as a private issue. By contrast, Figure 7.2. demonstrates that most of the professionals regard consent as a matter for public accountability. These views are consistent with the parental ideology and the prevailing orthodoxy of the 'normalisers'. It is interesting to note however that none of the respondents chose the option of "Law Courts" to be the most suitable to give consent to sterilisation. One 'normaliser' acknowledged the difficulties involved in decision-making. He considered the options saying,

"...god, it's so hard...'Parents and Doctor' just scares the hell out of me. The Law Courts are so detached from the situation, I don't know what decision they're going to make anyway....it's going to be based on a load of probabilities. It may take many years to go through there. I suppose if one had to pick one I would say 'Independent Committee' because at least you would be looking at some people who were detached from the situation"

(35,18,26-33)

For visual representation, the multiple-choice responses have been re-arranged to correspond in graduating terms with the groupings of 'Private' and 'Public' as follows:

- PRIVATE

1. Parents
2. Parents and Doctor
3. Tutor-dative
4. Parents and Independent Committee
- PUBLIC

5. Law Courts

Figure 7.1. Parents' Responses

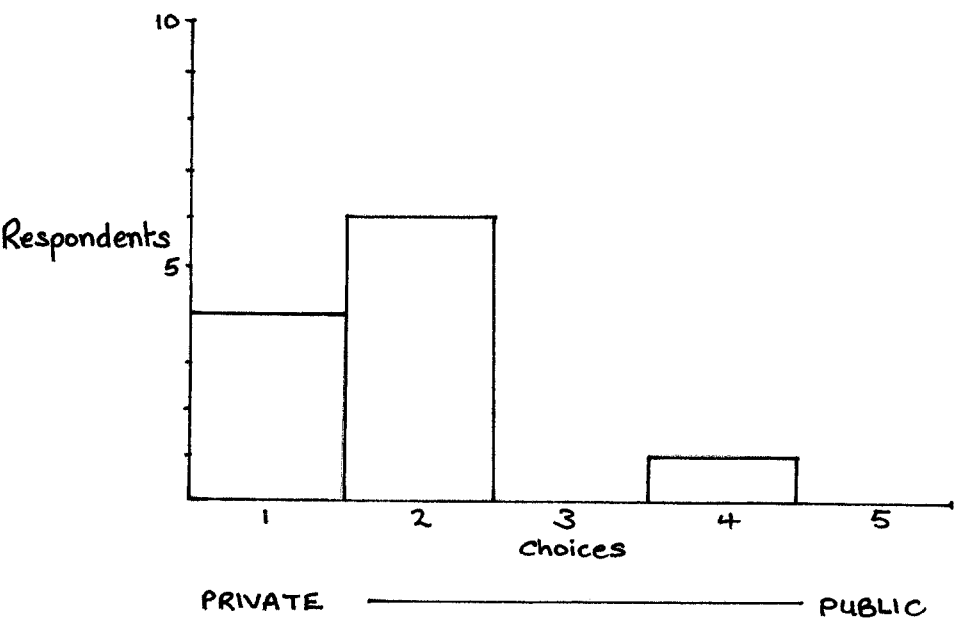
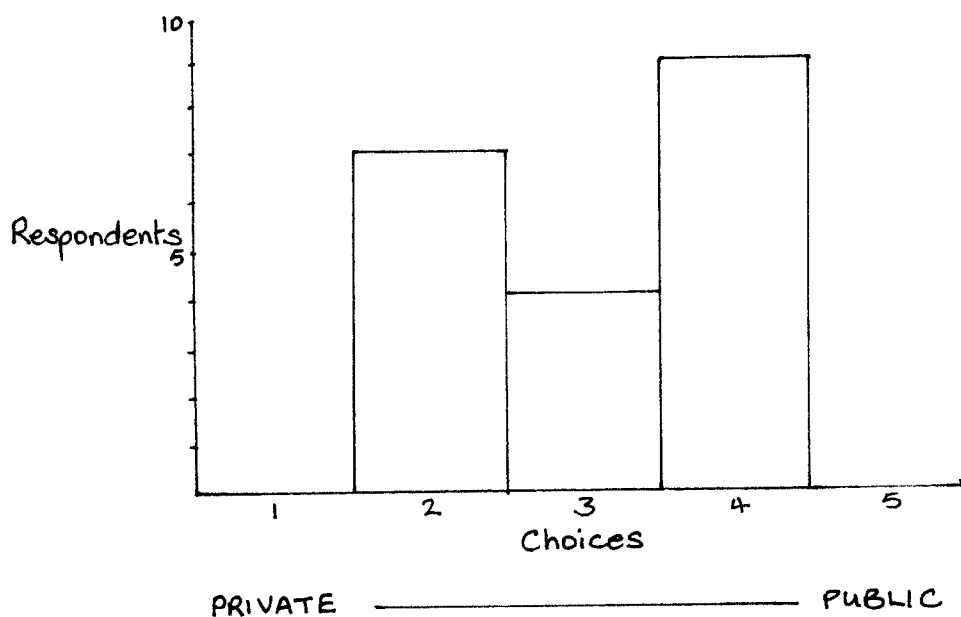


Figure 7.2. Professionals' Responses



Earlier studies (Whitcraft and Jones, 1974; Wolf and Zarfes, 1982; Pueschel and Scola, 1988; Bambrick and Roberts, 1991) have examined the attitudes of parents to the sterilisation of people with learning disabilities in general and to their own sons and daughters in particular. They reveal that positive responses to sterilisation from parents range from 50% to 85.8%. These studies have not been placed in the context of Scots law, but it is interesting to

note how favourably their findings compare with the present study, in which most parents held positive attitudes to their son or daughter being sterilised (see Chapter 6).

With regard to whether the decision and the consent given to sterilisation should be private or whether it should be a concern for a more public debate, two studies in particular bear relevance (Wolf and Zarfes, 1982; Bambrick and Roberts, 1991). Wolf and Zarfes (1982) state that "Although parents were divided on the need for legal regulation, when approval of such need was cross-tabulated with parental attitude toward involuntary sterilization, 80 per cent who felt that there should be legal involvement and 66 per cent who did not agreed with the need for involuntary sterilization."

Wolf and Zarfes also reported that when the parents and doctor had agreed to the appropriateness of sterilisation, they did not consider any legal intervention necessary. In addition, they found that parents were more in favour of making private decisions, without external interference, if sterilisation concerned their own son or daughter. By contrast, if it was a question of sterilisation and legal involvement of people with learning disabilities in general, the parents were less decisive.

Bambrick and Roberts (1991) asked parents whom they considered should have the power to consent to sterilisation. They claimed that the "majority of parents (84%) considered that they alone or in conjunction with a doctor familiar with the person with mental handicap should be able to consent to sterilization". This study again reflects the view that parents tend to favour private rather than public decision-making with regard to sterilisation. Bambrick and Roberts acknowledge the need for change in English law. In the Canadian study by Wolf and Zarfes (1982), it is suggested that there "should be a procedure codified in law to protect (the rights of people with learning disabilities) while considering these rights in the

context of the accompanying responsibilities". They believe that it is necessary to clarify the issue of consent to sterilisation. Similarly, Bambrick and Roberts (1991) claim that where "sterilization is being considered, modification of the law would appear to be necessary with regard to consent, obviating the need to resort to expensive and high-profile Court action".

This present study provides further insight into the situation by comparing parental attitudes with those of the professionals in the context of Scots law. Both of these groups were also asked for their views on the necessity for any legal involvement regarding sterilisation and people with learning disabilities. This is discussed below.

7.vi. The Issue of Legal Intervention

With most of the parents preferring that sterilisation of their son or daughter be a private decision, the question of whether there should be legal involvement did not appear relevant to them. It was considered to be an uncomplicated procedure involving a visit to their G.P., followed by what they expected would be a sympathetic discussion leading to formal consent to the operation. Some of the parents' statements illustrate this,

"I don't think there should be any rules.
I think it's up to the individual and the
parents and the G.P."

(6,10,22-3)

"I really do think it should be made
easier"

(7,7,6)

"I don't actually think there should be any laws. I think it should be common sense"

(9,5,21-2)

Only one parent in the study was vehement in his opposition to sterilisation. He believed that it was an intrusion of the civil rights of people with learning disabilities. He also referred to the historical events in Nazi Germany where involuntary sterilisation was performed on a large scale. His concern was that a similar situation could recur in the U.K. if legislation made sterilisation easier to obtain.

Reflecting the study by Wolf and Zarfas (1982), the parents' views differed if they were asked to consider people with learning disabilities in general rather than their own son or daughter. In these circumstances, the parents favoured more legal regulations. They considered legal intervention as being necessary for some of them. One parent said,

"I suppose it's up to whether folk think they be able to cope if they did have a family"

(7,6,29-30)

Although some of the parents were unclear as to what laws they felt should exist, they generally felt that some regulation was needed.

"There would have to be some kind of laws set out."

(10,12,2-3)

"I do think there should be laws, I think there should be."

(7,6,27-9)

One parent held particular concerns. She said,

"I suppose there's always some cases where maybe their parents are...not actually doing it for the benefit (of their son or daughter).....I mean, staff can't take that decision, they're not able themselves, so there should be something that keeps it all legal, so that safeguards the staff."

(20,15,15-16/ 23-5)

This view was echoed by some of the professionals. One said,

"legal safeguards could also be used for staff working with people with learning disabilities"

(33,3,35/ 4,1-2)

By contrast, the views of the professionals divided them as 'normalisers' and 'paternalists' (see Chapter 5), with most 'normalisers' in favour of some form of legal intervention making sterilisation more difficult to obtain. This was because of the fear that it might be performed for eugenic reasons and in the interests of carers rather than for the individuals with learning disabilities concerned. He explained,

"I know a number of people who've been sterilised who've never had any sexual expression which has led, for example, to

penetration.....I believe it has gone on in the past.....there is nothing to make me believe that it would have stopped. I think that there are still the same fears expressed out there as there were some years ago."

(35,17,13-15/ 32-5)

He also believed that there was an abuse of parental and medical power in sterilising people with learning disabilities who could not themselves give valid consent. Another 'normaliser' believed that people with learning disabilities should be able to be sexually active without first having to be sterilised. His view was that

"we all, throughout life, experience hurt and we've got to go through life with some sort of...risk factor in our lives and the risk factor of our emotions as well. I mean, none of us go through life, find an easy sail through life. We all have our ups and downs. We all have our problems and we've all got to learn to overcome them."

(28,22,26-32)

He believed that it would be better for a person with learning disabilities to have a child which is taken into care, than to be sterilised and there be no child at all. This view contrasts strongly with those of the 'paternalists' and the parents, who would strongly disagree with such a claim (see Chapter 4).

Some 'normalisers' believed that legislation should be clarified, or at least there

"should be some sort of legislation or groundrules somewhere that we, as professionals, can follow and give some guidelines to parents as well"

(12,11,9-11)

This 'normaliser' continued by saying that before legal procedures were to take place the circumstances would have to be of an extreme nature. This was because he believed that it would, in effect, be taking away that person's rights. The necessity for legal intervention is perceived differently among professionals. Some of them thought it could be used for guideline procedures, while others saw it as a means to a protection of rights. One professional said,

"I can see situations where a person is at risk and is vulnerable and because she isn't able to give that consent on her own, I could maybe see a point for having (sterilisation) done..."

(23,11,1-4)

Another added that he felt that there should be some legal intervention with regard to sterilisation. This was because people with learning disabilities were vulnerable and as a consequence, could easily be abused. One professional said that,

"For more vulnerable groups then, yes, I think there should be some type of mutual arbitrary group to be able to come in and actually give the favour of one side or another depending on the situation"

(35,15,29-32)

Another indicated that this could create problems and that law would be needed. She explained this was

"for protection, because sometimes none of those other people will agree. We need an ultimate."

(30,20,24-5)

Other professionals thought that because sterilisation is such a personal issue, the circumstances surrounding each person with learning disabilities would inevitably be different. This would make legislation very difficult, if not impossible, to achieve fairly. Although there may be a valid reason for legal intervention, it would have to be applied on an individual basis. A professional explained,

"I don't really think it's something we can legislate for. I think it's something that has to be dealt with individually....but in every situation I would say that there would have to be an outside agent, someone who hadn't, didn't, know the person and just see how they felt about it, you know."

(25,13,12-17)

Generally, the 'paternalists' felt that there should not be any laws at all concerning sterilisation. Their statements illustrate this:

"I can understand to a certain extent why the legal aspects have to come in, but I don't agree, I don't agree with it fully."

(21,17,1-3)

"Who are we to judge who's right and who's wrong?"

(25,13,32)

"No, I don't think we can really dictate a law to people, not really....where do you draw the line? Who's capable of deciding who is not capable? If you have a law, a grey area again..... there's too many grey areas in it."

(29,15,12-14)

The latter 'paternalist' also felt that such a decision to sterilise should be made privately, a view held by most of the parents.

7.vii. Conclusion

This Chapter has examined parental and professional views on the implications of Scots law on the sterilisation of people with learning disabilities. For parents, this is a double issue concerning making generalisations and of referring in particular to their own son or daughter.

