The Ethics of Preimplantation Genetic Diagnosis

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Preface

I worked as a clinical embryologist for several years, during which time many new techniques, including preimplantation genetic diagnosis, were developed. The Human Fertilisation and Embryology Authority was also established and the new laws implemented.

I became interested in the ethical implications of these techniques and this thesis is an attempt to explain how people, both clinical staff and patients, justify their use of them.

Abstract

Preimplantation Genetic Diagnosis is a fairly new form of prenatal diagnosis, which screens for genetic disease at the embryonic stage. Its use is expanding as more knowledge is gained about genetic disorders and tests for the causative genes are developed.

I examine how its use can be justified and which disorders are suitable candidates. These disorders could be ones that would confer an intolerable life on anyone with them. Chapter 1 discusses what could be regarded as an intolerable life by considering health: what it is, how we measure it and how the courts have regarded it. Chapter 2 then considers what other genetic factors could be screened for, and whether these would be justifiable uses of the technique.

Chapter 3 discusses how disability is viewed in society, the problems faced by people with impairments, and how the disability movement has argued it should be viewed. In chapter 4, I examine the medicalisation of society, the eugenics movement and the medical view of disability.

Finally I discuss the status of the embryo and foetus with regard to human rights and how this affects the practice of Preimplantation Genetic Diagnosis.

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Introduction

Preimplantation Genetic Diagnosis (PGD) is a method of testing for the presence or absence of genetic disorders. It is a form of Prenatal diagnosis (PND) but, rather than testing after the pregnancy has begun as in chorionic villus sampling or amniocentesis, it tests embryos before implantation. It is performed after In-Vitro Fertilisation (IVF) once the embryos have reached the 8 cell stage. A single cell is removed from the embryo and this is then tested for the presence or absence of a specific gene, or in the case of X-linked diseases, for the sex of that embryo.

By assessing what type of disorders could be suitable for PGD, I will try to provide a justification for its use of the sort that professionals in the field would find acceptable, and what sort of justification this may be.

I will begin by considering that justification to be one of stopping those who would have an intolerable life from being born and consider what constitutes such an intolerable life. I will then examine the fears that allowing PGD in these instances will lead on to testing for genetic traits or sex selection, moving on to more general societal worries which I have categorised as the sanitisation and medicalisation of society. Lastly I will consider PGD with regard to the sanctity of life principle.

I hope to show that PGD is an acceptable technique for the prevention of genetic disorders, but only those which confer an intolerable level of suffering on any affected individual. I also hope to provide, through consideration of what constitutes an intolerable life, a basis for decisions as to which disorders would fit into this category,

and suggest that the use of such a basis would prevent the technique being used for social reasons.

The nature of PGD

PGD is a technique for identifying a specific genetic disorder by using molecular biological techniques such as Polymerase Chain Reaction (PCR) or chromosomal analysis such as fluorescence techniques (FISH) or in the case of X-linked disorders, using FISH to identify the sex of the embryos.

IVF is the first step, with eggs harvested after superovulation and mixed with sperm from the partner. 48 hours later, when the fertilised eggs have reached the 8 cell stage, 1 or 2 cells are removed. This procedure requires a high level of skill to remove a single cell without damaging the embryo, and also requires that the embryos themselves are of good quality.

These cells are then individually tested using the techniques mentioned and the given gene identified as absent or present, or the sex of the embryo determined. The embryos that are free from the affected gene are then replaced as they would be after routine IVF, and those that carry it are discarded. In the case of X-linked disorders, the embryos are sexed and only female (XX) embryos cleared for replacement - thus all male (XY) embryos, whether they are affected or not, are discarded.

The genetic tests require high levels of technical expertise as the amount of biological material is very small, and they must also be highly accurate to ensure that no affected embryos are replaced. The whole procedure must be carried out within a very limited time scale as the embryos need to be biopsied, tested and replaced within 24 hours.

Most of the patients for PGD have come through the genetic counselling service, and have been alerted to their condition by having an affected child, having repeated terminations after pre-natal screening, recurrent miscarriage or another family member affected by the disorder. Thus all of them have experience of the disorder at first hand and face the option of not having children, risking to nature and possibly having another affected child or repeatedly going through PND and terminating affected pregnancies.

Chapter 1

1.1 PGD: a justification of its use

There are two scientific factors in deciding that a disorder is a suitable candidate for PGD: the aetiology and pathology of the disorder itself, and the technical aspects. In other words is the causative gene identifiable and, more importantly, is a reliable test for it available?

The technical aspects I don't intend to go into in depth - as I have said the technique requires skilled embryological staff to carry out the biopsy and the genetic tests must be efficacious. These are requirements of the licensing body in the UK, the Human Fertilisation and Embryology Authority (HFEA), and necessary for obtaining a licence to practice PGD.

The aetiological and pathological aspects concern the disease process of the disorder. If these would confer an intolerable life on someone affected by that disorder, then it would be a suitable candidate for PGD.

If the justification of PGD, and PND a whole, is to prevent the birth of those who would have an intolerable life such as it would be better that they were not born, then one must have some idea of what constitutes an intolerable life.

By looking at various ways of defining health (1.2), welfare interests (1.2.3), relevant legal decisions (1.3), and methods of health measurement (1.4), I will consider how these help identify factors which constitute an intolerable life.

1.2 Health & Welfare Interests

The concept of health can be regarded in a number of varying ways, the discussion of which can be divided into 2 main

sections - a narrow, negative 'absence of disease' view and a wider, positive view of overall health and well-being. The negative, narrow view is described by various models, discussed below. The broader state of well-being which some would equate with that of good health is not an entirely clear concept in that health in its narrow sense and well-being, as I shall discuss later, do not always go together. One often describes someone as in good 'health' when describing this broad, positive view, and so the terms appear interchangeable. Thus there can be considered to be a state of overall 'health' which is a combination of good health as defined in the narrow sense and a positive sense of well-being.

I will discuss the broad view of health, embodied in the WHO definition of health, 'health is a state of complete physical, mental and social well-being and not merely the absence of disease'[1] later in the chapter, and then consider it in relation to basic 'welfare interests'.

1.2.1 Models of health

In terms of the narrower descriptions of health, I will consider 4 models of health, all of which depend on the absence or presence of some state. They describe health as:

1. Absence of disease or illness.
2. A normal state.
3. A stable state.
4. Freedom from pain or suffering.

Firstly, health can be described as absence of disease or illness, such that anyone who is free from a definable disease or illness

will be adjudged healthy. But there are instances where the presence or absence of illness does not imply a 'healthy' state, such as a mild skin disorder or Rubella which has been diagnosed but remains symptomless. In the terms of this model, sufferers from these diseases would be unhealthy but in other views, including their own, they may be seen to be 'healthy.' Alternatively, someone may feel themselves to be in poor health but have no definable or diagnosable disease. This view of health is dependent on the definition of disease or illness which it has been argued is 'a value judgement, relatively unproblematic in cases where it is widely shared, but more contentious when people disagree about it.'[2] Sickness becomes a role negotiated with society, and 'this will depend on societal attitudes as to what constitutes a reasonable human life'[3] e.g. obtaining sick leave from work is negotiated between oneself and your doctor.

Secondly, ill-health could be considered as an abnormal state, where physiological and/or psychological functions are not operating as they should. This gives a mechanistic view of health so that, just as one takes a car to a garage to be repaired if it is not working properly, any abnormal functioning of the body means a visit to the medical workshop for repair. This view is based on 2 assumptions - that there is such a thing as a 'normal' state to which one can be returned, and that loss of function is an unhealthy state.

The notion of 'normality' is not the same for all however - many people do not have perfect eyesight and use corrective measures to compensate, such as glasses or contact lenses, but they are not generally considered to be unhealthy. Some people can throw a ball accurately, or hit it with a racquet - a level of 'normal' hand eye co-ordination but those that can't are not unhealthy, just poor sportsmen.

In this model, disabilities are abnormal states - someone who is blind cannot be said to have all their physiological functions working normally. Many blind people however would not consider themselves to be in ill health. The idea of normal functioning must be linked to those functions which are required to lead a 'normal' life within a given society - what purpose does the function have in our life, how important that purpose is, and whether lack of it can be compensated for in such a way that a 'normal' life can be lived without it. Someone who is blind can, with assistance, utilise their environment, live independently and be generally in good health. In the strict sense of this model they are in an abnormal state but to them that is their usual, and in that sense their normal, state in that it does not prevent normal everyday life.

Thirdly, perhaps if we consider health to be a stable state, this may give a more complete picture. No matter what the physiological and/or psychological state, if it is stable then that constitutes health for that individual. Illness is then regarded as an unstable state requiring treatment to regain stability.

If someone has no use of their legs, they could be considered in a stable state unless they suffered from an additional illness or disease which would require treatment to return them to their original state. They may be in a wheelchair and require assistance in day to day living but that for them is their normal, stable state.

In this model however there is a possibility that one could be in a stable state of poor health, perhaps with a chronic heart problem which makes someone housebound or unable to climb stairs. This could be a stable state, unchanging for years, yet one would not consider them to be in glowing health.

The final model of health is that of freedom from pain or suffering, both of which may prevent someone from doing what they want or need to do in their lives. In this case, medicine would be hoped to be able to control the pain, find the cause or make it bearable to an extent that the person could get on with their lives. But an acceptable level of pain is a very individual thing, and someone with chronic pain may be able to bear it and continue their lives normally. A better model might then be freedom from unbearable pain or untreatable pain such that it interferes with normal living.

1.2.2 Positive health

These models of health concentrate narrowly on negative aspects of health, whereas if we return to the WHO definition this implies an additional sense of overall well-being, a more positive concept. This idea of health and well-being as an ideal to be sought after was promoted by the ancient Greeks. The Alexandrian physician Herophilos summed this view up, saying, 'when health is absent, wisdom cannot reveal itself, art cannot become manifest, strength cannot fight, wealth becomes useless and intelligence cannot be applied.'[4] If we consider that he is talking about health in its negative sense, then he sees this as a necessary requirement for the greater concept of a 'good' life. This supports the idea of overall health as a positive summation of all aspects of life, with negative health as a component.

This view covers not just the physical dimension of health, but the mental and social components too. Mental and physical well-being may be dependent on absence of disease or illness but the whole well-being of an individual is greatly reliant on many other social and

environmental factors. To attain overall health all these factors must come together.

The social aspect of health are concerned with one's relationships, the environment in which one lives and works, the ease with which one can access and use that environment and the financial ability to maintain oneself, one's environment and utilise it.

To do so, one requires the ability to have control over these factors, an ability which 'arises from and reflects a process of empowerment.'[5] People need to be enabled to make the most of their environment and life in order to attain good health and well-being. The environmental and social aspects of health can be seen as health 'determinants'[6] leading to, or responsible for poor health - physically and mentally through poor housing conditions, inadequate finances and a feeling of lack of control over events. These are societal problems which can lead to medical ones which constitute poor health. Medical problems can also lead to social problems which may further compound a state of poor health. If one has a disease or disability considered unacceptable or incompatible with employment, then one will not have the means to improve one's social environment.

In a different expression of the idea of empowerment leading to good health, Aaron Antonovsky[7] has proposed health as dependent on what he terms a 'sense of coherence' theory. This involves the ability to comprehend information or problems in life in an ordered way, having the resources available to meet the demands of this information, and a meaningfulness in life which gives one a sense that some of the demands made on us are worth putting energy into. Thus he says that if someone has a good sense of coherence, or a good ability to sort problems in life and deal with them, this will in turn lead to a state of

good overall health. He sees this coping ability as a prerequisite for overall health, equatable with a sense of well-being or satisfaction with life.

As I mentioned in the introductory paragraph of this chapter, the state of well-being does not always correlate with one's health status. Poor health will not always equate to poor well-being - someone with terminal cancer may be entirely at peace with themselves, their family and their situation, perhaps describable as a state of well-being, but one would not say they were in the best of health. Similarly if someone is confined to a wheelchair, unable to walk and requiring assistance with their day to day life, they would not be considered to be in good health by some. If they have good support from their community, appropriate assistance and an accessible environment, in other words enabled to live to the fullness of their capabilities, then they may be in a state of well-being.

This view of overall health has negatively defined health as a component, but also depends on well-being, social and environmental factors all combining at their optimum levels.

1.2.3 Welfare Interests

To consider another view of well-being which involves many of the models of health discussed earlier, Feinberg has stated that there are basic welfare interests,[8] the harming of which constitutes the greatest wrong. He regards these as interests 'whose satisfaction is known to be indispensable to a decent life.'[9] He lists them as:

1. Continuance for a foreseeable interval of one's life

2. One's own physical health and vigour
3. Integrity & normal functioning of one's body
4. Absence of absorbing pain and suffering or grotesque disfigurement
5. Minimal intellectual acuity
6. Emotional stability
7. Absence of groundless anxieties and resentments
8. Capacity to engage normally in social intercourse and to enjoy and maintain friendships.
9. Minimal income and financial security
10. Tolerable social and physical environment
11. Certain amount of freedom from interference and coercion.

We can consider these in conjunction with the WHO definition of health, 'health is a state of complete physical, mental and social well-being and not merely the absence of disease.'[10] Fitting the list of basic welfare interests in with this statement, the first 4 are concerned with physical well-being, number 5 - 8 mental well-being, and the last 3 to do with social health.

Firstly, continuance of life for a foreseeable interval - the ability to know that one's life will continue so that you can plan for the future and try to direct it in such a way that will enable you to reach your potential. For children, they have plans made for them, are educated, kept warm and fed by their parents in the knowledge that this will give them a basis from which to carry on their own lives and have options available to them. If you were born knowing that your life

would only be 4 years long, this long term planning would be denied, if not to oneself, then to one's parents.

But it is often said that one doesn't know what lies ahead - the well known statement that 'you could be hit by a bus tomorrow' encapsulates this. So we continually make plans and work towards a future which is by no means a certainty, and of which we really know very little. If one is born with only a remote chance of reaching adulthood, then there is still an amount of life to live and plan for, the denial of which may be of greater harm to one's interests than not having an unlimited future. It may in fact be of greater harm to the parents as they will be aware of the facts from an early stage, know that a limitless future is not possible, and this will undoubtedly alter their perceptions of the child. It may be argued that as there is a limited future, why invest time and money into it. Certainly when an individual is born in such circumstances, and for their early years, they will be entirely unaware of their limited future and so it is debatable whether they are harmed by the fact.