There was little known by the respondents of the law relating to consent and people with learning disabilities in general and the tutor-dative procedure in particular. Most of the parents thought that the tutor-dative procedure was unnecessary because they believed that sterilisation was a straightforward contraceptive option available to their son or daughter, easily arranged by their G.P. without legal implications. Therefore with regard to making a decision about sterilisation, the majority of

parents believed that not only should they be involved, but that it was essentially a private matter.

Professionals, by contrast, considered the matter more in the context of objective discussion with outside agencies, but without necessarily concerning the legal system. This is possibly because of de-personalisation which legal involvement can effect. It was acknowledged however that some form of ultimate decision-making machinery should perhaps be available in the event of any dispute or doubt about sterilisation arising.

It is possible that the tutor-dative procedure can attract "unduly dominant or over-protective" parents (Ward, 1990). He counterbalances this however, pointing out that it also "extends to many concerned, responsible and caring parents, who feel that their role and views are largely ignored by professionals". This highlights the differences between parents and professionals and encapsulates the tension and conflict described in Chapter 4. Ward (1990) says that "Professionals who criticise parents' use of tutor-dative procedure, should perhaps ask themselves why they have failed to secure the confidence and co-operation of parents."

Decision-making in this matter emphasises the irreconcilable views of parents and professionals. This is illustrated by the results of the hypothetical question regarding who should decide whether sterilisation should take place. It reiterates the tension and potential conflict described in Chapters 4 and 6 and also highlights the diverse perceptions among the professionals (see Chapter 5). These differences are symptomatic of the ideological problems inherent in the prevailing orthodoxy.

Chapter 8

CONCLUSION

The foregoing examination of the problems surrounding the sexuality of people with learning disabilities has revealed the tensions and potential conflict which exist between their parents and the professionals.

Previous writers (Mittler and McConachie, 1983; Cunningham and Davis, 1985; Evans, Forder, Ward and Clarke, 1986) have referred to such difficulties, but as Mittler, P. and H. (1983) point out, they have "received relatively little attention" and, consequently, there is "remarkably little information" regarding them.

The "divergence between parents and professionals" (Brown, 1988), cannot be underestimated in its negative effects. Ultimately, people with learning disabilities are affected by the relationship their parents share with the professionals. In this sense it is a triadic, but unequal, relationship. It is the parent-professional relationship which is "a major source of problems (and) which often (assumes) greater importance than problems arising more directly out of the (person's) handicap" (Lloyd-Bostock, 1976). Lloyd-Bostock (1976) reiterates the view that "the point of contact between parents and professionals (is) extremely problematic".

However, the studies by Mittler et al, describe an ideal situation between parents and professionals. They offer prescriptive advice as to how effectively the relationship could function, but fail to recognise the major causes of disparity. There is a palliative remedy. They fail to provide an adequate solution because they do not examine the nature of the dissonance within the relationship. The description of the ideal relationship between parents and professionals centres essentially around the notions of collaboration and partnership. This suggests that the relationship is based on grounds of equality. The data collected in this study reveals little evidence to

support this. The disparity between parents and professionals creates an imbalance of power. This is not generally acknowledged in the literature. Instead, there is a common assumption that improved communication is the key to the solution. This is an inadequate and simplistic view.

Mittler, P. and H. (1983) trace a three stage evolutionary progression of this type of relationship. Firstly, they begin by describing how parents have not in the past received adequate information about their offspring with learning disabilities. Secondly, from this absence of communication, progress in the relationship was recommended by the professionals to take the form of "co-teacher" or "co-therapist". It is possible that the failure of this aspiration lay with the view that parents were expected to emulate the professionals. The professionals placed themselves in the 'expert' role, having superior knowledge, not only of learning disability, but also of their offspring. Thirdly, professionals subsequently began to view parents as "consumers". This, theoretically, allowed parents to participate in the decision-making regarding issues concerning their son or daughter, and encouraged a more active role from parents.

Ferlie, Pahl and Quine (1984) reiterate a historical development of the relationship between parents and professionals. Theirs depends on models of care perpetuated by the professionals, beginning with the medical model. This reflected society's view that learning disability could be alleviated through health care. As social work departments gradually assumed greater responsibility for people with learning disability, a social model of care emerged. From this came a developmental model of care where the potential of people with learning disabilities was acknowledged by the professionals.

Twigg (1989) describes carers from a professional viewpoint. She typifies the relationship between them, describing carers as "resources". This, she claims, is

unsatisfactory for professionals because in these circumstances parents are "not subject to supervision or control and they are, therefore, an undirectable as well as uncommandable resource". Twigg then describes carers as "co-workers". This, she believes, does not succeed and makes suggestions that are central to this study. She says that the "formal sector rests on a formal knowledge base, in which professionals are trained, and acquire particular technical skills. The informal sector by contrast is particularistic, marked by strong affect, frequently characterised by long-term reciprocity or by effectively inalienable relationships, and by ascriptive status judgements. Its knowledge base is rooted in daily experience and assumed to be open to all. It is a knowledge of persons and of localities. It is because of these essential differences that the two systems do not mesh easily or happily together."

Here Twigg accurately highlights some of the main problems found and explored in depth in this study. She goes on to describe carers as "co-clients". This, Twigg believes, is inappropriate because it leads social work departments to go "beyond the normal, essentially substantive, definition of their remit, and (become) involved in areas that merge imperceptibly into general social life and its responsibilities."

Brown (1988) differs from other writers in this area in that she takes a parental perspective. She also recognises the tensions and conflict that arise in the parent-professional relationship. Much of this is due to the professional "expertise". She says that "professionals are able to maintain a view of themselves as doing something essentially different to and (because we are paid for it) of more value than parents". Brown describes the aims of the professionals as including "independence and age-appropriate activities", "short-term goals", "risk-taking" and "optimism about community integration". By contrast, she describes parental concerns as involving

"dependence and abnormal caretaking demands", a "need for ongoing support and protectiveness" and "experience of hostility or rejection from (the) community".

Parental concern is for the daily pragmatic tasks and problems. They are not, according to Ferlie, Pahl and Quine (1984), "concerned with either bureaucratically tidy organisations or the implications of their respective budgetary systems." Overall, it is evident that there is a "desirability of closer partnership between parents and professionals (although) there is still considerable uncertainty about what to do and how to start" (Mittler, P. and H., 1983). The failure in this relationship is largely attributed to the lack of effective communication between the two groups. It is the poor quality of communication, indeed lack of communication, which is identified as being the cause of the problem.

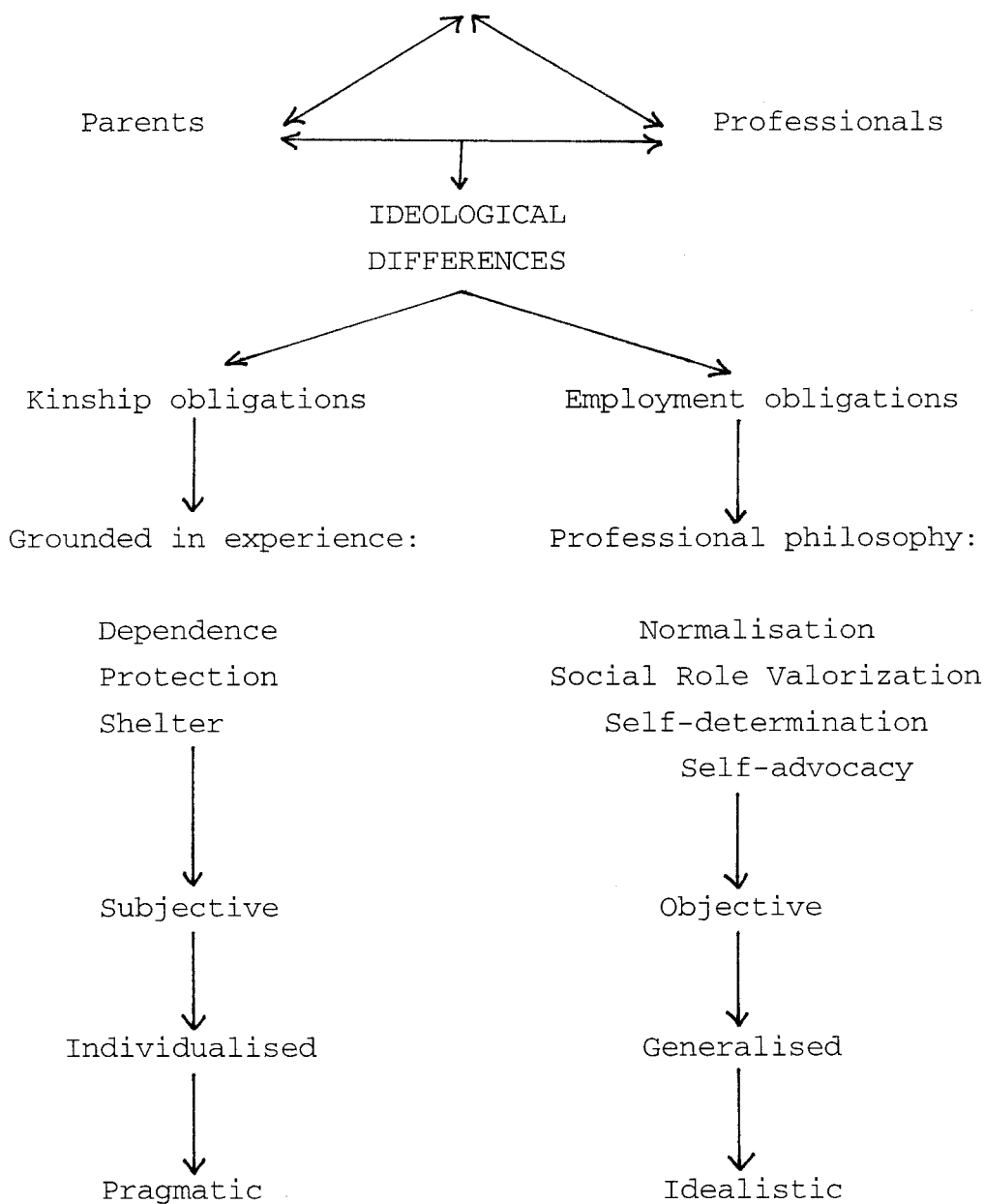
The data in this study suggests that poor communication is merely a symptom of the differences between parents and professionals. At the heart of the matter are two distinct ideologies of care which each group possesses. Being polarised, these ideologies are irreconcilable. To clarify this, the parent-professional relationship has to be seen within the context of people with learning disabilities. It is a triadic relationship (see Figure 8.1) and it is within the very nature of this relationship, that lies the fundamental differences between them. Basically, these are ideological.

One of the fundamental differences in attitude between them lies within the nature of this relationship. Parents, for example, have no choice regarding their position because they have kinship obligations to people with learning disabilities. By contrast, the professionals have chosen their position: theirs are employment obligations. The situation is however more complex than would at first appear because there are professionals who are parents themselves. This experience affords them a

degree of empathy with the parents' situation. They can understand, for example, their feelings of protectiveness and the inevitable problem of allowing children more independence as they get older, or what parents and professionals both called 'letting go'. This is especially difficult where people with learning disabilities are concerned because of their vulnerability to coercion.

Figure 8.1. Diagram illustrating Ideologies of Care

Mentally handicapped / People with learning disabilities



Parents have real fears of them being taken advantage of or sexually abused if they are out alone in the community. This is not uncommon. Roy, Corbett, Newton and Roy (1993) claim that parents very often over-estimate the risk of pregnancy in daughters with learning disabilities. This is the fear that lies behind giving them greater independence: if they go out alone they might have unprotected sex. A possible consequence of this, apart from the possibility of catching a sexually transmitted disease, is an unwanted pregnancy. This has particular implications regarding making a decision about sterilisation.

However, the empathy that professionals feel is moderated by what they see as parental over-protectiveness. From the parents' point of view, their life can be made easier if they do things for their son or daughter, rather than spend time repetitively teaching or supervising them to perform skills independently. Consequently, the professionals often felt resentful because they perceived parents to be hindering their work and the progress of people with learning disabilities. The parents' views are well-grounded in their personal, long-term and holistic experiences of their son or daughter. It would appear that the assumption of the professional role decreases their sensitivity to the parents' predicament. Olshansky (1962) and Wikler, Masow and Hatfield (1981) describe chronic sorrow as being a natural reaction to learning disability in one's son or daughter. Exacerbating the problem is the way in which professionals do not generally acknowledge it. Because they believe that parents have had sufficient time to come to terms with and accept the disability of their adult children, these emotional reactions are perceived as neurotic. Searle's definition of chronic sorrow (1978) matches the reactions of the parents in this study. He describes it as "the deep lasting changes that life with a retarded son or daughter brings to parents...the negative feelings - the shock, the guilt and the bitterness- never

disappear but stay on as part of the parents' emotional life. Most parents, I believe, never fully resolve the complexity of feelings about their child's retardation. They don't 'adjust to' or 'accept' (it)..."

There is a conflict of interests as professionals promote independence and parents maintain their protective role. Being confronted with professional idealism, the parents remain pragmatic. The attitudes of both groups are directed by their position within the triadic relationship and by the very nature of their relationship with each other. The parents, for example, are guided by their own experiences. Their views are grounded in tangible events. Although each family has its own subjective history and individual experiences, this is, paradoxically, a common factor among the parental group. Each family has different circumstances but together they share feelings of protection and the need to provide shelter for their dependent adult offspring. They all recognise these continuing responsibilities. It is these issues, in the face of a perceived lack of support from the professional organisations, that bind the parental group together.

Cunningham and Davis (1985) recognise three main differences between parents and professionals. They say that "the functions of parents are broader and more diffuse than those of professionals". They add that "the parents will have more interactions with their child in a wider range of situations than the professional". Finally they claim that "a major difference is that parents are more emotionally involved with the child than professionals. This means that parents will have more intense reactions and feelings to the total spectrum of the child's behaviour than professionals." Where learning disability is concerned, there appears to be no difference to parents if their child is in fact of adult age. By contrast, the professionals act according to their own professional philosophy. They do not generally have personal daily living experiences or responsibilities for people with learning disabilities. As

professionals they interact with numerous people with learning disabilities rather than an individual family member. Therefore, their views are shaped differently from parents. They are more objective and tend to be more idealistic. Their philosophy is based on normalisation and to a lesser extent, social role valorisation. The concepts of self-determination and self-advocacy for people with learning disabilities is of paramount importance. Although this is regarded with scepticism by parents, the professionals maintain that people with learning disabilities have hidden competence. Under the appropriate circumstances and given adequate training and opportunities, professionals expect them to achieve greater levels than the parents anticipate.

The disparity between the parents and professionals is stated in general terms and their simplification clarifies the issue. However, the situation is more complex than would initially appear. Within the professional group there is a degree of pluralism. This is intricately connected with the prevailing orthodoxy and how it co-exists with the superseded ideology of care, namely institutionalisation. The case-study as described in Chapter 5 exemplifies this situation. It is an illustration of two sets of relevant attitudes, according to Allen, Pahl and Quine (1990). One of these is the professionals' attitudes to people with learning disabilities, "especially in terms of their supposed abilities and potential" and also there are their "attitudes towards alternative models of care". They report that a "lack of belief in the potential of people with (learning disabilities) is related to reduced levels of performance in teaching and social aspects of care by care staff". Account must also be taken of the dominance of the prevailing orthodoxy. This affects the professionals in that they could have difficulties in openly criticising aspects of it. As Mittler (1987) points out, "The current ideology of integration into mainstream facilities is so powerful that some staff may find it difficult to voice their reservations openly, in case they are thought to be

either reactionary or merely defending their jobs out of self interest."

All these ideological differences, and their effects on the relationship between parents and professionals, are magnified with the subject of sexuality. It polarises the two groups. The tension and the balance of power between them become more tangible. This was clearly demonstrated by the use of the vignette. For most parents in the study, sterilisation of their son or daughter was considered to be the most appropriate form of contraception. Parents also tended to consider the practicalities of potential relationships of their sons and daughters. Examples of this included the emotional implications, the responsibilities and commitment to another person. Many of them felt that sustaining a sexual relationship was beyond the maturity of their son or daughter.

By contrast, the professionals, who do not have such kinship responsibilities, considered the reproductive rights of people with learning disabilities to be a fundamental issue. Their belief in the potential competence of people with learning disabilities justifies their belief in the existence of such rights and leads them to believe that they could cope with child care, although in most cases external support was deemed necessary.

The issue of sexuality is very complex because it invariably produces conflict and moral dilemmas, not solely between parents and professionals, but between professionals and within professionals themselves. It is also difficult for some parents to discuss the sexuality of their son or daughter. The problem is exacerbated when that son or daughter also has learning disabilities. In some instances, their sexuality is denied completely. It seems then that the issue of sexuality increases each group's tensions in addition to it emphasising, indeed magnifying, the basic conflict between parents and professionals.

Rose and Jones (1994) describe four types of communication regarding sexuality between these two groups. Firstly, they see a negative level, which constitutes no interaction and where sexuality is a "non-shareable" issue. It can be seen as a parental concern by professionals and as a professional concern by parents. A second type of interaction is where there is a reaction to incidents, where sexuality is perceived as a problem and is manifested in socially unacceptable behaviour. It is interesting to note Booth and Booth's (1992) claim that sexual guidelines issued by Social Service departments, health authorities and voluntary organisations generally present "sex as a series of problems (for staff) rather than part of a person's moral and personal development". A third type of interaction is the imparting of information from the professionals to the parents. Finally, there is actual dialogue between the two groups regarding sexuality as an "inevitable and valued part of life". This range of interactions regarding sexuality from negative to positive is reminiscent of Kempton and Caparulo's attitude scale (1983) which is also regarding sexuality. These interactions are found throughout the data in this study. The most negative view they describe is the elimination of sexuality. Kempton and Caparulo believe that most parents' views are in the next category of attitudes, because they have tolerance of the sexuality of people with learning disabilities. The next category of acceptance of their sexuality is the one which Kempton and Caparulo advocate. The most positive view is the cultivation of the sexuality of people with learning disabilities. They admit however that this "school of thought is not readily or widely accepted and seldom seriously considered but it offers a basis for a progressive policy that can be translated into healthy living practices".

This view is the one held by the professionals in this study who most vehemently adhered to the prevailing orthodoxy. The data revealed however a wide range of views encompassing the four categories described by Kempton and

Caparulo. It is the polarised ones which illustrate the essential differences between parents' and professionals' ideologies as well as between general societal views held in one era in comparison to those held in another.

Exemplifying this is the eugenic view which represents that of 'elimination' on Kempton and Caparulo's scale of attitudes. The period when institutional care was the prevailing orthodox ideology represents tolerance of the sexuality of people with learning disabilities. When normalisation was formulated in the 1960s and 1970s came the next category or stage of attitudinal development, that of 'acceptance' of the sexuality of people with learning disabilities.

From the data, it is evident that the whole range of views co-exist. Some, however, are more prevalent than others. It is these that are polarised and exacerbate the tension existing between parents and professionals. The data highlights the importance of such fundamental issues and emphasises the difficulties involved in resolving the apparent problems. The question regarding whether people with learning disabilities have a right to reproduce is counterbalanced by the question of whether they have a right to be sexually active without the fear of an unwanted pregnancy. A vital issue which arises from the data concerns the right to privacy for people with learning disabilities, especially in the light of decision-making regarding sterilisation. To whom belongs this ultimate responsibility is a key issue. The debate is whether it ought to be a private or a public responsibility. It is regarding this that there is further potential conflict occurring between parents and professionals. The orthodox view is that people with learning disabilities be self-determining and empowered to make their own, private decisions. This view is held by most professionals in this study. Paradoxically, it is a public body advocating a private solution. The parents, by contrast, believed that it was a private issue, but within the confines of the family and not the actual individual concerned. Notably,

Antonak and Mulick (1987) state that "on a pragmatic level, decision-making is a shared process more often than the principle of autonomy implies". This suggests that it may be unrealistic to expect people with learning disabilities to make such far-reaching decisions in isolation.

Sexuality and decision-making with regard to people with learning disabilities is a public as well as a private responsibility. Booth and Booth (1992) believe that the "needs and rights of people with learning difficulties have to be balanced against the moral scruples of staff, the concerns of parents and relations, the sensitivities of local politicians, the views of the wider public and the requirements of the law". However, the law is criticised: "as it stands (it) is a definite hindrance in trying to frame a forward-looking set of guidelines on sexuality....it is fragmented, confused and behind the times" (Law Commission, 1991). This study also illustrates this to be the case. Unfortunately, it results in people with learning disabilities living in limbo, with normalisation more of a philosophical, rather than a practical, ideology of care.

Although the prevailing orthodoxy dominates the philosophical and theoretical base for the professionals, this study reveals that superseded ideologies remain influential. There is a basic difference between parents and professionals in this respect, but the study also illustrates how this difference exists within the professional group. As with a range of attitudes that have been shown to exist, ideologies co-exist, not just in time, but also in space. An example of this is found in the case study. This was of a particular work establishment which was undergoing change through modernisation and as such encapsulated the co-existing ideologies. To witness this as it occurred was an unexpected but fortunate experience within the study. It was a prime example underlying the study's theoretical framework and was important because it brought together the past and the present in terms of ideology.

Similarly, the history of eugenics is important in the study because of its influence over societal attitudes. Although these have changed, there is evidence that similar views still exist. Some of these are illustrated by the data. Other indications of such views are in the media regarding debates about the abortion of fetuses with Down's syndrome and studies concerned with the ethics of the eradication of disability (Harris, 1995). Eugenic ideas therefore, continue to exist. When normalisation was being formulated, a genetic approach to reproduction continued to be debated (Ingle, 1973).

Although eugenic ideas co-exist with more progressive views of disability, each develops and thus changes in nature. Hence normalisation has created the grounds for the development of social role valorisation. Sorokin's theory of social, cultural and economic "transformation, modification, development, or evolution" (1957) is epitomised in the attitudes towards and experiences of people with learning disabilities. A historical examination places the present situation in its relation both to its past and to the future. He explains that, "any system changes incessantly during its existence: among all its properties something new is incessantly introduced and something old is incessantly lost from moment to moment of its existence. In this sense any socio-cultural process is ever new and unrepeated. Even a change of the system along the same trend is ever new, because it moves farther and changes at different (unique) moments of time."

Examining the attitudes to mental deficiency in the early twentieth century offers insight into attitudes today. Expansion of knowledge in technology has resulted in clearer understanding of DNA and genetic engineering. It has been claimed that the "more people know about genetic disorders, the better able they are to make decisions about avoiding them" (Ward, 1995). This has led to commercial

companies offering genetic tests to the public, with further implications regarding insurance or employment (Bird, 1997; Reece, 1997). With intensive genetic research, there has been increasing awareness of disability and the possibility of its prevention. The National Childbirth Trust (1997) claims that "Antenatal tests were being forced on some pregnant women, with health professionals making assumptions that screening was needed and that a handicapped foetus would automatically be aborted". Harris (1995) also examines the ethics of attempting to eradicate disability.

The vital issues were the popular beliefs that the mentally deficient were promiscuous and amoral; that they were more fecund and prolific than the 'normal' population and, more relevantly, that mental deficiency was hereditary. The overall impact of these beliefs led the eugenicists to support the view that there was a risk to society in allowing them to breed freely. The fear that society would be "swamped with incompetence" (Holmes, 1927) was transformed into the belief that the mentally deficient were a social problem. Additionally, the mentally deficient were held to be responsible for pauperism, alcoholism, prostitution and criminality. Ideas linking morality to crime remain extant. A report by the Institute of Economic affairs was said to claim that "sexual freedom and the lax moral attitudes of single mothers and the unemployed are responsible for the rising tide of crime" (Guardian, 1997). Although the responsibility for these vices is not now held by people with learning disabilities, negative attitudes towards their sexuality have not been totally eradicated. There are confusing and contradictory views regarding their sexuality. Although 83% of people with learning disabilities are born to parents of 'normal' intelligence, there still exists the belief that they can only produce children who also have learning disabilities. This, however, depends on the nature of the learning disability and whether it is of genetic origin. Another influencing factor is the genetic make-up of the partner of the person with learning disabilities.

Wolfensberger (1972) highlights the attitudes to the sexuality of people with learning disabilities with his list of images which are identified with them. The "eternal child" and "holy innocent" are examples of negative attitudes towards their sexuality. Consequently, if any sexuality is displayed, it is perceived in exaggerated terms because of its denial. Stewart (1979) believes that "Popular opinion tends to be divided as to whether the mentally retarded are perpetual innocent children with neither desire for, nor capability of sexual expression, or whether they are human satyrs with an overload of dangerous sexuality"

This polarisation of views does not allow for any moderation. The data collected in the study, although clearly demonstrating this polarisation, nevertheless also illustrates how views can be mixed and confused. Also, social expectations, social roles and professional roles interplay to cause a plethora of confusion within individuals and between individuals. However, it is useful to examine this polarisation of attitudes because these clearly reveal different ideologies of care.

It is within this pluralistic and complex situation that normalisation is the prevailing orthodoxy. It superseded an institutional-type ideology of care, but does not eradicate the attitudes it produced. This study reveals that attitudes and ideologies do not change abruptly, but are part of a continuum. They co-exist between parents and professionals, between professionals themselves and within individual professionals. The tension that these conflicting views generate create difficulties within relationships and for decision-making. Normalisation itself does not provide any simple solution to this. A degree of objectivity or dispassionate involvement from a legal framework could surmount problems of decision-making. The data, however, suggests that this would be vehemently resented, if not resisted, both by parents and

professionals. If normalisation cannot offer a solution to this, then such polarisation of views may not be reconciled. Such is the situation for people with learning disabilities.

By exploring the situation of sterilisation and decision-making, the wider issue of the parent-professional relationship has emerged. The data reveals that it is this issue which strongly affects aspects of the lives of people with learning disabilities. Being such a powerful and emotive subject, sexuality not only highlights, but magnifies the differences between the respective ideologies of care belonging to parents and professionals. However, the data goes beyond merely highlighting these differences. It reveals basic structural incompatibilities. Because of these, there is an omnipresent tension which potentially could lead to conflict within the relationship. The differences between the parents and professionals are essential and integral factors inherent within the relationship itself because of their ideologies. As such, these differences are at present irreconcilable. Recommendations regarding the development of a shared ideology of care are made later.