One's own physical health and vigour, the next welfare interest, could be taken as a statement of the ancient view of health or overall well-being. Can this ever be achievable as an aim? One can be in good health, free from any identifiable illness or disease but this added notion of well-being is dependent on many other external factors. As good health or poor health is a value judgement, one could be said to be only as healthy as the person assessing you thinks you are. It would be very difficult to assess the ability to attain an ideal of well-being at birth - there are plenty of healthy babies who go on to have no notion of health later in life. An assessment of the potential for health and well-being may be possible but the complete view of overall health involves so many extraneous factors that attainment of health is

difficult to predict. There may be circumstances where it may appear obvious that no level of acceptable health is possible and this may be viewed as a harming of one's interests, but as always this is a judgement based on the judge's view of health.

Integrity and functioning of one's body leads to the mechanistic view of health, where good health stems from intact physiological and psychological functioning. As stated earlier, this view is based on an assumption of normal functioning, the purpose of the function and whether it is necessary for everyday life. Certainly an anencephalic baby would be considered abnormal as it has no functioning brain and to keep it alive would be considered harming its interests. But if one considers a baby born with Cystic Fibrosis where their respiratory system will not function normally without daily treatment - admittedly not pleasant but is it a harming of their interests? With adequate treatment there are many people with Cystic Fibrosis who have a productive and normal life.

The fourth welfare interest to consider is that of absence of pain and suffering or grotesque disfigurement - this can be dependent on the ability of medicine to treat and alleviate the pain or correct any disfigurement, and the amount of interference with normal living that they cause. In terms of disfigurement, there is a judgement as to acceptability. A baby born with a cleft palate, which can be a major disfigurement and affect development through feeding problems, will be considered acceptable and treatable, even though there may still be a degree of disfigurement after treatment. Many children born after their mothers took thalidomide during pregnancy are certainly disfigured but many would argue that they have been able to lead productive and useful lives - a measure of good well-being. With regard to pain, there may be certain conditions which entail some amount of pain and

suffering, and what may be acceptable or bearable for one individual may not be so for others. The knowledge of certain pain in childbirth has certainly not stopped people from reproducing. Some regard childbirth as acceptable only without any form of pain relief, others only with total relief. Thus there should be caution in assessing what is an acceptable or bearable level of pain or suffering for any given individual.

The mental aspects of health, covered by the next 4 welfare interests are possibly even more difficult to evaluate.

The possession of minimal intellectual acuity is considered to be a requirement for a decent life. An anencephalic baby with no functioning brain will never be able to have intellectual acuity of any kind, but a baby with Down's syndrome will develop some level of intellectual ability. In some cases there will be a need for total care throughout life, but in others, given appropriate assistance and education, a contented and self-sufficient life may be attainable.

On a higher level of intellectual ability, there can be variation in what is regarded as normal within families. Thus where expectation is low, having enough intellectual capacity to obtain and keep a job will be considered an acceptable norm, but in other families, university education will be normal. These are certainly not comparable with anencephaly or Down's syndrome but do show the wide range of what is considered normal intellectual ability.

Emotional stability is an exceptionally arbitrary quality to assess or measure, and even more so when considering the potential children. A minimal intellectual ability is arguably a prerequisite for being able to consider one's emotional state. But to return to children with Down's syndrome many are contented, either through lack of

awareness of their situation or their innocence regarding future problems, and thus in a stable emotional state. One's environment and circumstances are also implicated in emotional stability, and in the case of PGD and PND, the prospective parents. As social services have found in many cases, to their and their clients cost, the emotional stability of parents is difficult to assess or predict. Several IVF programmes in the UK have included being in a long-term stable relationship as part of their requirements for acceptance for treatment. They have found however, not surprisingly, that this is almost impossible to quantify and given the high numbers of people who divorce following IVF treatment, perhaps impossible to judge.

The next 2 welfare interests - absence of groundless anxieties and resentments and a capacity to engage normally in social intercourse may be regarded as capacities of anyone with minimal intellectual acuity. When looked at from the viewpoint of potential children as in PGD and PND, both will be very difficult to predict. To take 2 examples - Down's syndrome children may be contented and happy in a well supported environment, free from anxieties and often with a great ability to enjoy friendships although not all their behaviour may be seen as acceptable to all.

Autistic children, on the other hand, may develop many anxieties about themselves and their environment. In general they will have various difficulties in engaging normally social intercourse and in many cases, even with extensive help and special education, those affected will never be able to do so.

Any potential child has to be assessed for social abilities bearing in mind the possibilities through education and assistance, and the inability to predict other problems which may appear at later stages.

The 3 welfare interests which remain will be considered in relation to the social model of disability in chapter 3.

By considering overall health as a combination of physical, social and mental factors, it can be difficult to assess in the living, and even more so in potential people as is required in PND and PGD.

In assessing disorders suitable for 'treatment' through PND and PGD, one has to use clinical expertise and experience of those born with given disorders, but given the wide variation of clinical symptoms within any disorder, a consensus may be hard to reach. Doctors may be influenced by their ability to treat a disorder, if they cannot then they will be more inclined to think of it as unacceptable or intolerable.

The experience of families coming for PGD especially will also be useful in that they will usually have first hand knowledge of the disorder affecting them. This experience may however have been of a particularly harrowing nature or very mild.

All assessment of health and well-being is a judgement based on values - what is considered 'good' or 'normal' to the assessor. These values will reflect their own experiences and those of society as a whole.

There are certain conditions which could be regarded as unacceptable by all, where the life would be 'intolerable'. Lesch-nyman syndrome for example where life is shortened, with no capacity for self-help and little treatment that can alleviate symptoms. The majority would take this to be an intolerable form of life. There are a whole category of other disorders, however, which to some people would be acceptable.

The list of welfare interests is useful as a basic checklist of the components of what is considered an acceptable, 'decent' life but any

assessment of health and well-being, especially when it is that of a potential life, must be viewed not as a scientific, clear cut decision, but rather one laden with the values and attitudes of doctors, parents and society.

Overall health is thus a series of value judgements, being made up of the narrow, model based health as an absence of disease or abnormality, social, mental and environmental factors and a sense of well-being. It is certainly a confusing term as seen by the various examples above, and the fact that we use the word health in so many different ways in everyday speech. Regarded as this overall concept it becomes evident how difficult it is to say what another person's health status is, and even more difficult to predict what it will be in the future.

In terms of the models of health, these involve judgements on what is a disease and what is a normal, stable state. When these judgements are combined with all the other factors, including well-being and good coping mechanisms, it is evident that overall health is not just an elusive concept but actually very hard to attain in life. Viewed from this way, health for an able-bodied person is just as difficult as it is for those with disabilities so we should be careful in our judgement of an intolerable life - someone who has no disabilities but lives in poor housing, with poor social support and no sense of control over their life may be in a far worse state of health than someone with Down's syndrome who lives in a supportive environment, had appropriate education and is thus enabled to live their lives to the best of their ability.

1.3 Legal criteria

Legally there have been several cases where the idea of an 'intolerable' life has been pertinent. These cases have displayed that there are certain basic qualities that the law considers to be essential factors in being alive and human. In reJ [11], where a child was born prematurely and suffering from severe and permanent brain damage, it was decided that medical treatment was not to be continued because of the child's quality of life. They stated that 'there must be extreme cases in which the court is entitled to say: "The life which this treatment would prolong would be so cruel as to be intolerable"' and went on to consider 'At what point in the scale of suffering and disability ought the court to hold that the best interests of the child do not require ..... treatment to prolong its life.'

In an opposite decision, the case of reB [12], where the child was born with Down's syndrome and required surgery, they ordered the operation because the child's existence was going to be acceptable. They put it as 'there is no evidence that this child's short life is likely to be an intolerable one. There is no evidence at all as to the quality of life which the child may expect.' So in terms of children already born the courts have said that the tolerability and prediction of tolerability of the life has a major part to play in their decisions. This does not just have to do with pain and suffering either, as was stated categorically in the case of Airedale NHS Trust v Bland[13] in which a young man was left in a persistent vegetative state (PVS) after the Hillsborough disaster and the courts were asked to consider whether treatment should be continued. On deciding that treatment should not be continued, they said 'To limit the quality of life to extreme pain is to take a demeaning view of a human being.' [14]

Cases of 'wrongful life' and 'wrongful birth' are even more controversial and more relevant to PND and PGD. In both instances, damages are sought for the birth of an unwanted and/or harmed child. The case of 'wrongful life' is one that is brought by the child himself, and these have not been considered favourably by the law either here or in the US. Their reason for this is that it would require the child to say that its life is so unfavourable that it would have been better not to have been born as non-existence is their only alternative.

In the UK the only case of this type was McKay v Essex[15] where a child was born handicapped following his mother's infection with Rubella during her pregnancy. The court found no negligence as the guilty party was the rubella virus. They said that for the case to succeed, it would be on the 'basis of a right not to be born deformed or disabled, which in the case of a child deformed or disabled before birth by nature or disease meant a right to be aborted.'[16] They accorded the foetus no such right, and also held that the doctor had no legal obligation to terminate a pregnancy. In conclusion they said, 'such a claim for wrongful life would be contrary to public policy as a violation of the sanctity of human life.'[17]

This judgement was in line with, and owed a great deal to, the case of Gleitman v Cosgrove[18] in the US. This also involved a Rubella infection during pregnancy which caused handicap. They ruled that 'they cannot weigh the value of life with impairments against the non-existence of life itself.'[19] and stated that 'A child must not be perfect to have a worthwhile life.'[20] In a forerunner of the comments in McKay, they felt there were 'substantial policy reasons' for not 'allowing tort damages for the denial of an opportunity to take an embryonic life.'[21]

The Law Commission in 1974, after Gleitman v Cosgrove but before McKay, felt that 'such a course of action [wrongful life cases], if it existed, would place an intolerable burden on medical advisors in their socially and morally exacting role. The danger that Doctors would be under subconscious pressure to advise abortions in doubtful cases through fear of an action of damages is, we think, a real one.' [22]

Thus the action brought by the harmed child, unless applicable under the Congenital Disabilities Act[23], is one that is not likely to succeed. The policy that they appear afraid of creating, however, would appear to be consistent with the policy apparently created by PND and PGD today.

In the action of 'wrongful birth', the case is brought by the parents of an unwanted and/or harmed child. These have consisted of failed sterilisation cases where the child has been born healthy or impaired and the failure to warn of disability and advise of a risk in time for abortion to be an option.

The failed sterilisation cases have varied in their outcomes and date from Christensen v Thornby[24] in the US in 1934. In this case the court felt that the birth of a healthy child was a blessing which conferred benefit and this was to be balanced against the perceived harm of an unwanted child. In this instance they decided that the operation was unconnected to the birth of the child and ruled against damages. This view of the child as a benefit has been a common theme throughout these cases, but as was pointed out in the Thake v Maurice case, 'every baby has a belly to be filled and a body to be clothed'[25]. Consequently the courts have usually awarded costs for the birth, loss of earnings and upkeep of the child as in Thake v Maurice. In a more recent case of this kind however, McFarlane v Tayside Health Board[26] ,

which went to the House of Lords, they decided on an economic law that the NHS was not liable for the cost of rearing a child, only for the pregnancy and birth. The court did not see an economic duty on a hard pressed NHS to pay for the upbringing of a healthy child.

Subsequently, in the case of Parkinson v St James & Seacroft University Hospital NHS trust [27] the court awarded damages for the extra cost of bringing up a disabled child. In this case the sterilisation had been performed negligently and although the mother had been warned during the pregnancy that the child might be born with a disability, she decided not to terminate. The child was born with severe communication and behavioural difficulties. The court did not allow basic maintenance costs to the mother but specifically awarded costs for the additional expense associated with rearing a child with disabilities.

In the case of a child born damaged or handicapped, which doesn't come under the remit of the Congenital Disability Act, costs have been awarded for the pregnancy, birth and upkeep of the child. In McLelland v Greater Glasgow Health Board[28], they went further and awarded damages to the father for the shock of having a child with Down's syndrome. In this case, there was a failure to offer an amniocentesis in the light of a family history of Down's. In this case too, the health board admitted liability.

In Salih v Enfield Health Authority[29] the parents defence was that they wanted a child but the cost of bringing up a handicapped child was not something that they wanted.

These cases are based on the assumption that if the parents had known of the risk of disability, they would have aborted the pregnancy. This brings us back to the case of McKay, where the court

did not want to encourage a public policy of favouring abortion over birth. I will discuss this later with reference to the aims of the medical genetics service in the UK.

The Congenital Disabilities Act states that there is a duty not to harm the foetus through surgery during pregnancy or negligence which affects either parent's ability to have unaffected children.

The question of compensation for having a disabled child where there is no negligence except a natural or genetic causative agent is still an awkward case for the courts. On the one hand they are saying they don't want to encourage a policy of abortion over birth, but on the other they seem willing to compensate for not providing an opportunity to do so. It appears that the woman's right to choice and a greater acceptance of abortion is swaying this policy toward PND and abortion. In addition, after the Parkinson case they seem to acknowledge the extra cost of bringing up a child with a disability and view it as something that should be compensated for.

Mason and McCall Smith have said that 'The disabled should be helped and if possible compensated for their suffering but the moral basis of such compensation should be the desire to make their lives more comfortable and bearable - not the notion that they shouldn't exist' [30]

Although the 'wrongful life' cases have been discouraged on the grounds of encouraging abortion, by awarding damages for having a disabled child the courts are reinforcing the view that this is a thing to be avoided and by awarding damages for the extra cost of rearing a disabled child appear to acknowledge that the state provision is inadequate. In many cases the causal agent has been nature but by not providing an opportunity to find this out in time to terminate the

pregnancy, the courts have deemed the doctors' actions as negligent. This would appear to contradict the statement in McKay v Essex[31] where they said that such a case would only succeed on the 'basis of a right not to be born deformed or disabled'[32] The recent judgements promote and encourage the fact that PND, and possibly PGD in the future, are requirements of a pregnancy. Doctors will be inclined to do all they can to avoid expensive lawsuits - a danger which the Law Commission [33] warned of in 1974 - and it also encourages the public to see the birth of a disabled child as an act of negligence not one of natural misfortune.

So the law acknowledges that there is such a thing as an 'intolerable' life and has ruled on withdrawing or withholding treatment accordingly. In the 'wrongful birth' cases, they have demonstrated their support for PND, and by extension PGD, by awarding damages for children born with a disability after screening tests were not offered or negligently performed. By so doing, they further the cause of PND and force doctors to include these tests routinely if they wish to avoid costly lawsuits. In the recent case of Parkinson v St James & Seacroft University Hospital NHS trust [34] the courts, by awarding costs for the upbringing of a child with disabilities after a failed sterilisation which had not happened in the case of McFarlane v Lords[35] where a normal child was born after failed sterilisation, they deemed this a compensatable fact.