This study has demonstrated the tensions and constant potentiality of conflict between professionals and parents. As referred to earlier, the examination of the origins of their different ideologies revealed that while the professionals had employment obligations to people with learning disabilities, the parents had kinship obligations. This highlights major themes influencing the relationship. Firstly, there is a conflict of ideologies of care. Secondly, there is an uncertain balance between personal issues and public ones. The professionals represent the public because of their accountability. By contrast, their parents symbolise the personal or private. However, the issues in this study reveal that such delineation is not so simple. Figure 8.2 illustrates how further division between the personal and the public can be made, although each component is interactive with the others.

Figure 8.2.

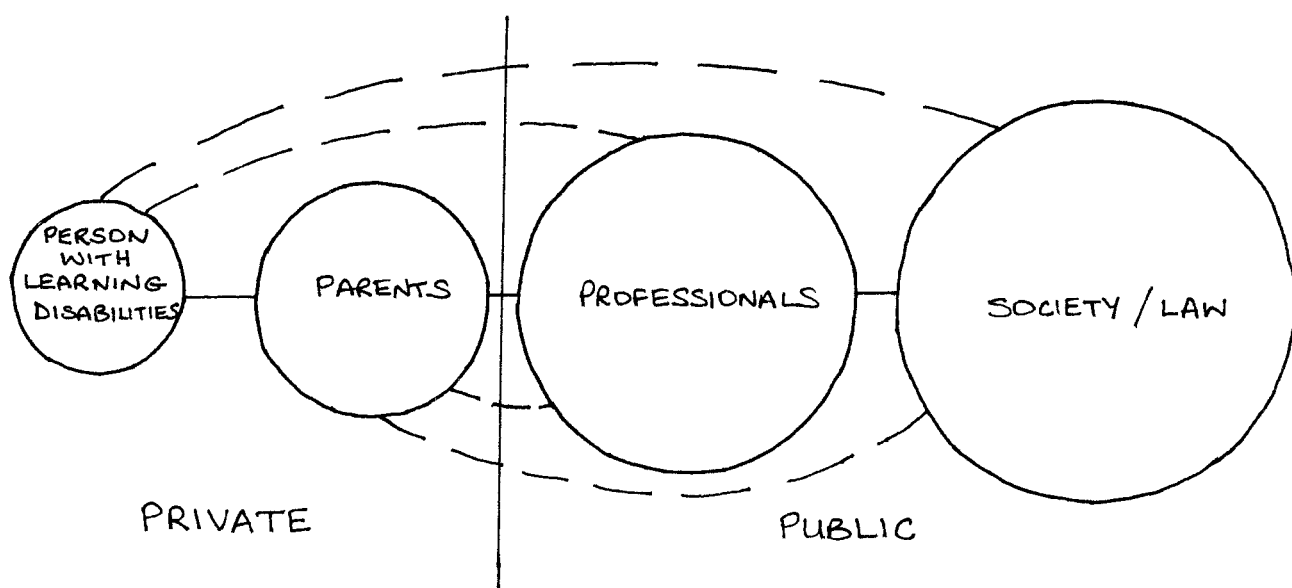
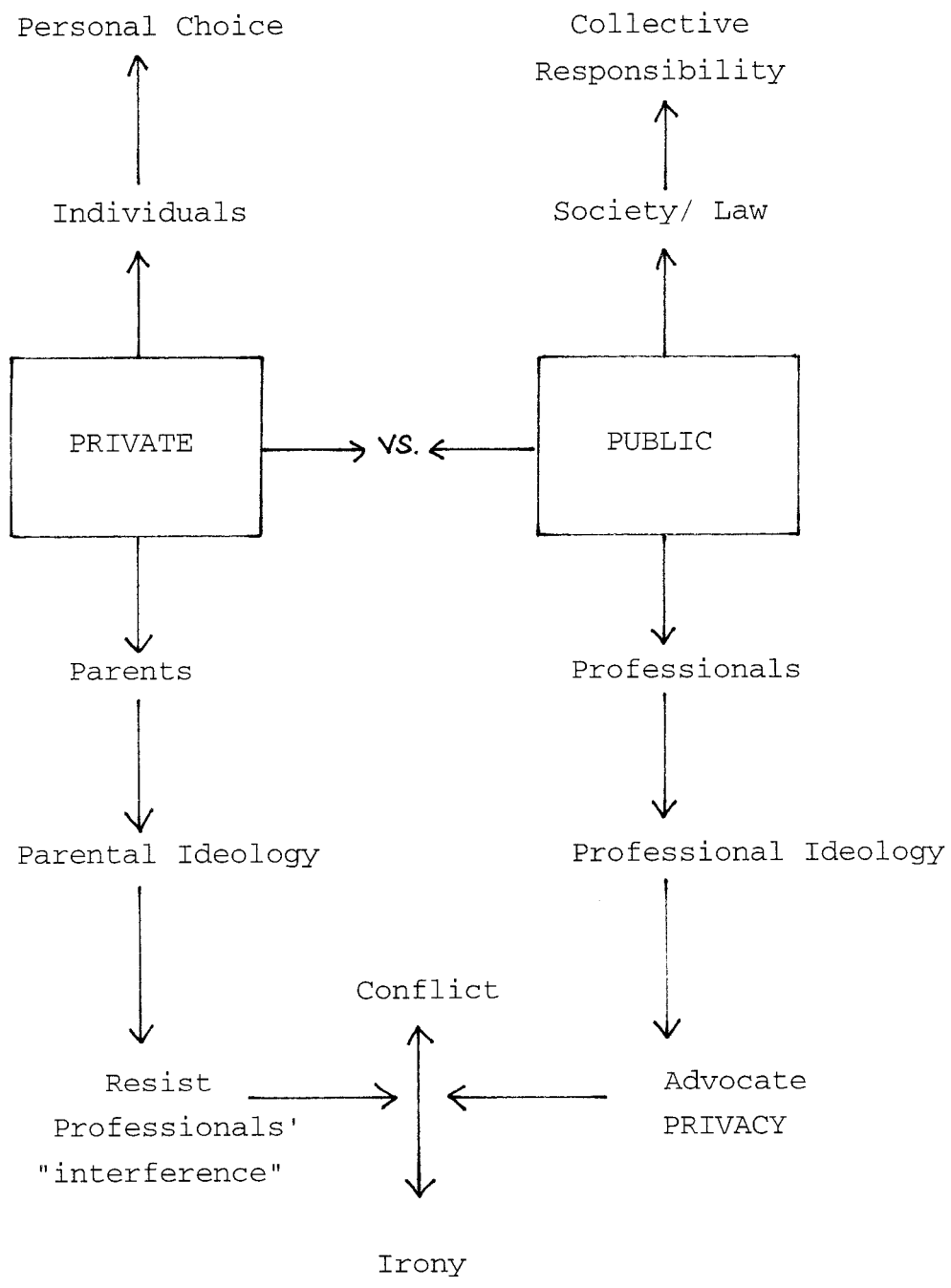


Figure 8.3 illustrates the differences between the personal and the public, with reference to individual choice regarding sterilisation. It is therefore ironic that professionals advocate personal responsibility for such decision-making. Furthermore, it is paradoxical that parents should resist and even resent professionals' 'interference' in these matters.

Figure 8.3.



To improve the quality of lives of people with learning disabilities, it is important that there is an attempt to reconcile parents and professionals. This is discussed below.

Implications of the Study

Addressing the issues of sterilisation of people with learning disabilities in the context of their sexuality, this study has encompassed the broader issue of ideologies. The collection of data from in-depth qualitative interviews gave rise to a grounded theory. This theory offers a descriptive and explanatory account of the difficulties inherent in the relationship between professionals and parents, and between professionals themselves. These relationships ultimately influence people with learning disabilities and decisions which affect their lives. It is possible that this substantive informal theory can be applied to other relationships between professionals, carers and dependent groups.

As referred to earlier, recommendations in the literature (Mittler and McConachie, 1983; et al) focus on an ideal relationship based on equality and partnership, the prerequisite being effective communication between parents and professionals. However, external factors exacerbate the problems involved. Organisational fragmentation increases professional separatism and a diffusion of responsibility. Even within social work establishments, there are differences between professionals. The data reveals that this is not associated with their age or gender, but rather it is dependent on their length of service. Exposure to the orthodoxy prevalent at the time of their entry into the profession has an overwhelming influence on their attitudes to learning disability. Additionally, professionals who hold senior positions are those who have received more training and who frequently are further removed from daily

experience or interaction with people with learning disabilities. They are therefore more imbued with theoretical ideas than practical realities. It is because of these factors that senior professionals are more likely to be 'normalisers' than other staff members. This lack of unity within the group of professionals is a result of co-existing philosophies which results in the conflict between 'normalisers' and 'paternalists'. Sexuality creates further problems for some 'normalisers', who, while espousing the prevailing orthodoxy, retain personal views contradictory to their professional ones.

The evidence presented in this study reveals that problems exist concerning social work-family relations. The underlying source of these problems was traced to the disparate ideologies held by parents and professional social workers. These ideologies influence the actions, reactions and interactions of each group, including the way in which each group views the other and how they perceive themselves. They also affect their attitudes and expectations of people with learning disabilities.

Fundamentally, the professionals are involved in the relationship because of their employment obligations. Their position is directed by professional philosophy. Their attitudes and expectations are based on their experience and observations of numerous individuals with learning disabilities. This gives the professionals 'objective expertise'. By contrast, parents have holistic experience of their son or daughter which influences their own perceptions and attitudes to learning disabilities. This gives them 'subjective expertise'. As shown by this study, there is an inevitable creation of tension and parental conflict as each group perceives this rivalry of expertise.

This study reveals two major barriers to an equal partnership between parents and professionals. These barriers are not insurmountable. With insight and

application progress to a solution is possible. One barrier concerns "professional socialisation" (Robinson, 1978) and the other concerns ideologies. This reflects the differences commonly found between theory and practice.

Professional socialisation

In brief terms, professional socialisation refers to the ways in which professionals think and the way in which they work (Robinson, 1978). This study reveals that the main problem with professional socialisation concerns the perceived expertise of social workers. Their role as 'expert' is questioned, and even resented, by parents because they feel that they know their own son or daughter better than anyone else. The parents are natural experts in this respect because of their personal knowledge and daily living experience. In the light of this, professionals strive to maintain their status and in extreme cases suffer from what Cunningham (1983) has called "expertosis". Schon suggests that another cause of this problem is that social work is a 'minor' profession. He goes on to explain that these professionals are "beguiled by the success of the 'major' professions of law, medicine, and business, (and) have tried to substitute a basis in scientific knowledge for their traditional reliance on experienced practice". This is because they "lack stable institutional contexts of practice, (with) fixed and unambiguous ends...(based in) systematic scientific knowledge" (Schon, 1992).

Schon also claims that their role of 'expert' is burdensome, creating expectations that cannot always be met. His recommendation is that professionals become more conscious or aware of their behaviour. He believes that "Many practitioners, locked into a view of themselves as technical experts, find little in the world of practice to occasion reflection. For them, uncertainty is a threat; its admission, a sign of weakness. They have become proficient at techniques of selective inattention" (1992). He therefore advocates 'reflective action' which entails the

self-analysis of their behaviour. He recommends the use of "stimulations, role-plays and rehearsals" in order to "slow down the pace of action, go back and try again, and reduce the cost and risk of experimentation". It is therefore important that professional socialisation encourages critical self-awareness and sensitivity in interactions with parents.

It is also vital that professionals acknowledge the wealth of 'subjective expertise' that parents inherently possess. Moreover, they must learn to value this in order to supplement their own knowledge. It is possible that this would encourage the growth of parental trust in professionals. The sharing of professional 'objective expertise' in a non-threatening manner would give parents the opportunity to select from it what they consider to be relevant to their own son or daughter, thus supplementing their own 'subjective expertise' and producing a balance within the relationship.

While parents and professionals retain their own ideologies, it is possible to create an additional and integrated shared ideology, based on the acceptance that both parties can effectively contribute to it. Towards this construction, it is necessary for professionals to adopt an open-door policy, welcoming parents in warm interaction. This would facilitate the development of trust in the relationship. The example of the "Tea and Chat" meetings in the data are a method of achieving this, although these particular meetings were unsuccessful in this respect. This was due, however, to negative personal interactions, where professional expertise, distrust and lack of collaboration were intimidating barriers to the possibility of a shared ideology.

The present study suggests that sexuality magnifies the difference between parents and professionals. There are two reasons for thinking this may be the key to their reconciliation in a shared ideology. Firstly,

sexuality is acknowledged as problematic for both groups. It would therefore be in their interests to work together in this area to achieve a consensus acceptable to both. Some initiatives have already been taken (Rose and Jones, 1994). An example of working together on an equal basis is the "Sexual Health Enablers Course", designed for joint participation by parents and professionals. The aims of the course are to "allow each participant the opportunity to examine his/her own attitude to sexuality...to develop an awareness and understanding of sexual health issues (and) to develop an understanding of his/her own roles and responsibilities" (Ayrshire Central Hospital). Although professionals and parents have conflicting expectations of the potential abilities of the people in their care, the topic of sexuality concerns both groups. Working together in this area to produce common goals serves to create a foundation of reciprocal trust.

Secondly, using sexuality to bond the two groups is effective because of its equalising nature. In this area neither professionals nor parents claim expertise. In addition, acknowledgement of their sexual needs enhances the status of equality of people with learning disabilities. Ultimately, this could help to redistribute the balance of power within the tripartite relationship. Furthermore, the concepts of empowerment and self-advocacy suggest that people with learning disabilities have the rights and opportunities to express their own needs and aspirations. Their views could influence parents and professionals towards effective collaboration and, subsequently, a shared ideology of care.

Ideological limitations

There are further implications of this study which arise from the prevailing orthodoxy of normalisation. It was revealed that the conflicts between parents and professionals (Chapter 4), between professionals and within professionals themselves (Chapter 5) challenge the

feasibility of normalisation, particularly in respect of sexuality.

Fundamentally, normalisation is concerned with making available to people with learning disabilities "patterns of life...as close as possible or...the same as the regular...ways of life of society" (Nirje, 1985). This implies that they have the opportunity to experience adult sexual activities. It therefore involves their making decisions about relationships, types of sexual activity, contraception and procreation. This is reinforced by Wolfensberger's statement that the "promotion of a valued socio-sexual identity" is a necessary part of social role valorization (1983). It is a component, he claims, of the enhancement of the social image and the personal competencies of people with learning disabilities which are necessary to achieve their acceptance in society.

Additionally, on a philosophical level, Neville (1978) describes acceptance in society through the means of a "moral community". This, he explains, entails individuals being held responsible for their own actions. Members of the moral community acknowledge and accept that other individuals are responsible for their own actions. Control over sexuality of people with learning disabilities is therefore, in Neville's terms, a denial of their entry into this moral community and a limitation of normalisation. Again, this reinforces the essential claim that opportunities and choices are salient factors of normalisation. These are, however, limited because parents and professionals do not at present have a shared ideology.

It is pertinent to note that normalisation also infers that people with learning disabilities can choose not to be sexually active or to deviate from an 'ordinary' sexual life. The basic principle is that their options are open. This is a source of potential conflict between parents and professionals and between the 'paternalists' and the 'normalisers'. As such, further limitations are imposed

on normalisation. The creation of a shared ideology would also overcome this. As discussed earlier, the way to achieve this is the collaboration of parents and professionals on sexuality issues. The limits of normalisation could then be eliminated if the sexuality of people with learning disabilities were 'cultivated'. Kempton and Caparulo (1983) recommend that this "philosophy can be generally practiced if society permits it, if parents feel comfortable with it, and care-givers can deal with it. With this attitude (people with learning disabilities) can be encouraged and helped to enrich their lives through sexual expression..."

The cultivation of sexual expression is not solely dependent on the attitudes of and the relationship between parents and professionals however. Another factor which limits normalisation involves service-provision. Brown (1994) claims that the effects of services include the "regulation of sexuality and the creation of sexual boundaries". This is manifested in limited facilities for choice and privacy within residential establishments where the opportunity for cohabitation is rare. This reflects society's expectations of a higher moral standard for people with learning disabilities than is generally expected from the rest of society (Sebba, 1983). The opportunities they do have are restricted, as Brown (1994) clarifies, "Living as a couple is seen to be conditional on independence skills and financial autonomy both of which are rarely attainable by people with learning disabilities". She adds that "the recognition of abstract rights has failed to break through the barriers of prejudice and isolation and to create opportunities for people with learning disabilities to live different kinds of partnerships and family groups or to enjoy a range of sexual relationships, contacts and activities". The problem underlying this is connected to social work organisation and financial restrictions. It is, she says, "administratively incompatible".

External limitations are therefore imposed on normalisation through attitudinal barriers of parents and 'paternalists' and the conflict which exists between them and the 'normalisers'. In addition, limitations are set on normalisation through the lack of facilities. The implications of this are that there is little support for people with learning disabilities to express their sexuality in either 'ordinary' or alternative ways. Because the attitudes towards the sexuality of people with learning disabilities and financial concerns are restricted, the practical application of normalisation is limited. As an ideology, it is at present limited ironically by its own radical implications with regard to sexuality. This is illustrated by a professional who commented:

"...in our society (we're) still very Edwardian when it comes to sex with people with learning difficulties with the sexual revolution in the sixties only for certain people."

(13,18,2-5)

To remedy this, parents, professionals and policy-makers must reconsider their perceptions of people with learning disabilities. In order to alleviate sexual oppression and allow normalisation to influence their lifestyles, people with learning disabilities must be regarded as sexually equal to the rest of the population, with responsibility for their own actions and access to the 'moral community'. This means that attitudes to sexuality in general and to the sexuality of people with learning disabilities in particular have to be readdressed. As one professional in the study remarked:

"...we're all a bit repressed and don't talk much about sex and sexuality. I

think we all still see it as for the young
and beautiful."

(25,5,30-2)

The limitations of normalisation are therefore those imposed on it by its interpretation. Nevertheless, these limitations are not insurmountable. The concept of a shared ideology developed through the issue of sexuality could be a means to eliminate such restrictions, as discussed earlier.

Normalisation has produced radical changes in ways of thinking and service provision for decades, but its implications regarding sexuality have yet to be fully realised. As such, normalisation is a long-term goal in addition to its being the means to achieve that goal.

APPENDICES

Appendix 1
Letter to Parents

Dear

I am writing to you with regard to a study I am doing at the University of Glasgow. I would appreciate your help in allowing me to interview you. I am researching problems that people with learning difficulties have when they become adults.

I would like to ask you a range of questions and, if you agree, tape-record your answers. Overall, it would not take longer than about 45 minutes and our meeting could take place at the Centre or in your home.

I would be very grateful if you could let me know your reply by completing the tear-off slip below and returning it to as soon as possible. Meanwhile, thank you for your time in reading this letter.

Your sincerely

(Mrs) Susan J Deeley

Please tick box ✓

☐ Yes, I am willing to be interviewed.

Name: _____ Tel No: _____

☐ No. Thank you. I am not willing to be interviewed.

Name: _____ Tel No: _____

Appendix 2

Interview Schedule Guide:

- (I) Initial Contact
- (II) Transition to Adulthood
- (III) Contraceptive Provision
- (IV) Sterilisation
- (V) Vignette

I. Initial Contact

Name and age of son/daughter

Where does he/she live: in parental home, hostel, group home, other

Does he/she attend A.T.C., College, has employment, other.

II. Transition to Adulthood

1. Does he/she show any signs of interest in the opposite sex?

Probes: Any talk of 'crushes' keen interest in pop or film stars, TV or sports personalities, people they know.

2. Does he/she have any special relationship with a member of the opposite sex?

Probes: Past or present, any talk of particular friends of the opposite sex, boyfriends/girlfriends.

3. Could a serious relationship be maintained?

Probes: Understanding of 'give and take', sharing, loyalty, caring, honesty, responsibility.

4. Is he/she capable of marriage?

Probes: Meaning marriage with or without outside support. Could he/she understand the meaning of a long-term relationship, idea of commitment, able to make such a decision, give consent, understand basic idea that it is a legal contract.

5. Could he/she cope with a child on his/her own?

Probes: Either with or without support from outside agencies.

If yes, then:

6. Could he/she cope with more than one child?

Probes: Either with or without outside help.

III. Contraceptive Provision

To be honest and frank, we know that pregnancies can occur outside marriage and without there being a steady relationship. With all due respect, this can happen even with the most attentive care and supervision. In the light of this, may I ask:

7. Have you ever considered protecting him/her against a possible unwanted pregnancy, for example, by providing him/her with some form of contraception?

(a) If reply 'NO',

Probes: Reasons why not, would it be considered in the future.

(b) If reply 'YES',

Probes: Are contraceptives currently being used, what method/if other than sterilisation, why this particular method.

(c) If reply, 'HYSTERECTOMY'

Probes: For details, type of operation, (egs. abdominal, key-hole surgery), after-effects, consent, decision, involvement of daughter, if possible would decision be repeated.

(d) If reply, 'NO CONTRACEPTION' being used, go back to (a).

If a contraceptive other than sterilisation is being used or there is no contraception at all:

8. Have you ever considered sterilisation for (son/daughter)?

If reply 'NO'

Probes: Would it ever be considered, at what particular point would it be considered, reasons for not considering it.

If 'YES', and sterilisation has been performed

Probes: Reasons for not having the operation, would they reconsider this option, what would instigate reconsideration.

IV. Sterilisation

9. Has son/daughter been sterilised?

Probes: When and at what age, what made you decide this,

was it an easy/difficult decision, if the decision could be made again would it remain the same, could son/daughter understand what was happening/the nature of the operation, was son/daughter involved in the decision, who was involved in the decision-making, GP's attitude, any pre-sterilisation counselling offered, does son/daughter have a tutor-dative, who signed the consent form, was it a straightforward procedure, how long did it take, would you recommend it to other parents in your position, satisfied/dissatisfied with the procedure.

Speaking ideally, if a person can't consent to sterilisation, who do you think should make the decision for them, should it be:

- a. Parents
- b. Parents and Doctor
- c. Parents and Independent Committee (Mencap recommends an Ethics Committee)
- d. Law Courts
- e. Tutor-dative

If there is a tutor-dative: who it is, relation/friend/other. Was there a petition for sterilisation, what was procedure, papers needed. Was anyone appointed to see what son/daughter's views were, anyone else involved, independent representative, was there an independent examination of the need for sterilisation, were alternatives to sterilisation looked at, did GP offer or suggest any alternatives.

At this point, can I thank you very much for sharing your views with me and for telling me so much about (son/daughter).

V. Vignette

Before we finish, would you mind having a look at this made-up situation. It's about a couple with learning difficulties who start to have a serious relationship and I'd like your opinion on when either of them should be given contraception, or be sterilised, if at all.

(Read through vignette).

Thank you again for your time and help today. It's very much appreciated.

Appendix 3

Vignette (1)

Situation 1.

Jane and Paul are both 25 and have mild learning disabilities. They are very friendly with each other. At an A.T.C. dinner-dance they spend the whole evening together, dancing closely and kissing.

Questions: Do you think that either Jane or Paul should be given contraception?

Do you think it would be better for either of them to be sterilised? If so, which one and why?

Situation 2.

Jane now says that Paul is her steady boyfriend and they want to spend time alone together. A holiday has been organised by the A.T.C. It is for a small number of people with learning disabilities and a few members of staff only. Jane and Paul will both be going.

Questions: Do you think it is now time to give Jane and Paul contraception?

Do you think that sterilisation would be better for either of them? If so, which one and why?

Situation 3.

Jane and Paul now talk about being in love with each other and they want to get married.

Questions: Do you think that Jane or Paul should now have contraception?

Would it be better for either of them to be sterilised? If so, which one and why?

Situation 4.

Jane and Paul do not get married, but very soon Jane is pregnant. Early in the pregnancy she has a miscarriage.

Questions: Should Jane or Paul be given contraception?

Should Jane or Paul be sterilised? If so, which one and why?

Situation 5.

Jane becomes pregnant again. After the birth it has been arranged that the baby will be taken into foster care.

Questions: Should Jane or Paul be given contraception?

Should Jane or Paul be sterilised? If so, which one and why?

Situation 6.

Jane now has a second child who is also taken into care.

Questions: Should Jane or Paul be given contraception?

Should Jane or Paul be sterilised at this point? If so, which one and why? If not, do you think there could ever be a time when it would be best for either of them to be sterilised?

Appendix 4
Multiple-Choice Answers

- A. Parents
- B. Parents and Doctor
- C. Parents and Independent Committee
- D. Law Courts
- E. Tutor-dative

Appendix 5
List of Categories

List 1: a. Mild
 b. Moderate
 c. Severe
 d. Profound
 e. Don't know

List 2: a. Educable
 b. Trainable
 c. Don't know

Appendix 6
Interview Guide-Parents (2)

Personal Introduction

- i. Initial Contact
- ii. Transition to Adulthood
- iii. Contraceptive Provision
- iv. Sterilisation
- v. Law
- vi. Vignette
- Close and Thanks

i. Initial Contact

Occupation (or partner's): either current job or last full-time employment of parent.

Name of son/daughter.

Age of son/daughter.

Where does he/she live?: parental home, hostel, group home, half-way house, other (specify).

Does he/she attend an A.T.C., college, have employment, other (specify).

There are different levels of disability.

Which of these categories would you choose to describe his/her learning disability? (Show list).

There are different labels used for people with disabilities.

Which ones are you comfortable with, or which one do you prefer, when you're talking about - (son/daughter) - ?

ii. Transition to Adulthood

1. Has he/she shown any signs of interest in the opposite sex?

Probes: Any talk of crushes, keen interest in pop/film stars, TV or sports personalities, people they know.

2. Does he/she have a special relationship with anyone of the opposite sex?

Probes: Past or present, any talk of particular friends of the opposite sex, boyfriends or girlfriends.

3. Do you think he/she could maintain a serious

relationship?

Probes: Understands the idea of 'give and take', sharing, loyalty, caring, honesty, responsibility to another person on mutual terms.

3a. Do you think they would like to have such a relationship, or perhaps benefit from having one?

4. Do you think he/she would ever like to get married?

Probes: With outside support if needed, would they understand that it's intended to be a long-term commitment, that it's a legal contract, could they make a decision on this, give their consent.