Through both of these decisions, encouraging screening and abortion of disabled foetuses through PND by deeming doctors negligent for not offering suitable tests, and by seeing the birth of a disabled child as an extra cost to be compensated for, the law is sending a strong message to medicine and the public that the birth of a disabled

child is something to be avoided and if not, compensated for, regarding natural misfortune as negligence.

1.4 Health Measurements

As discussed in 1.2.1, what is considered to be 'health' involves a combination of models and value judgements. It follows that it lacks uniformity and consistency and is therefore not a quantifiable concept. But that has not prevented many attempts to do so. It is easy to understand these attempts, for there are a multitude of clinical and economic reasons for wanting to measure health: to gauge the health of a population so that health policies can be formulated; to assess the success or failure of a given treatment; to optimise use of resources, among others.

The cost implications are one of the major driving forces behind health measurement. In Western countries especially, the cost of health care is expanding greatly as the population ages and treatment becomes ever more sophisticated and employs ever more expensive drugs and equipment. If we had a quantifiable scale we could have a means by which to ensure that health care use and distribution are maximised to provide the most benefit to the greatest number of people.

There is also a realisation that not only can countries not afford to provide all health care to all its citizens, but that all medical treatment for everyone may not be appropriate. In the face of growing public expectations of medicine, policy makers, health economists and doctors need to come up with justifiable reasons for not providing everything for everyone and data to support these decisions. It has been said however 'about the only point which commands almost universal agreement is that there are several different ways of measuring health states.'[36]

Health measurement is a wide ranging term covering many forms of scales, indicators and indices. They vary on who does the measuring, whether by professionals or self-report, what population is being measured, whether healthy or with a specific disease, and what is being measured. They can be looking at one specific aspect of health or disease or trying to assess the broader picture of overall health and well-being.

The important factors in judging a measurement scale are its validity, reliability, and ease of use.

Validity asks:

1. Is it covering all aspects of the attribute that you want to measure?
2. Does it really measure that attribute?
3. Can the attribute actually be measured accurately?

Reliability concerns its repeatability:

1. Between different scales.
2. Between different test subjects.
3. Its sensitivity to change.

The ease of use asks whether it is of an acceptable length, such that people will happily complete it, that it can be administered easily and that it is easily understood by the respondent and the investigator.

Types of measurement vary from simple biochemical tests, survival rates after treatment, through functional assessments, specific disease outcome tests, to general health scales and utility ratings which combine all data into one figure.

Initially assessments of health were crude indicators of morbidity and mortality which can be useful but give an incomplete picture and concentrate on the negative aspects of health without regard to well-being.

Biophysical markers such as blood counts can be used to assess health, but these concentrate on the narrow model of health, looking for normal functioning or absence of disease.

Functional tests have been widely used to assess levels or type of care needed, progress of a disease, progress of rehabilitation, ability to drive, award of benefits and so on. These concentrate on the ability or otherwise to perform certain functions considered to be necessary for normal life.

They can range from routine eye tests to assess sight, an important requirement for driving, assessment of suitability for work, or eligibility for state benefit, to measurement to gauge improvement through rehabilitation after injury or illness.

There are limitations to these tests, however, as the site of testing may be entirely different from the home environment. Aids that are available in hospital may not be available where the person lives and has to perform these functions daily. There may also be greater motivation and support within a hospital environment to try and do things which may be lacking at home. Ann Bowling says that they 'narrowly focus on a range of mobility, domestic and self-care tests, often....ignoring emotional and social needs which may be equally or more important.'[37]

So functional tests may give an idea of the capabilities of someone but give little information about the additional components of overall 'health'.

Specific disease scales can be useful when looking at a defined population. Clinical guidelines are an example of such a scale, which attempt to standardise treatments and their allocation across the country, thus ensuring fair distribution of health care.

The Royal College of Paediatrics guidelines on withholding and withdrawing treatment from neonates deal with instances which are considered examples of what constitutes an 'intolerable' life - if any disorder would cause an infant to be in one of these positions, and thus eligible for treatment to be stopped or withdrawn, then it might be appropriate to prevent the birth of that child using PGD or PND.

This is acceptable if the child is

1. Brain dead
2. In a permanent vegetative state
3. In a 'no-chance' situation, where the disease is so severe that life sustaining treatment simply delays death without alleviation of suffering
4. 'no-purpose' situation, where although patient may survive treatment, the degree of mental or physical impairment will be so great as to be unreasonable to expect them to bear it
5. unbearable situation, where in the face of progressive and irreversible illness, further treatment is more than can be borne. This is irrespective of medical opinion on its potential benefit.

Although these are defined guidelines, they are still open to discussion and medical opinion. Few would argue with being brain dead, there has been argument about PVS as seen in the various medical opinions offered in Tony Bland's case, but the other categories are assessments based on medical opinion and will vary from case to

case. As the patient cannot be consulted in the case of a neonate, it will be the decision of the doctors in consultation with the parents.

If there is dissent or uncertainty, the agreed way forward is to act in the child's best interests, again an assessment, not an objective stand. Extreme cases can be found which illustrate the problems of conflicting viewpoints. In the States, an anencephalic child, Baby K[38] was kept alive for many years, despite the fact that hospital physicians regarded the treatment as inappropriate, at the insistence of the mother - certainly not in the child's best interests and at huge cost to the state. On the opposite view, a couple, the Stintsons[39], were told before birth that their son was brain damaged, and he was born prematurely at 24 weeks. They requested no aggressive treatment but were overruled by medical staff and the baby underwent months of treatment until he died aged 6 months. They felt that they and their baby went through a pointless and harrowing experience because in their case medical opinion took precedence.

So although guidelines are useful, indeed necessary, they can only be guidelines and are susceptible to pressure from involved parties. But if strictly adhered to with regard to potential children, possibly a less emotive issue than an existing neonate, it might be possible to adjudge that any disorder which would cause a child to be in any of these categories for non-treatment would be a suitable candidate for PGD or PND. This would appear to be a good scientific measure but yet again it involves wide variation in manifestations of disorders, parental experience and attitudes and clinical experience.

As these scales relied on a negative view of health, which ruled out the majority of the population who were not in ill-health, attempts were made to define scales which could encompass all aspects

of health and well-being - physical, mental and social, negative and positive. Some health measurements try to measure all these aspects and then collate the information into one figure using sophisticated mathematical models which may also assign different 'weights' to items.

General health scales were developed initially, which tried to include all these aspects.

The Sickness Impact Profile was developed in the USA for use as an 'outcome measure for health-care evaluation.'[40] In it, 'sickness is measured in relation to its impact on behaviour.'[41] It concentrates on behavioural responses to illness, without measuring the feelings of patients as the authors felt that they were 'less subject to bias than feelings.'[42] It has been widely tested for reliability and validity and is thus considered a good form of measurement, but it is lengthy and can only be used with 'people who are regarded or who regard themselves as ill.'[43]

In the UK the Nottingham Health profile has been developed and is based on lay perceptions of health. It 'relates to how people feel when they are experiencing various states of ill-health.'[44] It has been tested for reliability and validity and is short and easy to administer, but it doesn't cover all aspects of functioning, or mental health. It also concentrates on negative aspects of health and so cannot be considered to be a measurement of overall health or well-being.

The McMaster Health Index Questionnaire was developed 'as a measure of physical, social and emotional functioning.'[45] It focuses on present ability, is simple to administer and is 'positive in its orientation.'[46] Its only drawback is that is has not been adequately assessed for reliability and validity and is of dubious value for older populations.

A refinement of functional testing has been produced by the WHO this year, called the 'International classification of functioning, disability and health'[47] or ICIDH-2 and has over 100 pages of test categories. It is split into 2 main sections - measuring functioning and disability of body functions and structures and 'contextual'[48] factors in activities and participation. It is said to be a 'classification of people's health characteristics within the context of their individual life situations and environmental impacts.'[49]

It tries to cover aspects of health - social, physical and mental health but does not touch socio-economic factors. The intention is to provide a 'scientific basis for understanding and studying health states.'[50] However they also ask users to not 'assume homogeneity among individuals classed similarly'[51] which would be a requirement of a scientific class.

Although the WHO stress that the categories should be expressed 'in a neutral way to avoid deprecation, stigmatisation and inappropriate connotations'[52], it must be used to classify individuals - that is its aim - and will thus provide data for cut-off points for state benefit and possibly medical treatment.

It is also a very lengthy, if comprehensive, test and could therefore be difficult to administer. It may be hard to persuade someone to go through such an invasion of privacy if they see no benefit afterwards in their lives other than their data being used to further health research.

In all of these tests, which all try to measure general health, there are advantages and drawbacks. As demonstrated by ICIDH-2 any attempt to cover all aspects of health and well-being becomes very large and unwieldy and thus difficult to administer. In consequence shorter,

more comprehensive tests are more widely used but this can lead to an unbalanced view or measure of 'health'.

One of the main tests finding favour with policy makers and economists at present, is the Quality of Adjusted Life scale or the QALY. This is a utility scale which aims to quantify 'quality' of life as part of a measurement of health care benefit. The term was first used in 1977 in a paper by Weinstein and Stason[53] where they described it as a ratio of health care cost against effectiveness of health care in terms of life expectancy and quality.

The scale has been further developed and is now almost universally used. Now 1 QALY is equal to one year of current life in perfect health - thus one can describe medical treatment with respect to the number of QALYs it will produce. The concept of the QALY is now described as 'health, conceptualised as years of life weighted by the health-related quality of life experienced in these years.'[54]

The calculation of the QALYs from a given treatment is obtained by multiplying the number of years life would be prolonged by the treatment by the improvement in quality of life that it would produce. The additional years lived are predicted from assessment of previous outcomes and the quality of life is based on ratings of various health states on a numerical scale which have been obtained from the general public, people in those states of health and health professionals.

These assessments of quality of life in various health states will be subject to the assessor's concept of quality of life. As seen previously, this will vary according to their past experience, whether personal or clinical and be influenced by the attitudes of society. It has been argued that, as with 'health' discussed earlier, there is 'no clear and universally accepted concept of quality of life.'[55]

Thus, if the numerical values that are required to calculate a QALY are based on an immeasurable concept, it follows that the QALY itself is not a true measurement, or to put it another way 'if the data put into the equation are invalid, so will the result be.'[56]

One of the other problems with the QALY is that if you start with a poor health rating, then any additional treatment will combine with this in the calculation to give a poor QALY outcome. John Harris[57] refers to this as 'double jeopardy.' This means that if all disabled states are rated as being poor states of health then no additional treatment will give a good QALY outcome, essential to justify your treatment in economic terms. But, as described earlier (1.2), health status in not solely linked to physical health. Thus to rate someone in a wheelchair as having a poor state of health just because they cannot walk is to give a negative and inaccurate assessment of their overall 'health'.

Similarly for older patients, their QALY outcome will always be lower than that of younger patients because the young will always have more years to live. If someone has a hip replacement however, this will not necessarily lead to more years of life but will certainly lead to greater mobility and freedom from pain, both enhancing the person's life. This increase in health and well-being would surely be considered a good health care outcome but not necessarily give a good QALY outcome. The same problem arises with QALY rating of palliative care, which although not increasing the number of years can give relief from distress and may lead to a state of well-being as described earlier (p8).

John Harris and others have also argued that the use of the QALY may lead to discrimination. 'Many diseases are fairly specific to

economic classes, or regions of the country or races'[58] and problems will arise if 'such groups are vulnerable to conditions that are not QALY efficient.'[59]

Alan Williams, who has done much of the work developing the QALY in the UK, has said that 'it is the responsibility of everyone to discriminate wherever necessary to ensure that our limited resources go where they will do the most good.'[60] But as Michael Lockwood has argued 'what justice actually requires is that we do not discriminate between people on the basis of unjust criteria'[61] and he cites race and sex as 2 examples. It is not evident that the QALY does discriminate fairly or justly.

As many QALY outcomes have not been as wished or are 'counter-intuitive'[62], mathematical models have been developed to 'weight' various factors to give the outcomes desired. However, as discussed earlier, if the basic data is flawed no amount of mathematical fixing will solve the problem. 'The concept is fundamentally flawed because one cannot rate the quality of life of a health state on a numerical scale.'[63]

In addition, the QALY models, according to Ann Bowling, 'suffer from severe limitations'[64] in that they have not been adequately tested for validity and reliability.

Evaluation of health procedure and outcomes is certainly a necessity if they are to improve and the most appropriate form of treatment given. Biochemical tests do give a scientific, though limited, view of the body's state. Functional tests may not give an accurate evaluation of function, depending on where and how they are carried out. Both of these measure only narrow parameters, not the concept of overall health that was discussed earlier. This concept involves the

coming together of many different factors with empowerment and as these factors all involve value judgements, it is immeasurable.

As a set or combination of judgements, the position of the assessor is also influential. 'The subjective assessment of the patient may allow more successful interpretations of the impact that disease and treatment have on his or her quality of life, whereas objective indicators may merely be projections of professional mores.'[65]

Health measurement will undoubtedly continue and expand as resources are limited and numbers of health economists grow. But it has been argued by many that the basis of health policy decision should not be an attempt to quantify in one figure immeasurable concepts, but rather the principle of equality. Thus everyone should have access to basic medical and nursing care whatever their health status. On a macroallocation of funds or formulation of health policies the basis should be to select beneficial treatments which are medically accepted as good practice and which have been proven in their results. This would create a fairer distribution of limited health resources than evaluation of the QALY outcome.

Health measurements can be general indicators of negatively defined health but categorisation of a state of well-being, an essential component of overall 'health', is not possible. Perhaps the most useful health measurement for assessment of candidate disorders for PGD are the guidelines for withholding or withdrawing treatment in neonates. Even these are based on subjective evaluation as described earlier, but given that decisions have to be made, and so long as decision makers are aware of the qualitative nature of the assessment, they provide a framework. So that, if a disorder would cause a child to be considered

under these guidelines, then that disorder would be a suitable candidate for PGD or PND.

1.5 Conclusions

In considering what constitutes an 'intolerable' life, a prerequisite for PGD and PND, one is met with serious difficulties. Health (1.2) is such a complex concept involving many internal and extraneous factors that assessing it in anyone's life is difficult, if not impossible, and it follows that doing so in predicting a future life will be even more so. On the other hand it may be easier, and less emotive, to give an account of the future health of an embryo or foetus, than making decisions on an existing child.

The courts (1.3) have shown that they are willing to make treatment decisions based on the 'quality' of life of the affected party. In the cases involving PND (no cases concerning PGD having come to court yet) they have come out strongly in favour of PND by awarding damages for failure to provide tests and failure to detect handicap in time to abort the pregnancy. By doing so, the law seems to view failure to weed out handicap as compensateable, commensurate with them saying that these lives would be intolerable if allowed to go to term. There are discrepancies in their decisions, however. In McLelland v Greater Glasgow Health Board[66] they awarded damages for failure to detect Down's syndrome and for the subsequent birth and upkeep of the child. On the other hand, in reB[67], a child with Down's syndrome who required surgery, they decided that treatment must go ahead because the child's life was tolerable and not predictable.