4a. Do you think he/she would ever like to get married?

Probes: Or live with someone, with outside support if needed.

5. Could he/she cope with a child of his/her own?

Probes: With help from outside agencies.

IF YES: could he/she cope with more than one child?

Probes: With help from outside agencies.

5a. Do you believe that people with learning disabilities should ever have children?

Probes: If there were adequate support services, parent-craft classes.

5b. Do you think he/she would like to have a child of their own?

5c. Does he/she know about the facts of life?

Probes: What makes a baby, how this can be prevented?

5d. Who do you think is the best person to tell them?

Probes: What are your feelings about sex education being taught by professionals, in consultation with parents or not.

iii. Contraceptive Provision

To be honest and frank, we know that pregnancies can occur outside marriage and without there being a steady relationship. With all due respect, this can happen even with the most attentive care and supervision. (And in the present day we have to take into consideration the risks of HIV infection and other sexually transmitted diseases).

In the light of this, may I ask:

7. Has contraception ever been considered for him/her?

If NO

Probes: Reasons why not, would it be considered in the future: GO TO QUESTION 8.

If YES, BUT NO CONTRACEPTION

Probes: Reasons why not, would you reconsider? What would make you reconsider? GO TO QUESTION 8.

If YES, HE/SHE HAS BEEN STERILISED

Probes: GO TO QUESTION 9.

If YES, CONTRACEPTIVES ARE BEING USED (NOT STERILISATION)

Probes: Which method?

IF SHE'S ON THE PILL/HAS DEPO-PROVERA INJECTION/HAS IUD FITTED

Probes: For how long has she had this?
(pill) does she take it herself?
Does she understand why she has this?
Who decided?
Was she involved in the decision-making?
What made you think the time was right for this?
GO TO QUESTION 8

IF SHE'S HAD A HYSTERECTOMY -

Probes: When was the operation?
How old was she?
Does she understand what the operation is and means?
How did it come about (symptoms, at the G.P.'s suggestion)
Do you know what kind of operation it was?
(abdominal, vaginal, key-hole surgery, length of hospital stay, after-effects)
Who made the decision?
Was she involved in the decision-making?
Who signed the consent form?
GO TO QUESTION 10

HE USES CONDOMS/SHE USES A DIAPHRAGM/FEMADON/SPONGE/SPERMICIDAL PESSARIES -

Probes: Does he/she know how to use them correctly?
Who taught him/her?
Does he/she know why they are used?
Where is/was contraceptive obtained?
If they are supplied, does he/she have to ask for them?
Does he/she know how to obtain them/it

independently?
(using vending machines/chemist/F.P. clinic)
GO TO QUESTION 8

iv. Sterilisation

8. Have you ever considered sterilisation for him/her?

If NO

Probes: Would it ever be considered?
At what point would you consider it?
What are your reasons for not considering it?

If YES, but he/she has not been sterilised

Probes: What are the reasons for not having the operation?
Would you reconsider this option?
At what point would you reconsider it?
How would you go about it? (Visit to G.P./Social Worker/Lawyer)
Would you involve your son/daughter in the decision-making?
Would he/she understand the meaning of the operation?
Who would sign the consent form to the operation?
What do you think his/her feelings would be knowing that they would never be able to have children?
GO TO QUESTION 10

9. Has your son/daughter been sterilised?

(The answer to this will already be established)

Probes: When was he/she sterilised?
How old was he/she?
What made you decide this?
Was it an easy or a difficult decision?
Who was involved in the decision?
Was your son/daughter involved?
Do you think he/she understood the implications/understands now?
How do you think he/she feels about it now? (i.e. not being able to have children)
Are you happy/satisfied with the decision?/would the same decision be made again if it were possible?/would you recommend it?
What was the G.P.'s attitude?
Were alternatives to sterilisation suggested or offered?
Was pre-sterilisation counselling offered?
Who signed the consent form?
Was the process straightforward?/were there any problems?/how were these overcome?

How long did the whole process take?

v. Law

10. Can you tell me if he/she has a tutor-dative?

If YES

Probes: Who is it/are they? (Relation/friend/other)
Was there a petition for sterilisation? (Or hysterectomy/vasectomy)
What was the procedure?
What papers were needed?
Was anyone appointed to see what his/her views were?
Was anyone else involved?/was an independent representative appointed?
Was there an independent examination of the need for sterilisation?
Were alternatives to sterilisation looked at?
Did the G.P. or anyone else suggest or offer any alternatives?

If NO

Probes: Would you consider having a tutor-dative appointed?
Who would you choose?
What would make you consider it?
What do you think of the tutor-dative system?
GO TO QUESTION 11

NO - NO KNOWLEDGE OF TUTOR-DATIVE SYSTEM

In Scots Law, a tutor-dative is someone, related or not, appointed by a law court on behalf of a person with a learning disability. They can have more than one tutor-dative.

At present, with permission from the court, a tutor-dative can consent to sterilisation on behalf of the person with learning disabilities, but there are proposals for change in this area.

11. Do you think it is a good idea to have a tutor-dative system?

Probes: Is it useful?/useless?
What are your reasons for thinking this?

12. If a person with learning disabilities can't consent to sterilisation, who do you think should make the decision for them? (Show list of choices)

Should it be: a. Parents

- b. Parents and Doctor
- c. Parents and Independent Committee
(Mencap recommends an Ethics Committee)
- d. Law Courts
- e. Tutor-dative

Probes: Why do you think this is the best choice?

13. Do you think that people with learning disabilities should ever be allowed or encouraged to make these decisions for themselves?

Probes: With support?/with pre-sterilisation counselling?

14. Do you think there should be laws about sterilisation of people with learning disabilities?

Probes: Making certain rules?/no rules at all?

Making it easier/more difficult for them to be sterilised?

At this point, may I thank you very much for sharing your views with me and for telling me so much about (son/daughter).

vi. Vignette

Before we finish, would you mind having a look at this made-up situation. It's about a couple with learning difficulties who start to have a serious relationship. I'd like your opinion on when either of them should be given contraception, or be sterilised, if at all.
(Give copy of Vignette and record reply)

Thank you for your time and help today. It is very much appreciated.

Appendix 7
Interview Guide - Keyworkers

Personal Introduction

- i. Initial Contact.
- ii. Transition to Adulthood
- iii. Contraceptive Provision
- iv. Sterilisation
- v. Law
- vi. Vignette

Close and thanks.

i. Initial Contact

- a. Can you tell me how long you've worked with people who have learning disabilities?**

Probes: Has it always been with the Social Work Department, if not, who were other employers?
What kind of work experience
Children/adults/residential/A.T.C./day-care/other
What levels of disability? Mild/moderate/severe/profound/multiple handicaps

- b. How long have you worked here?**

- c. Are you satisfied with the training you've been given?**

Probes: Can you describe the type of training?
What kind of training do you think would be most useful?

- d. Could you describe the aims of the service that's provided here?**

Probes: Do you think these aims are achieved?
If not, in what ways could they be achieved?
What criteria would you use to assess this?
How would you describe 'success' in this type of service?
In what ways would you like to see changes or improvement?
Do any of the aims involve the parents at all?
How do you see the role of this service? Does it complement other services?

- e. Would you say that there have been changes in the service in recent years?**

Probes: With regard to attitude towards and treatment of people with learning disabilities, self-advocacy

groups, sex education and counselling, other changes.

f. If 'YES' what is your opinion of these changes?

Probes: Do you see these changes as improvements or not?
How would you like to see the service changing, if at all?
What would be your ideal in the way of future provision?

I'd now like to talk about your role as keyworker.

g. How long have you worked with _____

h. Do you know his/her parents?

Probes: How well? How is contact made? Direct/through the O-I-C-/'phone/letter/circular/reviews/other

j. Do his/her parents visit here?

Probes: How often? Formal/informal basis/open-door policy/ social events/reviews/following particular behaviour/ challenging behaviour/other

k. Would you tell me which out of these categories you would choose to describe his/her learning disability?
(Show list)

ii. Transition to Adulthood

1. Does he/she know about the facts of life?

Probes: What makes a baby, how this can be prevented?

If YES: Who told him/her.

If NO:

2. Who do you think is the best person to tell him/her?

Probes: Parents/professionals/in consultation with parents or not/other. Should this be part of A.T.C. curriculum, part of staff training.

3. Has he/she shown any signs of sexual interest?

Probes: Any talk of crushes, keen interest in pop/film stars, TV or sports personalities, people he/she knows.

4. Does he/she have a special relationship with anyone of the opposite sex?

Probes: Past or present, any talk of particular friends of the opposite sex, boyfriends/girlfriends.

5. Do you think he/she could maintain a serious relationship?

Probes: Understands the idea of 'give and take', sharing, loyalty, caring, honesty, responsibility to another person on mutual terms, more commitment than a casual relationship.

6. Do you think he/she would like to have such a relationship, or perhaps benefit from having one?

7. Do you think he/she could ever get married?

Probes: With outside support if needed, would he/she understand concept of a long-term commitment, legal contract, could he/she make a decision about this, give consent?

8. Do you think he/she would ever like to get married?

Probes: Or live with someone, with outside support if needed.

8a. What are your views on people with learning disabilities living with a partner outside marriage?

Probes: i.e. within the law (this only concerns those with mild/moderate learning disabilities).

9. What are your views on people with mild learning disabilities having children?

Probes: If there were adequate support services, parent-craft classes, pre- and post-natal care.

10. Could he/she cope with a child of his/her own?

Probes: With help from outside agencies.

If YES: Could he/she cope with more than one child?

11. Do you think he/she would like to have a child of his/her own?

Probes: Can you pinpoint any particular reason(s)?

iii. and iv. Contraceptive Provision and Sterilisation.

I'd now like to talk about contraception for adults with mild learning disabilities.

12. Do you think that contraceptive provision should be made available before there are any signs of a sexual relationship?

Probes: With sex education and counselling being pre-requisites.

If NO: At what point would you recommend contraceptive

provision be made?

Probes: If the answer involves 'serious' relationship, then what criteria are used to define this?

13. Working as a professional, do you consider any part of this area to be within your responsibility?

Probes: If not, whose responsibility is it?
If it is, what provision is made for the 'clients'?
Who provides this provision?
Can you describe the training facilities for staff?
Is training adequate?
What do you think would be the ideal situation in respect of training and service provision?
Why do you think this situation doesn't already exist?
What level of importance would you give this within the service?

14. What type of contraception do you think would be most suitable for _____?

14a. What are your views of _____ being sterilised?

Probes: For/against/indifferent/depends on circumstances.
At what point should sterilisation be considered?
Who should make the decision, or be involved in the decision-making process?
Would he/she understand its meaning/implications?
Would he/she be able to sign the consent form convincingly?
What do you think his/her feelings would be knowing that he/she could then never have children?

15. What are your general views on sterilisation of people with learning disabilities?

v. Law

In Scotland, a person can be appointed by law to act on behalf of an adult with a learning disability. In some cases, this can include signing a consent form to sterilisation. There are proposals to change this.

16. What is your opinion of this system?

Probes: Also known as tutor-dative.
Useful/useless.
What are your reasons for thinking this?
Do you think people with learning disabilities can make these decisions for themselves, if given counselling and support?

17. Do you think there is a need for any legal intervention with regard to sterilisation of adults with learning disabilities?

Probes: Making it easier/more difficult for them to be sterilised, to protect/enhance their rights.
What are your reasons for this?

Can I give you this list and ask you:

18. If there was a person with learning disabilities who couldn't give their consent to a sterilisation operation, who do you think should make the decision for them?

Should it be: a. Parent
b. Parents and Doctor
c. Parents and Independent Committee
(Mencap recommends an Ethics Committee)
d. Law Courts
e. Tutor-dative

Probes: Why do you think this is the best choice?

vi. Vignette

Before we finish, would you mind having a look at this made-up situation. It's about a developing sexual relationship between a couple who have learning disabilities. I'd like your opinion on when either of them should be given contraception, or be sterilised, if at all.

I'd like to thank you very much indeed for your time and help today. It is very much appreciated.

Appendix 8
Interview Guide - Parents (3)

Personal Introduction

- i. Initial Contact
- ii. Transition to Adulthood
- iii. Contraceptive Provision
- iv. Sterilisation
- v. Law
- vi. Vignette

Close and thanks

i. Initial Contact

Occupation (or partner's): either current job or last full-time employment of parent
Name of son/daughter
Age of son/daughter
Where does she live?: parental home, hostel, group home, half-way house, other (specify)
Does he/she attend an A.T.C., College, have employment, other (specify)

a. What are your views on the service your son/daughter receives?

Probes: Unsatisfactory/adequate/satisfactory
Why?
What do you like most about it?
What do you like least about it?
What would you see as an improvement?

**b. What do you think parents feel about the A.T.C.?
What do you think about the A.T.C.?**

Probes: What do you like most about it?
What do you like least about it?
If you could change something about it, what would it be?
What would be an ideal service in your view?

**c. What do you think parents feel about the staff?
What do you think about them?**

Probes: Do they ask your opinion about what you think would be best for (son/daughter)?
Are you involved in the planning of any of his/her activities at the A.T.C.?
How do you feel about approaching staff? Do they make you feel welcome? Do they make you feel as

though you're pestering them?

d. How do you think staff feel towards parents?