In terms of health measurement (1.4), there are many different ways of assessing health or various aspects of it. I have argued that the concept of overall health is an immeasurable one, based as it is on a combination of value judgements. Even the functional tests are flawed in that they are dependent on where and how the tests are

performed. Thus these scales give some indication but no definitive assessment of what constitutes an intolerable life. The Royal College of Paediatrics clinical guidelines on treatment for neonates may be of greatest practical use, but these call for prediction of future outcome when related to PGD and PND.

In the case of PGD and PND the decision of what is regarded as acceptable form of life will be taken mainly by the prospective parents. However one has to consider whether they are considering what is tolerable for the prospective child or what is tolerable to themselves?

From a medical viewpoint, the pressure to perform PND from the legal decisions is immense. There is also pressure on the public through health promotion programmes which encourage people to take responsibility for their own health. These programmes promote participation in screening tests as responsible actions for those concerned with their health and PND and PGD are categorised as such tests.

If society, medicine and the law are all encouraging 'treatment' of handicap by screening and aborting through PND or non-replacement of embryos using PGD then there will be additional pressure on parents to act responsibly, take the tests and act on the results.

In PGD the disorders for which there are tests are not necessarily those which create the most intolerable lives, but rather those in which there has been the greatest research carried out, or which are sex-linked. These are often the most common genetic disorders in the western world, such as Duchenne Muscular Dystrophy, which was in fact the first candidate for PGD.

This consideration of what constitutes an intolerable life leaves a very limited number of disorders which would inevitably lead to such a life - possibly where there is unmanageable pain, limited ability to treat medically or complete lack of intellectual acuity.

If any of these 3 elements would be present in a sufferer from a given disorder then it could be argued that these are basic welfare interests (1.2.3) which would be harmed, thus not allowing a 'decent' life, or perhaps conferring an 'intolerable' one. Based on the justification of PGD and PND as prevention of intolerable lives, only those disorders whose disease process would harm these basic interests would be considered suitable candidates for PGD and PND.

So after considering what constitutes an intolerable life and its use as justification for PGD and PND, I will now consider whether the use of these techniques, especially PGD, could be justified for sex selection and the screening of genetic traits.

Chapter 2

Medical screening and PGD as a screening tool

2.1 Medical Screening

Medical screening has been described by Stone & Stewart as 'a preventative activity which seeks to identify an unsuspected disease or pre-disease condition for which an effective intervention is available'[68]

Wilson and Junger[69] drew up criteria for screening programmes in 1968 for the WHO. They noted 10 points, of which the following are pertinent to antenatal screening:

1. The condition sought should be an important health problem.
2. There should be an accepted treatment for patients with recognised disease.
3. Facilities for diagnosis and treatment should be available.
4. There should be a recognisable latent or early symptomatic stage.
5. The natural history of the condition, including development from latent to declared disease, should be adequately understood.
6. The cost of case finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.

It has also been argued that there are also ethical criteria for screening programmes: that

'they satisfy the criteria for any sort of medical intervention';

there is a 'responsibility for the [medical] professional to justify the intervention which may not have been requested';

'some screening procedures carry health risks, and all of them are likely to be accompanied by discomfort, anxiety and inconvenience';

'any screening programme carries with it the risk of the false positive or the false negative'.[70]

Thus it is said that 'screening requires as much ethical justification as other medical interventions.'[71]

In all the descriptions and discussions regarding screening, great emphasis is placed on the need for an effective treatment of the disease for which you are screening. In the case of prenatal diagnosis (PND) the only treatment that is available in the majority of cases is termination of any affected pregnancy. In Preimplantation Diagnosis (PGD) the treatment is non-replacement of affected embryos. PGD specifically deals with genetic disorders, of which it has been said 'the rapid molecular advances... have resulted in techniques that permit presymptomatic diagnosis before any rational approach to treatment has been developed.'[72]

Mason and McCall Smith have stated that 'We also call into question the ethical propriety of making available a plethora of tests for conditions for which no treatment or cure is available .....In these circumstances, the availability of such tests can only be justified to facilitate an abortion decision - otherwise offering them can be seen as little more than a waste of resources.'[73]

One of the justifications of PND and PGD is to provide more choice. By providing as much information about a given pregnancy, or of the tests that are available, it is argued that you increase the patient's choice regarding their future offspring. But, as

considered by Mason and McCall Smith above, this increase of choice appears only to provide the option of terminating the pregnancy.

Another justification of screening tests in general is that of reducing suffering, or with PND and PGD preventing intolerable life as considered in Chapter 1.

Screening has also been promoted in terms of cost-benefit. An article in 'The Independent' of August, 2001 states that 'since the costs of caring for Down's syndrome babies often fall on the state the costs of better screening strategies can be justified in economic as well as humanitarian terms.'[74] This way of judging benefit from screening places no, or indeed a negative, value on the affected child itself if it were to be born.

Screening programmes in general have been well received by the general population. They have been promoted as a way of taking responsibility for one's own health and a form of disease prevention.

There have been examples of genetic screening programmes, however, which have caused major problems. In America in the 70's, the programme of screening for sickle cell carriers caused problems among the black population screened. David Weatherall has said 'All that program achieved was public anxiety, stigmatization, job and health insurance discrimination and a variety of other undesirable effects.'[75]

The Human Genetics Commission (HGC) in 2000 stated, with regard to genetic testing in pregnancy, that protocols should be in place so that:

'- those who may benefit [from genetic testing] are offered the opportunity [to have it]

- no presumption that PND would be unacceptable to the patient

- no presumption by doctor that each woman should accept all or any test offered

- informed decision not to have test must be accepted'[76]

It is felt by some that it is very difficult for women to refuse antenatal testing. Angus Clarke has put it as 'perhaps every woman should attend an assertiveness training course before becoming pregnant'[77] The need for free choice in PND is highlighted by a group called Antenatal Results and Choices, which offers support to people going through the testing process. In October, 2001 they said 'There's a real need for a lot more input before, during and after the process so that women really understand not just what the tests are for, but what the information they've given really means.'[78]

The informed use of screening is dependent on patients' ability to calculate their risk, digest all the information they are given, and come to an informed decision. This may not be achievable if information is not given in a way that they can understand, or if time is not available for discussion. Julia Black argues that in a hospital situation, issues are informed by the medical profession, thus 'the individual's participation is restricted ...to the ability to say yes or no to what is offered, not to shape the choice.'[79] This reiterates the HGC view that as much emphasis should be put on information given before testing as to whether it is wanted at all.

All screening always has a certain number of false positives and false negatives, and this has to be considered along with all the other information. Some tests will only give the probability of an affected pregnancy - such as in the tests for Down's syndrome. Nuchal

fold scanning and the triple test will only give a figure of e.g. a 1:100 chance of the foetus being affected. This can only be definitively confirmed by amniocentesis, which is invasive and carries a risk of losing the foetus, whether affected or not. The patient has to be enabled to assess all these factors and come to an informed choice.

This, however, can only be achieved through a non-directive approach to counselling - something which studies have found not to always be the case. Michie et al carried out a study in 1997 and concluded ' genetic counselling was not characterised - by counsellors, counselees or a standardised rating scale - as uniformly non-directive.' [80] Others have argued that it not possible to achieve this, and Shiloh & Saxe suggested that it might not be useful. They found that 'the more neutral the counsellor was perceived to be, the higher the counselee perceived his or her own risk to be'[81] Lippman-Hand & Fraser also found that 'counselees interpreted non-directiveness not as neutral but as tacit approval of their stated course of action.'[82]

Another screening programme that has been considered a success is that of neonate testing for phenylketonuraia (PKU). But as the US President's commission[83] stated in 1983, they had problems in setting the threshold for a positive outcome. At the time of the test, when the baby is 3 days old, many hadn't eaten enough protein to raise their levels of the product that the test is based on. This led to a great number of undetected cases, so the threshold value was lowered. This in turn led to a rise in the number of false positives, in fact it was found that more than 90% of babies with initial positive results were found on further testing not to have PKU.

This setting of a threshold is a problem of all screening tests. In PND for Down's syndrome for example, the initial tests only give a

probability. The definitive test is amniocentesis but this is too risky and expensive to offer to all pregnant women so other tests are used to indicate those most at risk.

If a test is available, especially through public funding such as in the NHS, this implies that it is in the public interest, encouraging good health in the population. This also reinforces the abortion of non-perfect foetuses as part of policy. As Ruth Chadwick says 'if government takes an interest in the genetic health of the population, there may be pressure on individuals to make certain sorts of reproductive decisions'[84] Angus Clarke says rather pessimistically that 'the common public image of geneticists [is] as a type of orwellian reproductive police force' [85] Thus social and medical pressure may combine to affect the decision of patients.

As Barbara Katz Rothman has said 'For all the "non-directionality" a given counsellor may strive to achieve, the technology changes cultural meanings'[86]

There is an underlying suspicion that one of the motivating factors in this service may be the fear of litigation. As stated earlier in 1.2.2, the courts have been behind patient's claims against the medical profession when they have a disabled child. Thus any clinician will have to be able to prove that they offered all available tests and provided all available information, otherwise they may find themselves facing charges of negligence.

The question of evaluation is also raised within screening programmes - how do we evaluate genetic testing success? Ruth Chadwick has stated it simply as 'success consists in individuals making choices in the light of relevant genetic information.'[87] It is difficult to assess good dissemination of information but relatively easy to measure

the number of abortions carried out as a result of that information. This form of evaluation would change the emphasis of the service toward that of aborting any affected pregnancy.

Angus Clarke has said about evaluation 'When carrier screening programmes are judged by the uptake rate achieved and by the money "saved" by terminating pregnancies, we will know that cost-benefit-based, "public health genetics" (eugenics) has arrived.'[88]

I will discuss eugenics in Chapter 4, but, as we have already considered, the value of PND and PGD has already been vouched in terms of saving costs to society of care of affected individuals.

Angus Clarke has stated that 'there are several ways in which genetic counselling can operate to reduce the suffering caused by genetic disorders.'[89] He gives 6 examples:

1. Achieving 'a precise diagnosis of the cause of a child's handicap can itself be therapeutic for the family'
2. The screening for complications of genetic disease may assist in the management of the affected individuals
3. Providing practical and social support for the affected individuals and their families
4. It may help to reduce 'handicap' by minimising 'the stigma associated with disability and handicap, hoping to develop the self-esteem of affected individuals'
5. Helping to develop specific therapies and their application.
6. Providing information about future reproductive risks and options will benefit couples at risk to make an informed choice.

None of these options would provide a 'cure' per se - they just aim to adjust the position of the parents toward and the social attitude to their children.

PGD has been suggested to be a better form of treatment than PND. This fact was stated in the first report of successful PGD in 1990[90] - patients viewed it as preferable to PND and termination.

I will discuss the arguments surrounding the status of embryos and foetuses in chapter 5. Here I will consider this preference in terms of whether it is a less traumatic treatment. Both procedures have the same intended outcome for the pregnancy, but the prospective parent may be able to relate more to a 16 week foetus as a potential child rather than an embryo in a laboratory dish. Many reports have also said that the medical profession find terminations traumatic, so that non-replacement of embryos may seem preferable to them too.

IVF, an integral part of PGD, is not a risk free procedure however, and many people find it extremely stressful. It is also not particularly successful, with national averages of around 15-20% live births per treatment cycle. Thus PGD should not be considered to be an easy alternative to PND.

In terms of the criteria listed on page 1, both PND and PGD offer only termination or prevention of an affected pregnancy as 'effective intervention.' The argument that these tests offer greater choice has been contested by many. PND has now become a routine part of antenatal care and there is often little time for explanation of the tests or consideration of what the outcome may be or entail.

Patients coming for PGD will generally have been through the genetic counselling service because of having an affected child or

relative. They will then have had more time to discuss the procedures and options available to them.

2.2 PGD as a screening tool

The existence of PGD as a screening tool has led to many fears that its use will be expanded as it becomes more accepted by patients and society. Thus it could be used not only to detect serious genetic disorders that cause harming of welfare interests as discussed in Chapter 1 but also for behavioural traits, minor disorders or selecting the sex of the child.

As PGD is based on detection of the presence or absence of a gene, anything with a genetic component could feasibly become a factor to be screened for. The huge amount of media coverage of the Human genome Project means that hardly a week goes by without a 'gene for' being announced. As scientists unravel the genome, which has now been completely mapped, and discover what function each component part plays in human life, then it is argued that we will have a blueprint for what makes each of us individuals.

Many of the genes now being investigated are not disease specific but rather purport to control behaviour or personality traits. There has been news of a gene for homosexuality, and for aggression, and work is being carried out to see if there is a genetic component to intelligence. Once scientists state that they have found a 'gene for' then a test for that will follow closely and thus the ability to use PGD to screen for its presence or absence becomes a possibility.

PGD could then become a tool for selection of the 'best' child rather than screening for potentially harming genetic disorders.

In the light of the justification for the use of PGD that I proposed in Chapter 1, I will consider whether these uses of PGD could be acceptable.

2.2.1 Sex Selection

One of the potential uses of PGD is for sex selection such that prospective parents could have the child of the sex they want.

As mentioned in the introduction and the nature of PGD (p1) some of the disorders that are presently screened for are X-linked. This means that females can be carriers of the gene but only males will manifest the disorder itself. Duchenne Muscular Dystrophy is one such disease and the first use of PGD was to help families known to carry the gene for Duchenne Muscular Dystrophy. They used sex selection of embryos to prevent the birth of affected children as a test for the gene was not yet available. Thus all embryos were sexed and only female ones replaced with all male embryos discarded whether affected or not.

The primary function of these tests was not however to enable people to have children of a specific sex but to prevent the birth of children with Duchenne Muscular Dystrophy.

At least one couple in the UK have requested PGD to enable them to have a female child after they had lost their only daughter in an accident. Their request was turned down by the HFEA who decided after public consultation that this use of PGD should only be to prevent sex-linked disorders and not for social reasons.

If the stated aim of PGD and PND is to enable people to have healthy children then can one argue that selecting the sex of the child will be beneficial to their health?

If we consider the concept of overall health from the previous chapter, then none of the welfare interests could be considered harmed by being born of a given sex except those relevant to social health or one's parents carried a sex-linked disorder. Thus the ability to earn a living, live free of interference or coercion, absence of groundless anxieties and capacity to engage normally in social intercourse (p9) could be affected. This would only occur because of societal discrimination not because of any natural misfortune. Although it has been said that 'from the future child's point of view, it will make little difference, other things being equal, whether her quality of life is diminished by social prejudice or by natural endowment.'[91]

So there could be harming of an individual's interests by being born of a given sex into a discriminatory society. Most western societies however now have anti-discrimination legislation and regard it as a form of justice that one should not be prejudiced just for being of a given sex. In the UK at least one would find it hard to obtain an abortion solely on the grounds of foetal gender, so selection at the embryonic stage should be based on the same anti-discriminatory principles.