Probes: Why is this?

If there is conflict - how do you think this can be resolved?

e. Staff often talk about giving mentally handicapped people 'choices' and about letting them make their own decisions. How realistic do you think this is?

Probes: Would you agree with them?

Are there limits to giving them choices, or letting them make their own decisions?

What are the limits?

If parents and staff felt differently about these limits, there could be a problem. How do you think it could be resolved?

Positive - through communication/working together/compromising

Negative - parents' rights/staff interfering/withdraw from A.T.C.

There are different levels of disability.

f. Which of these categories would you choose to describe his/her learning disability? (Show list)

As you know, there are different labels used to describe people with disabilities. The term 'mentally handicapped' has been used, but now some people are saying 'learning difficulties' or 'learning disabilities'. What would you say?

ii. Transition to Adulthood

1. Does he/she know about the facts of life?

Probes: What makes a baby, how this can be prevented.

If YES: Who told him/her?

If NO:

2. Who do you think is the best person to tell him/her?

Probes: What are your feelings about sex education being taught by professionals, in consultation with parents or not?

3. Has he/she shown any signs of interest in the opposite sex?

Probes: Any talk of crushes, keen interest in pop/film stars, TV or sports personalities, people he/she

knows.

4. Does he/she have a special relationship with anyone of the opposite sex?

Probes: Past or present, any talk of particular friends of the opposite sex, boyfriends or girlfriends.

5. Do you think he/she could maintain a steady or a close, intimate relationship?

Probes: Understands the idea of 'give and take', sharing, loyalty, caring, honesty, responsibility to another person on mutual terms, more commitment than a casual relationship.

6. Do you think he/she would like to have such a relationship?

7. Do you think he/she might ever get married?

Probes: With outside support if needed, would they understand that it's intended to be a long-term commitment, that it's a legal contract, could they make a decision on this, give their consent.

8. Do you think he/she would ever like to get married?

Probes: Or live with someone, with outside support if needed.

9. Do you believe that people with mild learning disabilities should ever have children?

Probes: If there were adequate support services, parent-craft classes.

10. Could he/she cope with a child of his/her own?

Probes: With help from outside agencies.

If YES: Could he/she cope with more than one child?

Probes: With help from outside agencies.

11. Do you think he/she would like to have a child of his/her own?

iii. Contraceptive Provision

To be honest and open about this, we know that pregnancies can occur outside marriage and even without there being a steady relationship. With all due respect, this can happen even with the most attentive care and supervision. (And in the present day we have to take into consideration the risks of HIV infection and other sexually transmitted diseases).

In the light of this, may I ask:

12. Has contraception ever been considered for him/her?

If NO:

Probes: Why not? Would it be considered in the future?
GO TO QUESTION 13

If YES, but contraception is not being used:

Probes: Why not? Would you reconsider? What would make you reconsider? GO TO QUESTION 13.

IF YES, contraceptives are being used (Not sterilisation)

Probes: Which method?

If she's on the pill/has depo-provera injection/has IUD fitted:

Probes: For how long has she had this?
(Re: pill) does she take it herself?
Does she understand why she has this?
Who decided?
Was she involved in the decision-making?
What made you think the time was right for this?
GO TO QUESTION 13

If she's had a hysterectomy:

Probes: When was the operation?
How old was she?
Does she understand what the operation is and means?
How did it come about (symptoms, at G.P.'s suggestion)
Can you tell me something about the operation?
(abdominal, vaginal, key-hole surgery, length of hospital stay, after-effects)
Who made the decision?
Was she involved in the decision-making?
Who signed the consent form?
GO TO QUESTION 15

If he used condoms/if she uses a diaphragm/femadon/sponge/spermicidal pessaries:

Probes: Does he/she know how to use them correctly?
Who taught him/her?
Does he/she know why they are used?
Where is/was contraceptive obtained?
If they are supplied, does he/she have to ask for them?
Does he/she know how to obtain them/it independently?
(Using vending machines/chemist/F.P. clinic)
Does he/she know about post-coital contraception and how to obtain it?

GO TO QUESTION 13

iv. Sterilisation

13. Have you ever considered sterilisation for him/her?

If NO:

Probes: Would you ever consider it?
At what point would you consider it?
What are your reasons for not considering it?

If YES, but he/she has not been sterilised:

Probes: What are the reasons for not having the operation?
Would you reconsider this option?
At what point would you reconsider it?
How would you go about it (visit to G.P./social worker/lawyer)
Would you involve your son/daughter in the decision-making?
Would he/she understand the meaning of the operation?
Who would sign the consent form to the operation?
What do you think his/her feelings would be knowing that he/she would never be able to have children?
GO TO QUESTION 15

14. Has your son/daughter been sterilised?

(The answer to this will already be established?)

Probes: When was he/she sterilised? *(If a tutor-dative was involved use later probes in Question 16 as well)
How old was he/she?
What made you decide this?
Was it an easy or a difficult decision?
Who was involved in the decision?
Was your son/daughter involved?
Do you think he/she understood the implication/understands now?
How do you think he/she feels about it now? (i.e. not being able to have children?)
Are you happy/satisfied with the decision?/would the same decision be made again if it were possible?/would you recommend it?
What was the G.P.'s attitude?
Were alternatives to sterilisation suggested or offered?
Was pre-sterilisation counselling offered?
Who signed the consent form?
Was the process straightforward?/were there any

problems?/how were these overcome?
How long did the whole process take?

v. Law

In Scotland, a person can be appointed by law to act on behalf of an adult with a learning disability. In some cases, this can include signing a consent form to sterilisation. There are proposals to change this.

15. What is your opinion of this system?

Probes: Also known as tutor-dative
Useful/necessary/useless/interfering
Why do you think this?
Would you consider having one appointed?
Who would you choose?
What would make you consider it?

If (son/daughter) has a tutor-dative:

Probes: Who is it/are they? (Relation/friend/other)

16. And is sterilised:

Probes: Was there a petition for sterilisation? (Or hysterectomy/vasectomy)
What was the procedure?
What papers were needed?
Was anyone appointed to see what his/her views were?
Was anyone else involved?/was an independent representative appointed?
Was there an independent examination of the need for sterilisation?
Were alternatives to sterilisation looked at?
Did the G.P. or anyone else suggest or offer any alternatives?

17. Do you think there is a need for any legal intervention with regard to sterilisation of adults with learning disabilities?

Probes: Making it easier/more difficult for them to be sterilised?
To protect/enhance their rights?
Why do you think this?
Do you think adults with mild learning disabilities can make this type of decision?

Can I give you this list and ask you:

18. If there was a person with learning disabilities who couldn't give their consent to a sterilisation operation, who do you think should make the decision

for them?

- Should it be:
- a. Parent
 - b. Parents and Doctor
 - c. Parents and Independent Committee
(Mencap recommends an Ethics Committee)
 - d. Law Courts
 - e. Tutor-dative

Probes: Why do you think this is the best choice?

At this point, may I thank you very much for sharing your views with me and for telling me so much about (son/daughter).

vi. Vignette

Before we finish would you mind having a look at this made-up situation. It's about a couple with learning difficulties who start to have a serious relationship. I'd like your opinion on when either of them should be given contraception, or be sterilised, if at all.

(Give a copy of Vignette and record reply).

Thank you for your time and help today. It is very much appreciated. It will be of great value to my research.

Appendix 9
Interview Guide - Professionals

i. Initial Contact

a. Can you tell me how long you've worked with people who have learning disabilities?

Probes: Has it always been with the Social Work Department? If not, who were the other employers?
What kind of work experience? Children/adults/residential/A.T.C. day-care/other
What levels of disability? Mild/moderate/severe/profound/multiple handicaps

b. How long have you worked here?

c. What do you think about the training you've been given?

Probes: Why do you think this?
What were the main aims of the training?
What kind of training do you think would be most useful?

d. Could you describe the aims of the service that's provided here?

Probes: How is independence achieved?
Which objectives are used:
Control ('widgets')
Instruct (life and social skills)
Support (integration)

e. Do you think these aims are achieved?

Probes: If not, in what ways could they be achieved?
What criteria would you use to assess this?
How would you describe 'success' in your day-to-day work?

f. What are your main hindrances to your work?

Probes: If you could change some aspect of your work, what would it be?
Do you see the role of this service in any way involving parents?
Why?/Why not?

g. In general, what do you think staff feel about parents? Why?

And what are your feelings? Why?

Probes: Are parents seen as: resources/co-workers (co-therapists/co-teachers)/co-clients/consumers
Do you think parents have generally been give help and support in the past?

h. How do you think parents view staff? Why?

Probes: Caring/respice/helpful/meddling/busybodies/do-gooders

j. What do you think of adults with mild learning disabilities being given opportunities to make their own decisions? (Through choices)

Probes: Why do you think this/(Source of commitment?)
Do you actively encourage/discourage it?
How?
Are there limits?
How realistic is this?
What do you think parents' reactions are to this?
What do you think are the views of staff to this?

k. What do you think about them making decisions about their own sexuality?

Probes: (Same as previous question)

m. Would you say that there have been changes in the service in recent years?

Probes: Regarding attitudes to and treatment of people with learning disabilities/self-advocacy groups/sex education and counselling/other changes

If YES: What do you think of them? (Improvements/or not)

n. What do you think of the proposed changes?

Probes: Why do you think this?
What would be your future ideal provision?

(Some questions taken from 11. Transition to Adulthood)

a. Do you think adults with learning disabilities have sexual needs?

Probes: Would you say that they were different to those of people who do not have learning disabilities?
How different?
In what ways different?
What do you think are the main problems regarding sexuality for people with learning disabilities?
Do you think they should be given opportunities/privacy in order to express/explore their sexuality/sexual relationships?

8a. What are your views on people with mild learning disabilities living with a partner outside marriage?

Probes: This is within the law. With support if needed.
If disagree, is it acceptable that they live together within marriage?
If this is unacceptable, why is it?

b. What are your views on adults with learning disabilities having gay or bisexual relationships?

Probes: If disagree, why?

9. What are your views on people with mild learning disabilities having children?

Probes: With support services if needed.
If disagree, why?

12. Do you think that contraception should be freely and easily available to people with mild learning disabilities?

Probes: Irrespective of their relationship(s) or marital status.

If not: At what point would you recommend contraceptive provision be made?

Probes: If the reply includes being involved in a steady/serious intimate relationship, which criteria would they use to define/affirm this.

13. Working as a professional, do you consider any part of this area to be within your responsibility?

Probes: If not, whose responsibility is it, or should it be?

If it is, what provision is made for them?

Who provides it?

What are the training facilities in this particular area?

Is training adequate?

If not, what would you suggest?

Why do you think this situation doesn't already exist?

How relevant or important is this to people with learning disabilities?

15. What are your general views about sterilisation of people with learning disabilities?

Law

In Scotland, a person can be appointed by law to act on behalf of an adult with a learning disability. In some cases, this can include signing a consent form to sterilisation. There are proposals to change this.

16. What is your opinion of this system?

Probes: Also known as tutor-dative.

Useful/useless/necessary/interfering

What are your reasons for thinking this?

Do you think that people with mild learning

disabilities can make these decisions for themselves? Given counselling and support.

17. Do you think there is a need for any legal intervention with regard to sterilisation of adults with learning disabilities?

Probes: Making it easier/more difficult for them to be sterilised, to protect/enhance their rights
What are your reasons for this?

Can I give you this list and ask you:

18. If there was a person with learning disabilities who couldn't give their consent to a sterilisation operation, who do you think should make the decision for them?

Should it be:

- a. Parents
- b. Parents and Doctor
- c. Parents and Independent Committee
(Mencap recommends an Ethics Committee)
- d. Law Courts
- e. Tutor-dative

Probes: Why do you think this is the choice?

vi. Vignette

Before we finish, would you mind having a look at this made-up situation. It's about a developing sexual relationship between a couple who have learning disabilities. I'd like you to tell me at which point you think either of them should start to use contraception, or be sterilised, if at all.

I'd like to thank you very much indeed for your time and help today. It is very much appreciated.

Appendix 10

Additional Questions - Sex Education

1. What is the course called?

Probes: Why is it called this?
Who decided to call it this?

2. What are the aims of the course?

Probes: How are these achieved?
Who decides the course content?
What are the main topics covered by the course?
How is it monitored?
How is the course evaluated? By whom?

3. Can you explain to me how it started?

Probes: Why did it start?

4. Can you tell me who is involved in the course?

Probes: Why were the particular staff chosen?
What kind of training in sexuality have they received?
How many adults with learning disabilities attend the course?
What levels of disability do they have?
How are they chosen?

5. What was/is the parents' reaction to the course?

Probes: How was this managed?
How much parental involvement was/is there?
What are your views on this?

6. What was/is the reaction of other members of staff to the course?

Probes: How was/is this managed?
What are your views on this?

7. What would you say were the main areas of difficulty with the course?

Probes: How can these be overcome?

8. What would you say was the most positive outcome of the course?

Probes: What do you describe as 'success'?

9. What is the general view of sexuality of people with learning disabilities in the A.T.C.?

Probes: What are your views?
Is sexuality ever regarded as a 'problem'?
How do you think it is perceived by the adults with learning disabilities?