The difference between natural impairment and social prejudice is that society can act to change prejudice. This is the basis of anti-discriminatory legislation. Even if one does not feel that it succeeds in many ways, the majority would still support the idea that prejudice is wrong. As Berkowitz stated 'Preconceptive sex selection represents sexism in its purest most blatant form as prior to conception, before any psychological or physical manifestations appear, before parents can possibly know anything about their child, a child's worth is based in large part on its sex'[92]

Thus assumptions of the best interests of the child are based solely on one aspect of its life, its gender. These assumptions find their support in stereotypical social roles and sexist preconceptions which legislation has tried to alter in western society.

To justify the use of PGD on the basis of prejudice would not be considered acceptable in a fair and equal society.

2.2.2 Non-disease genetic traits

Other traits which may be found to have a genetic component may be considered possible candidates for PGD. These range from those that most would consider trivial such as eye or hair colour through to intelligence and behavioural traits.

Firstly the idea of screening for eye or hair colour. It could be argued that society favours certain characteristics more than others - being blond and blue eyed may be an advantage in some societies, as was the case in Nazi Germany. Even without the extreme example of the notion of Aryan supremacy this favouring of certain characteristics is wholly based on societal prejudices. Certainly people do already try to select these characteristics in their children by selecting their partners for characteristics that they value.

To select an embryo on the basis of its looks has no basis in harming of welfare interests as its justification, rather it once again values the child for one specific aspect of its appearance and bases that value on prejudices in society.

It has been suggested that behavioural traits such as aggression may have a genetic component. Again this leads to suggestions that screening for this using PGD would lead to a better society and would be in the interests of the child. The basis for this is that aggressive behaviour if not controlled leads to violence in society and that anyone born with such a genetic tendency would not have a good life and lack opportunities in their life. This presupposes however that behaviour has its main roots in genes and cannot be influenced by upbringing or societal environment.

The same argument for increased opportunities in life is also used to support selection for intelligence if such a gene is found to

exist. This once again depends on accepting the fact that environmental factors play no part in how an individual turns out. No matter what the basic intelligence of a child what is important is the support and help they receive when young to enable them to learn about their surroundings. This is then continued through school where once again if there is poor support and encouragement, whether from their teachers or at home, the ability to fully utilise what intelligence they have will be hampered.

It was demonstrated in the use of IQ tests in the US among draftees during WW1 that these tests do not necessarily measure what they claim to. In this instance a good result was dependent on knowledge of the language and customs of America, something a lot of emigrants and poorly educated people did not have.

Perhaps it could be argued that if a genetic factor were isolated then this would provide a more accurate assessment of intelligence. But if that were the case then education for all would be a pointless concept as there would be no point in wasting valuable resources and time on educating those without the gene who supposedly could not derive any benefit.

So to say that we should only allow the birth of intelligent people would be wholly dependent on ensuring their continued support and development throughout life otherwise the potential would be wasted.

Another 'gene for' that has been suggested is that for homosexuality. In this instance even the investigation for such a gene carries with it some hint of prejudice. It has been suggested that given the prejudice and discrimination that being homosexual means in society it would be in the best interests of the future child to screen for

and select against the gene. Again this is reacting to a societal problem wrongly by avoiding the issue of stereotypical prejudice by eradicating the people themselves.

It has been argued that basic welfare interests are harmed because of prejudice but as in the case of gender selection, this should be an impetus to change irrational prejudice in society not to use genetics to support them.

In addition to the above traits, Julian Savulescu[93] has argued that minor diseases such as asthma should be screened out if a gene is discovered. Asthma can certainly be a dangerous disease but one which can be adequately controlled with good treatment. When it is controlled it is not an impediment to living a productive and fulfilling life, thus would not be considered to harm welfare interests to an extent that life with asthma would be intolerable.

2.2.3 Conclusions

In raising the prospect of using PGD to screen for the above traits one begins to be faced with the idea of creating a perfect child. Most prospective parents will try and create the best possible environment for their child and indeed many select partners on the basis of having characteristics they would like to pass on to their children.

But children are not consumer objects to be selected from a range on the shelf. Genes may confer predispositions toward certain traits, behaviours or diseases but the environment in which we live and grow needs to interact with them for the final outcome. Thus upbringing, education and choices made either by the individual themselves or their parents in childhood will all combine with genetic factors to produce that person's life.

To select on the basis of genetic traits what one hopes will be the best child could lead to huge disappointment, possibly neglect, if the genes don't live up to expectations. Will we then be faced with court cases demanding compensatory damages because the carefully selected child fails to display what was expected from them?

As the genome is dissected and more genetic factors uncovered, this may lead to the idea of a perfect set of genes. Thus any genetic factor that can be screened for becomes an imperfection to be selected out. Many genetic factors interact however and these interactions are hard to identify. Thus in screening out a perceived imperfection we could in fact be deleting a useful gene from the population. This selecting of the perceived best genetic information will also unnaturally alter the overall gene pool of the population thus limiting the genetic diversity.

If as I stated at the beginning of this section (p51) the aim of PGD and PND is to produce healthy children, we should bear in mind what has been argued previously that health is extremely difficult to delineate and indeed achieve. Thus we should be wary of placing too much emphasis on specific genetic factors in trying to achieve what is a multi-faceted concept.

2.3 Deafness - a candidate for PGD?

Deafness often has a genetic component especially in those born deaf. PGD could thus be used to screen for, and select against, these genes. But there are those in the deaf community who would argue that deafness is not a disability in a medical sense but a trait of those in their community. They have raised the idea of deaf prospective parents utilising PGD to select for deafness so that their children could also be part of their community.

This argument as to whether deafness is a disability caused by medical problems or societal ones has been going on for many years. I will discuss the social and medical models of disability more fully in the following chapters, but here I will consider how it forms a basis of the argument over how to teach deaf children.

The first school for 'deaf-mutes' was founded in Paris in 1794 and taught pupils from all over France using sign language. Up to this point deaf-mutes had been left within their families, communicating through rudimentary sign language, receiving no education and working within the household. The general consensus was that their lack of hearing was indicative of mental retardation and that there was no use in even attempting to educate these children as they would be incapable of utilising it.

As Laurent Clerc, one of the pupils and later a teacher at the Paris school, said 'Deaf-mutes have always been thus confused with another class of the dumb, the retarded; under Roman law they were given a curator. It was not until the twelfth century that they were allowed to marry.'[94]

In Spain in the early part of the 16th century a priest did try to educate some deaf children. He used sign to teach, formulating a

sign alphabet and taught writing, languages, science and arts. He did also try to teach speech through imitation of tongue movements but the main reason for this was not educational. In Spain at this time anyone who was mute was not considered a person legally but if they could speak, even although they were deaf, they had legal status. Thus the priest was employed by a wealthy noble family of the time whose sole heir was a deaf-mute. They required him to speak in order to retain their title and keep the wealth within the family.

It wasn't until the opening of the national institute in France nearly 200 years later that teaching through sign was fully developed. Deaf children and some adults came from all over France and a French sign language was formed from the rudimentary sign language that all deaf children naturally use.

This sign language was used to teach writing and reading in class and then further education much as any normal school. It had a full curriculum with science, history, theology, arts and so on. The founder abbe de l'Epee acknowledged that one could teach the deaf to speak but also that it required so much time that it squeezed out the rest of their education.

The achievements of the school were noted across Europe and many countries sent teachers there to learn their techniques in order to set up similar schools at home. There were other schools however who persisted with teaching speech - in Britain this was the predominant form. There was fierce argument between the advocates of these 2 methods which still persists.

Laurent Clerc, quoted earlier, was persuaded to go to America in 1816 to set up a school. This opened in the following year and it spawned many schools across the continent. He taught using sign

language and some of the pupils became teachers themselves who went off to found schools. The school also taught various trades so that pupils could have options of how to earn a living on leaving.

Clerc developed the version of American Sign Language which is still in use today, adapted from his French sign. He fought hard for the rights of the deaf to receive a full education and one of his pupils went on to found a college of higher education for the deaf.

He said of his deafness 'am I truly ill because I do not speak your language, or because I am more exposed than you to the danger of a runaway horse approaching from behind?'[95] He regarded the deaf as a linguistic minority rather then a group of people disabled by illness.

He had been exposed when young, as were many of the deaf before his time, to various painful and futile attempts to 'cure' his deafness and was firmly against the medical view of deafness.

After his death in 1869, however, oralism - the teaching of the deaf to speak - took over as the main form of deaf education. In the US a strong supporter of this was Alexander Graham Bell. Ironically he was the inventor of the telephone - one of the main tools of exclusion of the deaf from modern society. His wife was deaf but communicated solely by speech and lip-reading and abhorred others who were deaf and their sign language.

The difference between his and Clerc's attitude is striking ' where Clerc found strength in human variety, Bell found weakness and danger.'[96] Bell said of deaf children 'We should try ourselves to forget that they are deaf. We should teach them to forget that they are deaf.'[97] Bell was also a supporter of the eugenic movement and thought that

letting the deaf congregate together would lead to their intermarriage and thus to more deaf children.

The aims of the 2 men were also very different. Bell said that 'the main object of the education of the deaf is to fit them to live in the world of hearing-speaking people.'[98] Clerc felt that 'the overriding purpose of education was personal fulfilment.'[99]

But as Clerc and the founder of the French school stated it is very time consuming to teach a deaf child to speak. It is easier, as Clerc always pointed out, if the child becomes deaf after birth. In these instances they will have knowledge of language, of the hearing world and may still have a residual knowledge of the language. In the congenitally deaf it is extremely difficult and time consuming to teach them speech and this then led to their exclusion from education. In Michigan the law stated that 'The oral system shall be used exclusively but if, after nine month's trial, any child shall be unable to learn by the oral method, no further expense shall be incurred in the attempt to educate it.'[100]

It also led to the exclusion of deaf teachers from education as they could not be part of this form of teaching. The debate on education for the deaf was thus held among hearing people. They ignored the achievements of those such as Clerc who was born deaf and assumed that the deaf should just be educated into being part of a hearing society.

In any deaf child, whether deaf from birth or not, as has been stated earlier, the time taken to teach them to speak is so great that their general education is necessarily diluted. What is produced is not an educated deaf child but rather one that can speak.

Clerc and his teachers always felt that as sign language was the natural language of the deaf it should be used to teach. By receiving such a full education through sign, the deaf could become useful and productive members of society. Communication with the hearing who didn't know their language could be achieved through hearing interpreters or the written word.

If we consider deafness with regard to the welfare interests listed in Chapter 1, are any of these harmed? Certainly deafness could not be considered as a normal functioning of the body, but then if one has never heard as in those born deaf then this is a normal state to them.

The interests pertaining to social health can be achieved through appropriate education and support. As the pupils from the school in Paris and Clerc's schools in America showed, the deaf can become full, productive members of society.

It is through trying to deny the status of sign language, and forcing what could be considered to be a linguistic minority like any other to see themselves as a medical problem to be 'cured', that these interests are harmed.

It is sad to think that a century ago Clerc's pupils, and indeed himself, were living happy, fulfilled lives. They received a comprehensive education in a safe and caring community and then went out into the world and earned their livings. By forcing the hearing world's interpretation of the afflictions of the deaf onto their community and teaching, and insisting on making them like 'us', society has taken away that ability to lead happy, productive lives.

The argument about education of the deaf continues to this day. A letter to The Times of 9th October, 2001 states, with regard to

the poor use of sign language in education, ' It is a national disgrace that deaf children of normal intelligence are being allowed to grow up functioning as if they were learning impaired.'[101]

The use of cochlear implants has also raised similar issues. Their use in pre-lingually deaf children, before the age of 3-4, has not been proven. Results of trials have shown that they 'do not improve their oral communication skills sufficiently to enable them to become functioning members of hearing society.'[102] Again the arguments would sound familiar to Clerc and Bell, 'when the child receives a cochlear implant, he or she is put on a lifelong course of education and habilitation, the focus of which is the acquisition of an oral language, and ultimately a meaningful engagement with the hearing world.'[103]

So deafness as a candidate for PGD would appear to be another attempt by the hearing majority to stigmatise the deaf community. Carl Elliott has described this community as 'something closer to an ethnic or cultural identity, a condition to be proud of rather than to overcome.'[104] By suggesting that they may wish to select for deafness, shows that it feels embattled enough to select for children who would be part of their community rather than the outside hearing world.

In considering the deaf community as an ethnic or linguistic minority, the use of PGD to select against genetic deafness can be regarded as societal discrimination. It thus becomes similar to sex selection and other non-disease traits where social discrimination rather then medical problems harm the welfare interests of the individual.

Chapter 3

PGD as a means of eradicating disability

3.1 Societal health

The promotion, and indeed existence, of PGD and PND appears to advocate an ideal of a disability-free society. Thus screening out disability before birth is a way of utilising scientific advances to realise this ideal.

An initial response would be that it is an impossible ideal to achieve in that there will always be disability. Accidents, whether natural or man-made, which cause disability will always happen. As the population ages in Britain and life expectancy increases, there will be a concomitant increase in age related disability.

The next response, and possibly the more important one, is that of whether or not a disability-free society is in fact an ideal, or rather a way of ridding us of a problem we'd rather not deal with. If it is not an ideal, then what benefits are there of having disability present, not in terms of individuals themselves, but to society as a whole?

Certainly people in their communities are rewarded for their fund-raising and voluntary work for those with impairments. These public awards imply that these activities are viewed as morally good and to be encouraged within society. But for whose moral good? By helping 'those less those fortunate than ourselves' we can make ourselves, the able-bodied majority, feel virtuous but this does not provide a sufficient reason for the presence of disability within society. It also means using other human beings for our own ends, rather than respecting them as individuals and implies that we regard those with impairments as less human than ourselves.

The presence of disability, it could be argued, is a humbling experience for society in that it reminds it of the fragility of the human state, but again this seems a less than sufficient reason for having disability within society.

Another argument is that diversity makes for a 'healthier' society. The idea of the health of a society is based on human beings being of equal worth and the principle of respect for the individual. This way of looking at societal health is dependent therefore on the promotion of empowerment for the individual, who is then enabled to control their own life.

The presence of those with impairments may increase tolerance of others. As one mother of a disabled child said, 'My [able-bodied] children have much more compassion than they might have had otherwise. They're very patient and take time to include and explain things to Joshua.'[105]

Societal health also recognises that health has a lot to do with social interaction and structure. A society's health is more than just the sum total of its healthy individuals, it also involves the ethos and attitudes of that society. This is borne out by society advocating social justice for all its members.

Social Justice would demand that society includes those with impairments and enables them to be full and active members of society. Anti-discrimination laws serve to promote and reinforce this principle.

3.2 Social model of disability

The disability movement has argued that there are two models of disability - the medical and social models. I will consider the medical model in the next chapter.

The social model contends that the problems faced by those with impairments are caused by society rather than the impairment itself. This view can be clarified in the UPIAS (Union of the Physically Impaired against Segregation) definitions of impairment and disability.

'Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment.

Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.'[106]

Thus the environment or society that we live, are educated or work in creates disability through discriminatory activities and poor access. This model cites problems with schools, housing, transport and workplaces which all contribute to disable those with impairments and prevent them from becoming full and productive members of society.

In chapter 1, our list of basic welfare interests included 4 criteria of social health:

1. Capacity to engage normally in social intercourse and to enjoy and maintain friendships
2. Minimal income and financial security
3. Tolerable social and physical environment
4. Certain amount of freedom from interference and coercion

If we consider how each of these are affected by society as seen through the social model, it could be said that society harms those with impairments in terms of social health. The exclusive nature of the special education system discourages development of social relationships outwith their narrow environment. Social interaction is further limited through poor transport and facilities for those with impairments to go out and meet friends. In failing to provide suitable education, and employment, society also does not guarantee financial security.

Although society tries to make amends by providing a social welfare state, it is argued that this in fact further disenfranchises those with impairments by creating a dependency on state benefits and others for care in their day-to-day lives.

In promoting a societal view of disability, those with impairments confront society with its failings and encourage it to be inclusive rather than exclusive. They contest that through improvements in housing, public buildings, transport and education they can become full and productive members of society. Although this may have initially higher costs, in the long term they would be able to contribute more and thus be of benefit to society.

I will now consider these various aspects of society that are considered disabling by advocates of the social model.

3.2.1 Education

The social model of disability encourages, indeed demands, inclusion in mainstream society for those with impairments. This inclusion begins with the education system - it is argued that special

segregated schooling has helped to develop many of the problems encountered throughout life by the disabled.

One author said 'segregated and special schools are a fundamental part of the discriminatory process...'[107] Special schools discriminate in various ways. They are often far from the child's home, which can create transport difficulties for their families or the child must be resident. This can be difficult for young children and takes them away from their siblings and local community.

It is also argued that the emphasis in many special schools is on medical intervention and therapy rather than education. This has two effects, firstly it creates dependency on the medical profession and secondly, by reducing the spent on teaching, it contributes to the poor education of the disabled. Michael Oliver has argued that 'If children are brought up to believe, through experiencing a range of medical and paramedical interventions, that they are ill, we cannot be surprised if they passively accept the sick role.'[108]

By providing a poor education, it is argued that special schools do not prepare children for life after school. They are then forced to accept poorly paid jobs or rely on state benefit.

The social model would say that these factors combine to stigmatise and discriminate those with impairments. They are removed from society, encouraged to become dependent and are ill prepared for life. The removal from society reinforces notions of difference and intolerance. Thus society does not come to accept the disabled or believe that they are capable of being part of that society.

The trend is now toward inclusive education. In America the Education of all Handicapped Children Act[109] of 1972 mandated free, appropriate education for all children with disabilities.

In the UK the Education Act of 1983 placed increased emphasis on inclusion but left it to the discretion of local authorities. There was little change in policy but this may have been planned. Mary Warnock, whose report provided much of the basis for the Act, said 'People say we fudged integration, but we fudged it as a matter of policy.'[110]

There is a new Bill to be introduced next year, the Special Education Needs and Disability Bill[111]. This will mean that schools will have to accept children with impairments unless 'admitting him or her would harm the education of the other pupils.'[112] Schools must also make 'reasonable adjustments to their policies and practices'[113] and improve access to their premises.

Inclusive education does not have universal support however, and its success depends largely on the type and extent of impairment.

Laurent Clerc, as described in 2.3, felt that deaf children benefited from being educated and living together. Far from excluding them from society, his opinion was that through communication within their own community they developed better social skills and through education could become useful and productive members of society.

Hearing aid technology has improved greatly since Clerc was teaching, enabling more children to have some level of hearing, and making inclusive teaching more effective. But for profoundly deaf children inclusive teaching is not achieving its aims. A study in 1979 in the UK found that half of the children with profound hearing loss were illiterate. Despite these figures the number of schools for the deaf has been steadily decreasing over recent years.

In The Times[114] in October this year, a grandmother of a profoundly deaf boy, Charlie, described his educational experience. He

had started at a 'normal' school but quickly became very disruptive and was eventually excluded for biting a teacher. At 6 years old a place was found for him at a school for the deaf. Despite having to be resident there at such at young age, his demeanour changed completely and he was keen and attentive in class. The headmaster of his original school said that his school 'was not equipped to communicate with, and educate, Charlie in the way his intelligence demanded.'[115]

In America, where inclusive teaching of the deaf is mandatory, it has been said that 'increased access to oral education for deaf children at the cost of a dramatic decrease in the quality of their education.'[116]

Thus for deaf children, particularly those congenitally deaf, inclusive education seems to fail them, as Clerc felt it would.

People who have attended schools for the blind have said that it made them feel safe and part of a community that understood them. Sally French, partially blind from birth, stated on attending a school for the blind that 'for the first time in my life I was a standard product and it felt very good.'[117]

For those with physical handicaps other than deafness and blindness, such as wheelchair users, the main handicap to mainstream education is one of access. The new Bill will change this by requiring schools to improve access, but at the moment suitability of school premises is variable.

Those with mental handicaps will vary greatly in their educational needs. Mothers of severely handicapped children felt that the special schools their children attended were of great help.[118] The schools provided care for their children during the day and the mothers felt that they taught them necessary social skills. They also had the

necessary facilities and expertise to help the children achieve their potential. The emphasis here was greatly on the therapeutic and social value of schooling rather than education.

One of the greatest concerns of teachers and parents is that of inclusive education for children with behavioural problems. The new Bill does allow schools to refuse a child 'if admitting him or her would harm the education of the other pupils.'[119] If the behaviour of one child disrupts the whole class then this will be inclusive education to the detriment of the majority.

One mother whose child was in a class with a severely disruptive boy wrote 'is it fair that my child and others should be used in group therapy to try to calm this boy?'[120] Although this child was later removed from the school and went to a special school, the mother still felt angry that her child and his class had 4 months of schooling disrupted through an experiment in inclusion.

One of the proposed solutions to the problems of inclusive schooling has been to have special education units within mainstream schools. Thus children with special needs will receive appropriate education for their needs and mainstream classes will not be disturbed. But by having the units on the same site as the main school and encouraging integration at breaks, children from the special unit will experience 'normal' society and the other children will mix with those with disabilities.

Many in the disability movement have argued that the poor education and exclusive nature of special schools has had a major role in exclusion of the disabled from society. But blanket inclusive education can be just as detrimental and discriminatory. It has to be the

best and most appropriate education which enables the child to reach their potential that takes priority, not inclusion at all costs.

Mary Warnock said in 1988 that 'Integration in its widest sense is about how to fit special education into mainstream education rather than how to devise a single system of education for all.'[121]

3.2.2 Employment

Those who advocate the social model of disability state that the poor special education system has been a major factor in the poor employment status of many disabled people. If they leave school with few qualifications and poor social skills then they will only be eligible for poorly paid, menial work.

This then compounds discrimination in that it perpetuates the idea that the disabled are not capable of more qualified work. It also reinforces dependency on the state through low income. A study in 1991[122] stated that over 60% of the disabled population in America and the UK live below the poverty line.

There has been legislation to try and overcome this problem, especially in America where positive action has been advocated. The Americans with Disabilities Act of 1990 requires 'reasonable accommodation to the known physical or mental limitations of an otherwise qualified individual with a disability.'[123]

In the UK, the Disabled Persons (Employment) Act of 1944[124] required companies with 20 or more employees to employ a minimum of 3% registered disabled people. This bill was framed toward the end of the Second World War and was specifically aimed at disabled ex-servicemen.

In practice however, it was rarely enforced and there was a system of permits which released companies from their obligation. Ostensibly these were for instances where there were no suitable disabled candidates, but they were given out freely by authorities. There have been only 10 prosecutions under the Act and none since 1975 despite 80% of employers not meeting their quota.[125]

This system also required those with impairments to undergo assessment to become a registered disabled person. Many felt that this stigmatised them and, when the Act was not enforced, did not see any benefit in registration.

The sheltered workshops which were set up to provide employment for the disabled have now fallen out of favour. It is said they provide 'unskilled and manual labour', managerial posts are almost always occupied by able-bodied employees' and 'the wages are desperately low.'[126] It has also been said that they 'ghettoise disabled workers and restrict their employment opportunities.'[127]

The 1944 Act was amended as part of the Disability Discrimination Act (1995)[128]. The quota was abolished, as was the requirement for registration and workshops specifically for the disabled. Instead employers can face prosecution if they are found to have discriminated against a disabled person. Employers are also expected to 'take such steps as it is reasonable'[129] to accommodate disabled people. These steps include adjustments to premises, altering working practices, allowing time off for treatment and providing training, among others.

To bring a prosecution under this Act however, it has to be proved that any steps required are practicable, financially feasible and reasonable.

Many of the problems facing those with impairments seeking employment stem from a lack of awareness of their abilities. It has been said that 'There is a tendency for many people, including employers, to equate physical disability with mental inability.'[130]

Those with impairments thus find themselves disadvantaged by their poor education and discriminatory attitudes of employers.

The disability movement has argued that only by positive action, as in America, will employers take on disabled workers. This can only be enforced through legislation, which in turn must be enforced, unlike the 1944 Act. The amendments to this Act in 1995 do not propose positive action, rather that disabled people must prove that any accommodation required to employ them is reasonable.

Once disabled workers are accepted, it is argued, society will become more aware of their abilities and attitudes will change. It will also in the long term relieve the welfare state of some of the burden of benefits as more disabled people earn enough to achieve financial security.

3.2.3 Social welfare

In Western societies there is a system of social services to provide assistance, financial or otherwise, for those unable to provide for themselves. Thus there is provision for those with impairments to assist them with various aspects of life.

In the UK there are several laws which aim to provide help for the disabled. These range from welfare benefits for those unable to work to grants to buy necessary aids or fund adaptations to housing.

Local authorities are required to have a register of all disabled children in their area. They must also assess their needs and provide help where required. Families with disabled children are faced with additional costs in caring for them. These may be increased laundry costs, adaptations to their house, additional transport costs or a member of the family having to give up work to care for the child.

Although all children are assessed, the process can be lengthy and complicated. This delay, and the uncertainty that stems from it, can cause anxiety for the family. A mother that killed her 2 sons earlier this year, both of whom suffered from cerebral palsy, stated that one of her reasons for doing so was the length of time taken for community care assessments.[131] In her case this was 8 months.

The complexity of the system also causes problems for families. Different grants may be administered by different departments and have different eligibility requirements. Many parents have reported that they had difficulty finding out information about all the help available and often did not receive all that they were entitled to as a result.

All of these benefits and grants require assessment of the child, which some may find intrusive and they may feel themselves under scrutiny as a family. 'The anxiety and frustration was compounded because funding for many services is reassessed on a regular basis....so the whole procedure has to be repeated over and over again.'[132]

Families have also complained that some of the care provisions are not suitable to their needs. In one study they complained of a 'lack of flexibility, responsiveness and creativity in service

provision.'[133] This results in them not being used, leading authorities to assume they are not required and discontinuing them.

The complexity of the system has now been recognised and attempts are being made by several authorities to provide a more integrated service.

In adulthood, disability benefits are available for those unable to work because of their impairment. It has been argued that this system is demeaning because of the means of assessment. In order to 'secure the maximum economic advantage from the benefit system, disabled people are forced to present themselves in the worst possible light.'[134]

The social model of disability sees these assessments as concentrating on the medical nature of impairment. However, assessment of eligibility for any benefit must be carried out and it seems appropriate that the medical profession is best positioned to judge the nature of impairments. Many authorities now employ occupational therapists to carry out these assessments.

If the 1995 Act does have an effect on increasing the numbers of disabled people in employment, then not only will this decrease the need for benefits, it may also provide an incentive for disabled people to seek employment. As a wider range of employment opportunities becomes available and disabled people are encouraged and empowered to seek better employment, dependence on welfare will reduce.

The provision of care has also been criticised by the disability movement. They have said it provides 'services that the state thinks you should have or is willing to pay for, rather than those that you know you need.'[135] Some authorities are now supplying funds directly to those

with impairments so that they can directly employ such help as they require. This has been important in enabling people to take control of their own lives, and remove what has been called 'the sullen apathy of dependence.'[136]

3.2.4 Housing

In the same way that residential schools are now being phased out, institutional accommodation for adults with impairments is also being closed. The new approach is for care in the community, which is provided in many different ways.

For families with disabled children, community care in reality means that they provide much of the care themselves. As stated in the previous section, many families feel that provision of services is inadequate. There are grants available to help with any alterations which may be required to the home, but, as stated before, applying for these can be complicated and time-consuming. One commentator said 'getting the right adaptation requires a certain amount of knowledge and, often, a considerable amount of fortitude.'[137]

There are now alternatives for adults with impairments - some residential homes do still exist, and there are also small hostel type accommodation within communities and independent housing.

The independent living movement began in 1979 with a group of young disabled people who were living in a Leonard Cheshire home. They were frustrated at their lack of control over their lives and started promoting various ideas for living in 'normal' communities. However, as one author has commented, 'intention, determination and information was ahead of bricks and mortar.'[138]

There is still a shortage of suitable housing for the disabled. A report in 1993 said that 'wheelchair users rely on public sector housing to a greater extent than other people, not only because of their relative economic disadvantage, but because most housing stock is inaccessible.'[139]

It has been suggested that we should build 'lifetime' housing which is accessible to wheelchair users and is so designed that adaptations would be easy as the needs of the owners changed. These would not be notable as special housing specifically for the disabled. Some people have expressed a fear that having ramps outside their house signals to others that there is a vulnerable person living there, and consequently feel threatened.

Housing provision for those with disabilities is the responsibility of housing authorities and social services, and it can be confusing as to who provides what. Those with impairments need to be assisted and guided to obtain the best possible option for them. Various groups run by disabled people have been started across the country to provide that support, and also support for people who may be moving out of residential care for the first time.