Appendix 11
Interview Guide

People With Learning Disabilities (Group)

i. Initial Contact

Introduction
Names
Ages
Levels of disabilities

ii. Opportunities to make personal decisions

1. Do you always decide what you want to do?

If NO: Who Decides?
What do you feel about this? Satisfied/
dissatisfied.
Why?

2. Do you think you should always be able to decide what you want to do?

Probes: Why do you think this?

If NO: Who should help you to decide?
Why do you think this?

3. Do you sometimes feel you need help in deciding?

Probes: Counselling in personal matters/relationships/
sexuality

4. Do you ever feel you get more help than you need when trying to decide?

Probes: Why do you think this?
What do you feel about it?
Why do you feel this way?

iii. Living with a partner

5. What do you think about the idea of living with your boyfriend/girlfriend?

Probes: Do you think it matters whether you are married or
not?
Does it matter to you what other people say about
this?
Which people would matter most?

iv. Having children

6. What do you think of the idea of having a baby?

Probes: Whose choice would it be?
Do you think it matters whether you are married or not?
Who would look after it?
Would it be easy/hard work?
Do you think you would need some help?

v. Not having children

As you know, you can be close to your boyfriend or girlfriend. You can have sex with them but you have to use some form of contraception if you don't want to have a baby.

7. Do you think it is easy to get contraception?

Probes: Do you find it easy to get contraception?
Do you think it should be made easier to get contraception?
Do you think you would want to talk about it with someone else first?
How do you feel about asking for contraception?

Some people decide that they never want to have children, or that they don't want to have any more children. They can have an operation and they are sterilised.

8. Would you ever think about being sterilised?

Probes: When would you think about it?
What would make you decide to be sterilised?

If NO: Why not?
Why do you feel this way?

9. How would you feel if someone else made that decision for you? (i.e. decided that you were never to have any children).

Probes: Why would you feel this way?

Appendix 12
Interview Guide

People With Learning Disabilities (Individuals)

N.B. Confidentiality/anonymity/consent/use of tape recorder.

i. Initial Contact

Introduction

Name

Age

Address

Do you see your parents/family at all?

ii. Sterilisation

- 1. Sometimes when a man and a woman are having sex together they might think they would like to have a baby. What do you think of that?**

Probes: Does it matter whether they are married or not?
Does it matter what other people think or say about them having a baby?
Who would it matter to, do you think? (Parents/staff/friends/other)

- 2. But say they didn't want to have a baby at all, ever, and they thought it best that one of them was sterilised. What do you think of that?**

Probes: Do you think anyone else should have a say in their decision to be sterilised?
Why? Why not?
Who do you think should have a say? Why?
How would you feel if it was you who wanted to be sterilised?

- 3. If you did want someone else to advise you or help you, who would you choose?**

Probes: Parents/other relationships/staff/friends/other

- 4. Do you think other people should decide for you?**

Probes: If not, why not?

- 5. Do you think everyone should be able to decide for themselves?**

Probes: Are there any exceptions?
Who? Why do you think this?
Who would best help them?

- 6. Do you think there should be a law to say that someone**

else could decide for you?

7. If someone didn't want to be sterilised, but other people said they should be, do you think there should be a law to protect them from being sterilised?

iii. Personal Information

What you say to me today is private.

8. Would you like to tell me if you have been sterilised yourself?

Probes: If 'NO, have not been sterilised' - Would you consider it?

If 'YES, I would consider it' - What would make you think of being sterilised?

If other people wanted you to be sterilised, would you consider it? (Parents/staff/friends/other)

If 'No, I would not consider it' - Why not?

If other people wanted you to be sterilised, do you think you would? (Parents/staff/friends/other)

If 'Yes, have been sterilised' - Would you like to tell me why you were sterilised?

Why did you want this?

What made you think of it?

Was it easy to make that decision?

Did anyone help you to make the decision?

Do you think anyone should help you/or other people decide?

Who should help? (Parents/staff/friends/other)

How would you have felt if someone you know/someone you don't know had made that decision for you?

How would you have felt if someone had stopped you from being sterilised?

9. Who do you think should be involved in decisions about sterilisation?

Probes: Just you

You and your partner

Doctor

Parents/other relations

Staff/key worker

Friends

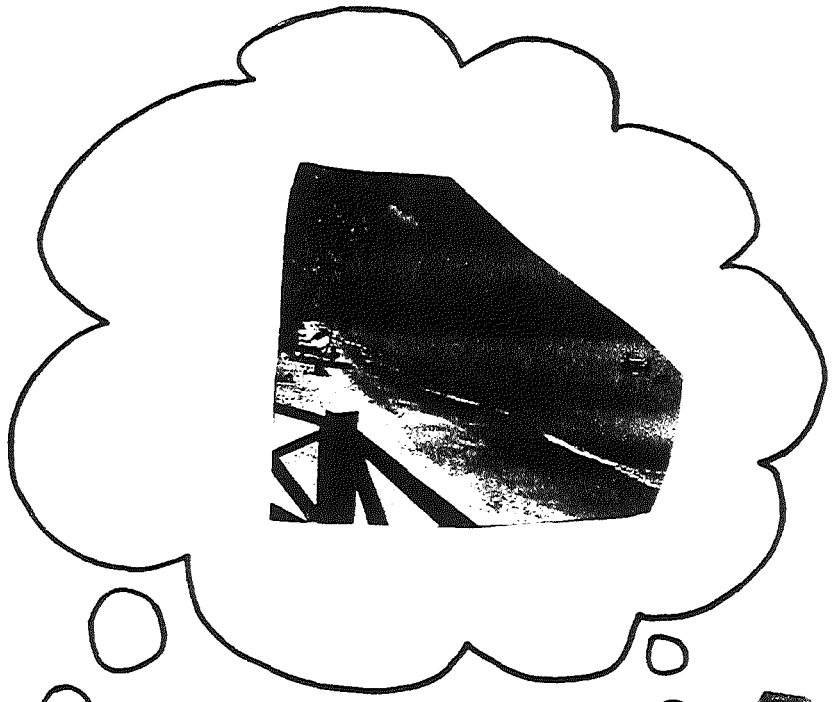
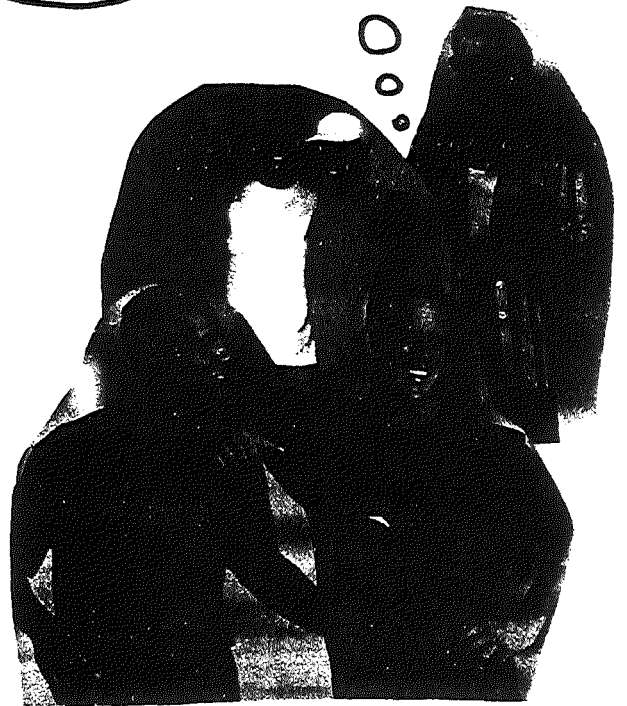
Law

Other

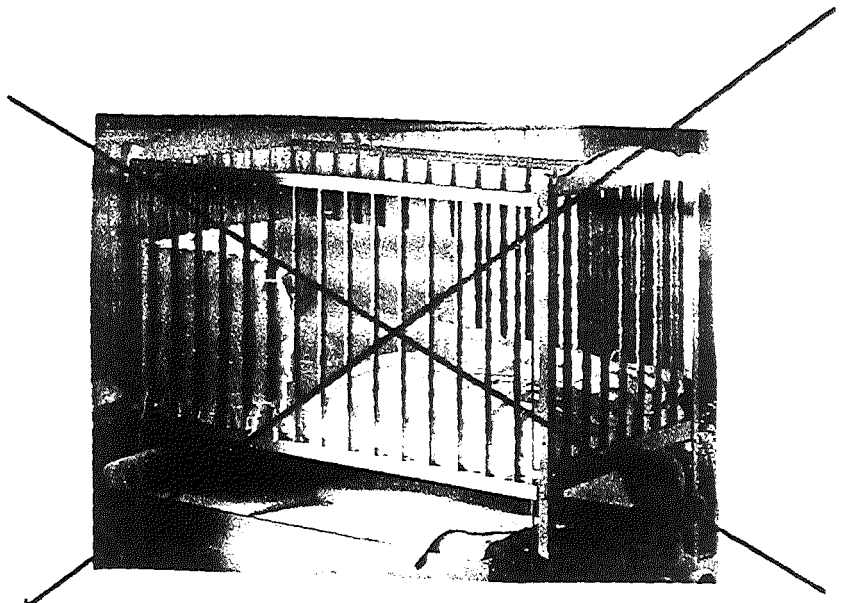
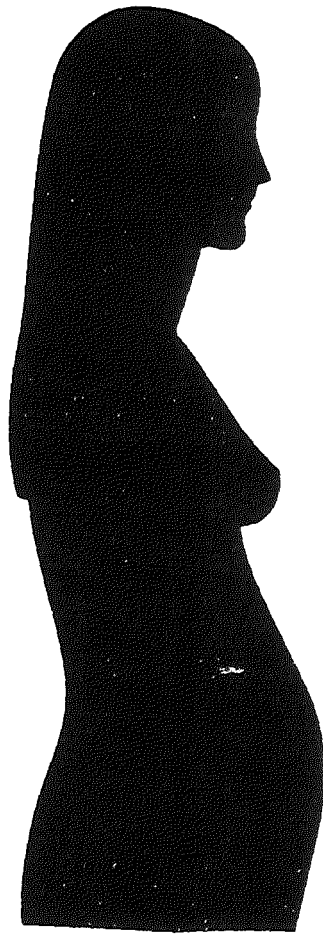
More than one of the above - indicate which ones.

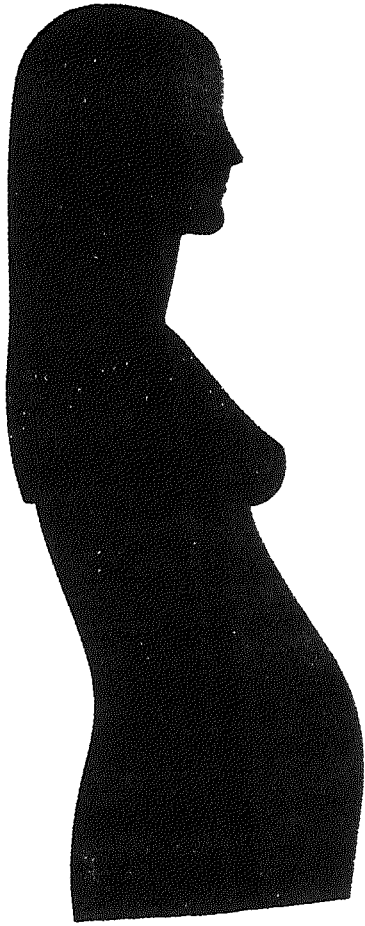
Appendix 13 Pictorial Vignette

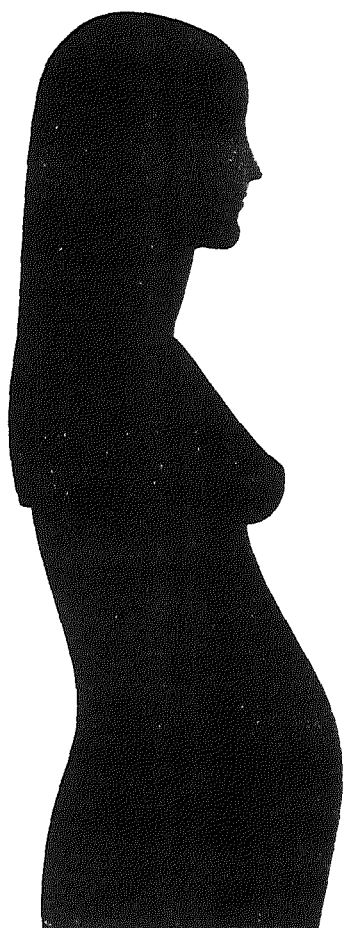












Appendix 14

Vignette

Situation 1

Jane and Paul are both 25 and have mild learning disabilities. They are very friendly with each other. At a dance they spend the whole evening together, dancing closely and kissing.

Situation 2

Jane now says that Paul is her steady boyfriend and they want to spend some time alone together. A holiday had been arranged for a small group of people with learning disabilities and a few members of staff. Jane and Paul will be going.

Situation 3

Jane and Paul now talk about being in love with each other and they want to get married.

Situation 4

Jane and Paul do not get married but Jane becomes pregnant. Early in the pregnancy she has a miscarriage.

Situation 5

Jane becomes pregnant again. It has been arranged for the baby to be taken into foster care after the birth.

Situation 6

Jane has a second child who is also taken into care.

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