As argued in the first chapter, to attain good health, people need to enabled and empowered to take responsibility for their own lives. By supporting, and having, choices in housing for the disabled they are enabled to take control of their day-to-day living. They are also able to live in a location of their choice.

By having disabled people living within ordinary communities, and being seen to cope with living there, it is hoped that people will then be able to experience the reality of living with

disability. This will then hopefully lead to more integration and less discrimination for those with impairments.

3.2.5 Conclusions

The social model contends that all problems related to living with impairments are caused by society. They argue that society would be much more tolerant of disability if there was more integration through inclusive schooling, positive action in employment and improved provision of suitable housing in all communities.

These measures would not only enable those with impairments to become full, productive members of society but also increase tolerance of the population by increasing their knowledge of disability and dispelling the myths around it.

Undoubtedly enabling the disabled to live independently and receive the best education possible is a commendable aim for society. But some question whether all problems stem from society. Sally French has said 'I believe that some of the most profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation.'[140]

However if the problems that already exist through having an impairment are compounded by those caused by society then it is society's responsibility to remove them. The difficulties caused through implementation of care in the community and the arguments about inclusive education show that integration is not achieved easily. It must be well planned and enacted if integration is to benefit everyone in society.

Integration in society for the disabled may also change attitudes toward screening programmes. A study in America found 'that when prospective parents obtain more accurate information about what life with disability is like, many realise that parenting a child who has a disability can be as gratifying as parenting a child who does not.'[141]

Chapter 4

4.1 Medicine as technology

Medicine as a profession has been steadily growing in stature since the 18th century. George Engel stated in 1977 that 'the biomedical model has achieved such vast power in the early 20th century that it attained the status of "dogma".'[142] Now medicine is so technologically based that the ex-director of the WHO has said ' Everywhere it appears that health workers consider that the "best" health care is one where everything known to medicine is applied to every individual, by the highest trained medical scientist, in the most specialised institution.'[143]

The successes of medicine over this time have mainly been achieved through environmental measures however, not technology. The major infectious diseases were already on the wane before the discovery of vaccines and antibiotics.

In the 18th century there were some therapeutic advances such as Edward Jenner's discovery of a vaccine for smallpox. There was also increased knowledge in obstetric care, with more doctors becoming involved in childbirth. Hospitals specifically for teaching doctors were established, but there were still few therapeutic interventions available. Improvements in health were mainly due to improving social conditions.

There was growing knowledge during the 19th century that poor nutrition, sanitation and housing conditions were factors contributing to poor health. There was also awareness of how infectious diseases were spread. In 1848 a London doctor, John Snow, traced the source of a cholera outbreak to a water pump and halted the spread of the disease by stopping its use. In the same year the Public

Health Act[144] was passed which covered refuse collection and construction of drains and sewers among other measures. In the following year this was amended to include reporting of disease and maternity and child welfare.

These measures led to a reduction in the spread of infectious disease, and better housing and nutrition led to a fall in infant mortality. Scientific medicine also started to gain momentum as microscopes improved and new discoveries were made. Specialities in science were established and new methods of chemical analysis developed.

These analyses, combined with the development of the stethoscope, ability to measure blood pressure and X-rays, increased the diagnostic capabilities of doctors. Medicine began to concentrate on disease mechanisms. Awareness of the need for antiseptic conditions and developments in anaesthesia changed surgical practice and also led to improved obstetric care.

Thus technological medicine gradually became the norm and with new scientific advances at the beginning of the 20h century the mechanistic view of disease took hold.

20th century advances in bacteriology and immunology led to a growth in the number of diseases that could be treated or vaccinated against. These advances 'concentrated the activities of medical practice and science on the investigation and treatment of disease, perhaps at the expense of considering patients in their broader environmental contexts.'[145]

The development of antibiotics in the middle of the 20th century led to further reductions in the incidence of infectious diseases and a drop in maternal mortality.

The use of antibiotics has demonstrated one of the perils of modern medicine. While solving problems, it has also brought with it new ones. Resistant strains of diseases have developed so that different, more powerful antibiotics have had to be produced. New treatments for cancer which affect the immune system of patients have also led to new infections.

At the beginning of the 20th century, it was found that biological processes could be studied and interpreted by laws of chemistry and physics. This led to the study of molecular biology which gave one of the most exciting discoveries of the century, that of the structure of DNA in 1953. Now most medical research is based on molecular biology.

Much basic research is not clinically orientated - one study[146] found that 40% of research at 2 medical schools was for no clinical end. Historically it has been shown however that clinical breakthroughs are often based on basic medical research which may have taken place many years before.

All of these developments have combined to create a dependency on medicine now. This is the opposite of the notion of empowerment in health that I discussed in chapter one. Many have argued that this has now gone too far and that people have lost the ability to assimilate normal life experiences. By basing medicine on scientific technology which many of the population may not understand, the ability to control their health is removed. David Cooper has said that technology 'erodes the traditional conception through shrinking our understanding of what belongs in the sphere of the person, of his or her accountability.'[147]

With the removal of many life threatening infectious diseases through immunisation programmes, our expectations of health have also risen. David Weatherall has said that 'Forty years ago ill-health, and even death, was a much more common occurrence, even among young people, and seemed to be accepted as part of the natural course of things.'[148] Instead the situation is now such that 'many western populations feel that constant rude health is their right and that they will go to any lengths to obtain it.'[149]

The major causes of death now are cancer and cardiovascular disease. These are often the result of environmental or lifestyle factors, although there is some genetic basis in certain cases.

The advent of HIV infection, and the devastation that it continues to cause, should act as a strong reminder that nature can often advance faster than medicine. Indeed one of the greatest fears about the epidemic was that no treatment was available. High tech medicine was seen to have failed and modern populations had not experienced that before, at least not in western countries.

This assumption that high tech medicine is the way forward has reached its apotheosis in the human genome project. This has been portrayed as the ultimate in medical control over our bodies. It will provide a blueprint of each individual which can then be used to tailor treatment.

But when the whole genome has been mapped, as has been achieved this year, this will only provide the basis for further research. In the words of David Weatherall, 'we will understand the anatomy of our genetic make up but will then face the extraordinarily difficult task of trying to find out how it works.'[150]

Developments in research often take many years to reach clinical practice. Although the organism that causes tuberculosis was discovered in 1882, it wasn't until nearly 60 years later that effective treatment was developed.

The knowledge that scientists have now gained is incomplete. It has also been argued that because genes will always mutate, indeed this is the basis for the theory of natural selection, our knowledge will never be complete. Added to this there is a great complexity in the interaction between different genes and also interaction between the environment and genes.

It is also questionable whether complete knowledge of our genetic make up and future is desirable. Many people who have a family history of Huntingdon's Chorea, a late onset fatal disease, do not always want to undergo tests to find out their status. In fact this has led to PGD clinics being asked to keep any information about the treatment secret, if it would reveal the status of the patient with the family history.

As with Huntingdon's, many of the genetic disorders that can be tested for at present, have no cure. Thus it is debatable what use the knowledge can be. In an American study[151] of 65 genetic diseases it was found that nearly half of them had only completely useless treatment and only a quarter of them had successful treatments available.

The main use of the genetic information has been in PND and PGD. 'By applying these new methods, we have been able to offer parents the option of terminating pregnancies...and hence allowing them to have normal babies.'[152] It does not allow people to have normal children however, it just prevents them having abnormal ones.

The use of these technologies has raised concerns that by enabling carriers of genetic diseases to reproduce the number of carriers in the population will increase. Before, asymptomatic carriers might not have taken the risk of having an affected child, but now the screening process allows them to avoid having affected children. It does not however prevent them from having children that carry the defective gene and so the incidence of that gene may rise.

As discussed in chapter one, the notion of overall health has many constituent parts. If we concentrate on the medical aspects to solve all our ills, then this is based on a narrow model of health. It ignores the many facets over which medicine has no control.

Thomas McKeown has argued that by concentrating on what is technologically possible, the real aim of medicine is lost. 'If we are neither cured when we are ill nor well cared for when we are disabled, what is the role of medicine in which so much has been invested, in hope and resources?'[153]

There is no doubt that medical science will continue to pursue molecular research and much work will be carried out on the human genome. The benefits of this work will not be seen in clinical practice for a long time. The main clinical use for this research will be to find more and more conditions for which PND and PGD can screen.

One of the concerns of this elimination of genetic diseases is that once a test for a disease is found then research into the disease may not continue, as an effective 'treatment' is now available. There is also concern that practitioners 'will specialise in the treatment of the treatable.'[154] Thus there will be additional pressure on people to take all tests that are available.

It has been argued that technological medicine has not delivered all that it was hoped it would. John Lantos has said that despite all the advances 'the net amount of disease and suffering does not seem to decrease.'[155]

The new form of medicine is also extremely expensive and as mentioned in 1.4 it is not able to deliver everything to everyone, despite the raised expectations of the population.

Through health promotion and making people more aware of how they can help themselves and enabling them to do so, it is argued that people will become more aware of their own health.

Just as in the 19th century it may be that changing environmental factors will prove to be the best way of improving general health. It has been said that 'Biology is a common and convenient explanation for intractable social problems.'[156] In the long term the genome project may deliver its promised clinical advances but at present it is just more scientific knowledge.

4.2 Eugenics

Plato was the first advocate of eugenic methods to improve a population. In his 'Republic'[157], which has as its theme 'how society could be reshaped so that man might realise the best that is in him'[158], he suggests regulations for the marriage and breeding of his 'Guardians'. These included the 'rulers', and the group of educated people, below the rulers and from whom the rulers were chosen, the 'auxiliaries', but excluded the artisans and farmers.

He noted that in breeding animals, selection of stock of the highest quality was used to produce improvement from one generation to the next, and figured that the same theory could be used to improve human stock. He devised a system whereby the best men and women would be selected by the rulers and through lots drawn, festivals of marriage arranged. In doing so, the population numbers could be controlled by the rulers, although without the knowledge of the guardians 'otherwise our herd of guardians may become rebellious'[159].

There was also to be a system of reward so that 'young men who acquit themselves well in war and other duties, should be given... more liberal opportunities to sleep with a wife, for the further purpose that.... as many as possible of the children may be begotten of such fathers'[160]. This was not to encourage promiscuity among the class, but to be arranged through preference for these men in the lots for the marriage festivals.

After birth, the children would be cared for by the state and 'those of the inferior parents and any chidden of the rest that are born defective will be hidden away, in some appropriate manner that must be kept secret'[161]. These proposals appear to be that children of lesser birth

would be relegated to the third class of craftsmen and farmers although there was infanticide of defective children practised at that time.

Once past the best ages for bearing children, men and women would be free to marry as they wished, within certain limits to avoid incestuous relationships, but only after the rulers 'have exhorted them to see that no child if any be conceived, shall be brought to light, or if they cannot prevent its birth, to dispose of it on the understanding that no such child can be reared'[162].

The utopian society thus envisioned never came to fruition, although there were distinct levels of society in Greece and intermarriage between them was not encouraged. Thus the notion of improvement of human society through marriage of the best people was seeded in the 4th century BC, and continued to some extent through history as class distinctions defined who was suitable for marriage with whom. This is plainly seen in the intermarrying of various European royal lines, to keep power within specific families.

The scientific practice of eugenics did not come back to consideration until Francis Galton wrote about it in 1883. He is generally considered to have coined the word 'eugenics' which was defined by him as 'the science of improving stock, not only by judicious matings, but by all the influences which give more suitable strains more chance.'[163]

He noted the inequality of human beings and attributed these inequalities to heredity factors. In this he was influenced, as was much of society at the time, by Charles Darwin's 'The Origin of the Species' which had been published in 1859. The themes of Darwin's book made many think that the problems of their society could be corrected by social Darwinism - the basis of survival of the fittest did not work in

such an unnatural, industrialised environment, but by manipulating the heredity of the population they could ensure only the fittest reproduced.

There was a problem in the cities at the time as industrialisation had led to mass migration from the country, growth of slums and what was seen as a concomitant growth in criminality, alcoholism and prostitution. The Poor Laws and the setting up of workhouses not only did not solve these problems but added an extra burden to taxpayers, so social reformers were open to any new ideas that could provide solutions to these problems.

Galton felt that the middle and upper classes were not producing enough children, and the lower classes too many, leading to a growth in what was then termed 'feebleminded' individuals. He felt that by selecting certain qualities, and encouraging those with such qualities to marry and produce children, the general intelligence of the population would increase. He said that 'marriage was a social and eugenic duty.'[164] Darwin was sceptical about many of these ideas, saying in a letter to Galton in 1873, 'the greatest difficulty I think would be in deciding who deserved to be on the [eugenic] register. How few are above mediocrity in health, strength, morals and intellect; and how difficult to judge on these latter heads.'[165]

Galton's great belief was that intelligence and feeblemindedness were inherited and could thus easily be bred in or out of the population. He felt the way forward to be scientific study of data from families, however, and did not want to be involved in a public society which looked for political and social change. He thus set up the Eugenics Record Office, which was subsequently renamed the

Eugenics Laboratory, and which is still running today as the Galton Laboratory.

Here he worked on statistical analysis of possible hereditary factors, in order to work out laws of inheritance. He did observe and describe the normal distribution of some characteristics but was unable to shed any light on the heritability of talent or intelligence. He acknowledged that 'the great problem of betterment of the human race is confessedly, at the present time, hardly advanced beyond the state of academic interest.'[166]

It is of note, considering what was to be done in future years in the name of eugenics, that Galton never advocated compulsion, but hoped to convince people that eugenic breeding was a good thing for society. Thus he supported positive eugenics - fostering more breeding among the socially meritorious - rather than negative eugenics - encouraging the socially disadvantaged to breed less or not at all.

The actions of eugenicists in Britain and other countries varied enormously. In Britain and America for instance they both looked for sexual segregation in institutions, sterilisation and marriage restrictions to control reproduction of the feebleminded. In Britain these were all voluntary options, more or less, whereas in the States there was great support for legal backing and compulsion.

In 1907 the first sterilisation law was passed in Indiana[167], and by 1917, 16 states had laws, most of which gave power to sterilise habitual or confirmed criminals. In Iowa, they passed a law[168] in 1911 which was far more wide ranging and covered inmates of institutions because of drug addiction, epilepsy and sexual offences. There were also marriage laws in 30 states by 1914, which restricted marriage among the 'unfit' e.g. the feebleminded and those with venereal disease.

The definition of 'feebleminded' was still an arbitrary matter and many different attempts were made to quantify intelligence. In 1908, a French psychologist Alfred Binet started to work on tests that would measure mental ability, and in collaboration with Theodore Simon, they devised a scheme that could classify each child taking their test in terms of mental age. This was taken to America in 1908 and although it was not initially of great interest, it was used extensively during World War 1 amongst draftees. There was a need to be able to show scientifically what many in the states felt - that feeblemindedness was on the increase.

The problems there were similar to those in Britain at the time but compounded by increasing numbers of immigrants, especially from eastern and southern Europe. The eugenicists were mainly white, middle class Protestants who felt that the intelligence of the population was being diluted by the immigrants, but they needed evidence that this was so. The testing in the army proved their fears, and incidentally the fact that the black population were also intellectually inferior, as had always been thought. The facts that the tests were dependent on knowledge of the country and the language and that education depended much on the background of the individual, were passed over and in 1924 an Immigration Act[169] was enforced, limiting the numbers to a small percentage of foreign-born of the same nationality in the US census of 1890.

Although the sterilisation laws were present, they were not always promoted, but a case[170] came before the courts in 1924 which was to reinforce and encourage their use again. It involved a 17 year old girl named Carrie Buck who was defined as a 'moral imbecile'. She was an inmate of the Virginia Colony for epileptics and feebleminded, as was her mother who was defined only as 'feebleminded'. Carrie had a

daughter whose IQ was tested and found to be of low mental age, and the colony ordered that Carrie be sterilised.

The evidence at the trial was less than scientific - the diagnosis of the daughter, who was then 7 months old, was that she had ' a look that was not quite normal.'[171] The case went all the way to the US Supreme court where Justice Holmes regarded it as one of public welfare. In his opinion he stated that 'The principle that sustains compulsory vaccination is broad enough to cover cutting the fallopian tubes'[172] and just to reinforce his thoughts he added, 'Three generations of imbeciles are enough.'[173] Carrie was duly sterilised, but it is worth adding that although her child died before finishing school her 'teachers reportedly considered her very bright.'[174]

The sterilisation rate for eugenic purposes thus rose again and continued to do so throughout the 30's. Against this there was a growing doubt about the accuracy of the IQ tests, and genetics as a science was continuing to improve. During the interwar years, there was greater emphasis on experimentation and the application of physics and chemistry to sciences.

Gregor Mendel, an Austrian monk, had described the process of genetic transmission in 1866. He had crossed peas in the monastery garden and suggested that there were 2 forms of hereditary elements, dominant and recessive. The recessive characteristics would only be expressed in the next generation if 2 recessives bred together, and would be masked by the dominant characteristic if bred with a dominant. This experimental work, which forms the cornerstone of modern genetic transmission, was overlooked until the 30's when it was rediscovered in the new age of experimental science. This rather

discredited the eugenic theories of heritability, and led to further questioning of feeblemindedness.

In Britain, there was an interest in examining the causes of mental handicap and in 1930, Lionel Penrose was assigned a project at the Royal Eastern Counties' Institution at Colchester, which at the time had more than 1000 patients. He noted great variation in the patients and eventually concluded that 'most of the Colchester cases were in origin principally neither environmental, pathological, nor genetic but some combination of the three.'[175]

While he was there he made 2 interesting observations: He described and diagnosed phenylketonuraia (PKU) in several patients and, predating the modern treatment by some 30 years, suggested that dietary alterations could treat the disorder; He also studied the mongol population in great detail. This disorder had been described by John Langdon Haydon Down in 1866 who noted the facial appearance of those affected and attributed it to some genetic throwback from the Mongol population of Asia who he believed to be earlier versions of humans. Penrose looked at blood samples of the children in his study and noted that they showed a normal distribution of blood types, inferring from this that the mongol theory of genetic throwback could not hold. By further studying the families of the children he concluded that there was a connection with the age of the mother at the time of the pregnancy and therefore Down's syndrome was not hereditary in a Mendelian sense.

In the 30's in America there was an experiment[176] carried out at an orphanage in Iowa, where babies were taken from mothers who were feebleminded, and tested for IQ. They were then put into

adoptive homes and normal schools and tested for several years. In all cases their IQ rose to within 'normal' levels.

Evidence such as this and Penrose's conclusions from the Colchester study gave new impetus for Mendelian genetics and discredited eugenics as being based on unsound science.

In Scandinavian countries there was a surge in interest in eugenics in the 30's and 40's. In Sweden for instance there had been a Society for Racial health set up in 1909, and their ideas were popular before the First World War. The impetus for this came, as in America and Britain, from the rising costs of institutional care, special schools and poor relief. In Denmark it was seen as a political trade off, with help for those who needed it in return for them not reproducing.

In all 4 Nordic countries the majority of sterilisations were on the mentally retarded. The available figures show that there was an average of 1000 eugenic sterilisations per year in Sweden between 1942 and 1949.

The most sinister example of eugenics taken to its extremes, however, was in Germany under the Third Reich. There was, as in other countries, great interest in the theory of eugenics around the beginning of the 19th century. Germany was suffering from the same problems of industrialisation seen elsewhere in the western world, and was keen to find solutions as the cost of welfare rose. Policies of health for the nation were promoted and doctors and scientists who were involved came into positions of authority to administer these policies.

After the loss of World War 1 in 1918, the country faced many additional crises, with food shortages meaning that many in the state institutions were left without while the wider population, more important to the national economy, were fed. There was a growing

feeling that the German race was degenerating and that to create a strong country again, selective breeding among 'good' Germans was needed. This idea of being healthy for the good of the country instead of oneself mirrors Plato's theories in his 'Republic'.

The situation in Germany at this time has led one commentator to state that 'virtually every aspect of eugenic thought and practice.....was developed during the turmoil of the crucial years between 1914 and 1924.'[177]

In the 30's Germany suffered from an economic depression and concern about the state of the nation and the cost of welfare increased. In this environment, the Nazi party took full advantage to push their nationalistic ideas. There was a battle between those racial and social hygienists as to how best to solve the problems, but events under Hitler quashed these debates.

In 1933 Hitler's cabinet declared a eugenic sterilisation law which went far beyond any of the US laws. It made sterilisation compulsory for sufferers of any allegedly heredity disabilities, including: feeblemindedness, schizophrenia, epilepsy, blindness, severe drug and alcohol addiction, and physical deformities that seriously interfered with locomotion or were grossly offensive. They called this 'an exceptionally important public health initiative.'[178]

Within 3 years some 250,000 people were sterilised, of whom half were said to be feebleminded. These moves found acceptance and support from many doctors who had been advocating such policies previously. They also profited from the laws, as these were medical procedures for which they were paid, and they were in the majority on the tribunals that selected patients for sterilisation.

In addition to this negative eugenic policy, the government provided loans to 'biologically sound couples'[179] to reproduce with some cities adding subsidies for subsequent children. Himmler formed the SS, a group of elite soldiers and doctors. In markedly similar terms to Plato's suggestions about rewards for men who 'acquit themselves well in war'[180], he encouraged the members of the SS to father numerous children with 'racially preferred'[181] women. Again following Plato's suggestion that these special offspring be looked after by the state, special homes were created for the confinements of these women - called Lebensborn.

Not all doctors and scientists agreed with the way the eugenic measures were carried out, but by a process of control and infiltration, those in agreement were supported and others pushed out of positions of authority. Thus the Nazi state had a biological and medical basis, but a 'racial and nazified version of it.'[182] In 1934 the deputy leader of the party said that 'National Socialism is nothing but applied biology.'[183]

In 1935 the Nuremberg Laws were passed which forbade marriage between Jews and Gentiles, and other categories such as the mentally handicapped, although exemptions could be made if they had been sterilised. The expulsion of Jewish scientists and other professionals was internationally criticised, leading to further isolation of Germany, but there were those in the States who praised the sterilisation laws.

In 1937 SS medical officers gained public health powers, and the expansion of eugenic measures towards the 'final solution' began. The centralisation of administrative and medical powers which had happened over the previous years made the policies easier to implement. In 1938, the first policy was 'extermination' of new born

and young children suffering from diseases that made their lives 'valueless.' This included mentally retarded and congenitally deformed infants, but in some instances also of those of 'lesser races.' Later the policy was expanded to include the mentally ill in institutions.

Initially these practices were secret with each 'euthanasia institute' having its own registry office to issue false certificates of death. There were protests from relatives which grew to include the general public and the churches when they realised what was happening. It was ostensibly dropped as a policy in 1941, but in fact they just moved the operation and sought to make it more it more efficient by building the first death camps. A year later, the categories were expanded further to include Jews, mixed race children and gypsies, no matter their state of mental health.

Once these people were regarded as degenerates akin to animals, the way was open for experimentation on them. The scientists claimed that they were working on pure scientific research, and used the same defence after the war.

The steady creep of the eugenic moves toward the holocaust, with the support of many scientists and doctors, serves as a warning to all involved in genetics now, as to where small shifts in policy can eventually lead.

It is said that these policies were based on the writings of Neitzsche, who created the concept of the 'Ubermensch'[184], commonly translated as the superman. He, however, often stated that he abhorred the German racist tendencies, and in fact forfeited his German nationality after his experience in the Franco-Prussian war. His sister, married to a man Nietzsche termed a 'racial German' with anti-Semitic views, was responsible for his estate after his death. She, in the eyes of

one commentator, 'By systematic falsification and misediting....prepared the way for the Nazi appropriation of Nietzsche's thought.'[185] She was even photographed with Hitler at the house where Nietzsche spent his last years.

This evidence about Nietzsche was uncovered in the 50's by an American Jew whose family had suffered at the hands of the Nazi, Walter Kaufmann. In view of the similarities between Himmler's policies and Plato's ideas of his 'Republic', perhaps Plato should have been the one to be vilified.

As the full extent of the German utilisation of eugenics became known, interest in the concept faded, although strangely not in the Scandinavian countries whose enthusiasm for eugenic sterilisation continued into the 50's. Geneticists tried to establish themselves as a proper science and further distance themselves from eugenics.

J.S.Haldane, a British geneticist said that 'many of the deeds done in America in the name of eugenics are about as much justified by science as were the proceedings of the inquisition by the gospels.'[186] The medical profession did not display much enthusiasm for the new science however as 'if a malady was hereditary,....it must be neither treatable nor preventable.'[187]

In the 40's and 50's there were a series of new developments in the science of genetics and their analytical techniques, which led to major discoveries. The most important of these in scientific terms was the discovery of the double helical structure of DNA by Watson and Crick in 1953. In medical terms, the development of chromosomal analysis was possibly more important and in 1956 the number of human chromosomes was established. This was followed 2 years later

by Lejeune's work, where he demonstrated that Down's syndrome children had an extra chromosome.

There were a few clinics established where rudimentary genetic counselling began - they could test prospective parents for a few disorders, and give informed estimates of future risk for those with an affected child. It was not until the advent of amniocentesis in the late 60's that more use could be made of the genetic information. Initially this test was used to identify Rhesus factor disease which could be treated by blood transfusion after birth, but within 10 years foetal cells could be cultured, leading to diagnosis of chromosomal disorders.

Medical interest in these diagnoses grew and the treatment of PKU was seen as a paradigm example. By screening all new borns and providing those affected with a special diet, the condition was treatable, and it was felt to be extremely cost-effective.

The passing of the Abortion Act[188] in Britain in 1967 and the constitutional right to abortion established in America through Roe v Wade[189] in 1973, meant that the option of testing through amniocentesis and abortion of affected foetuses was available to prospective parents.

This 'treatment' of genetic disorders was not greeted with universal enthusiasm though. Lejeune, who discovered the extra chromosome in affected children, stating that 'Amniocentesis and abortion....have transformed the traditional goal of medicine from a cure to an attack on the patient.'[190] He went on to say that he thought of 'trisomy-21 [the extra chromosome in Down's syndrome] as a symptom of a disease. The students think of it as a symptom of death.'[191] It was also noted that the technique as said in 4.1 would lead to many more carriers of genetic disease being born as their parents

now had the freedom to reproduce with the knowledge that they could abort affected foetuses.

The huge growth in the number of disorders which could be tested for led to a growth in the number of genetic counselling centres. In the States they also recognised that certain disorders were predominant within certain ethnic groups, with Sickle cell anaemia prevalent amongst blacks, Tay-Sachs in Ashkenazi Jews and Thalassmeia in those of Mediterranean origin.

Many states made genetic testing compulsory but it was not always with satisfactory results. 'In practice, the sickle-cell programs, many of them short on follow-up counselling, often left people detected as carriers unnecessarily anxious about their procreational futures.'[192] It was later seen as discriminatory, creating stigma within the population and against civil liberties.

In Britain because of the lesser racial mix, there was no such screening processes, the only one that was compulsory being the new-born test for PKU, which is treatable condition.

The genetic counselling service is anxious, as were the scientists before them, to distance themselves from eugenics but there are cautionary signs that similar language of genetic unsuitability is being used today. While no one could accuse it of being in the same league of horror as Nazi Germany, that should always serve as a reminder of where excessive emphasis on genetic purity can lead.

As argued in 4.1, concentration on medical or biological factors has not always produced improvements in health. It has been said of genomics and eugenics that 'both have taken root in a climate where many people believe that the large part of human talents and disabilities are heritable through the genes.'[193]

One of the early scientists, Lionel Penrose said in 1969 that 'he would rather live in a genetically imperfect society which preserves human standards of life than in one in which technological standards were paramount and heredity perfect.'[194]

We still do not know what genetic make-up creates a genius and Lejeune felt that the emphasis on testing and aborting, the lynch pin of PND, detracted from biomedical research on congenital disorders. In 1970, he said that he looked forward 'to the day when a mongolian idiot, treated biochemically, becomes a successful geneticist.'[195]

4.3 The medical model of disability

As argued in 4.1, there appears to be a growing dependence on medicine in society and an intolerance of illness. This view is based on a narrow model of health as the absence of disease. Health, as discussed in chapter one, is much more complex and involves many different factors.

The disability movement has argued that the predominant way of regarding those with impairments is through this narrow, medical model. They would like to see a shift in opinion toward the social model discussed in 3.2.

They have said that 'historical connections between hospitals and disabled people have helped to perpetuate the widespread belief that impairment is the same as ill-health.'[196]

This medicalisation of disability began with the creation of workhouses for those unable to earn a living. In the Poor Law Amendment Act of 1834 there were five categories of inmates given. This meant that those with impairments, 'defectives', were categorised with the sick and elderly, laying the basis for the medical view of disability.

In the 19th century there was a huge expansion of industry. This led to more people moving into cities and changed the values of society. Whereas work had been a part of life before and the disabled were tolerated within small rural communities, now 'social fitness became measured by wealth.'[197]

More disabled people had to seek help from workhouses which then led to large institutions being 'constructed to house specific categories of deviant groups.'[198] These institutions were managed by the

medical and nursing profession and run as hospitals with inmates treated as patients.

Further laws were brought in which meant that the inmates lost many of their rights and which 'legalised the collection and retention of many disabled people.'[199] They also isolated the disabled from society, said to be for their own protection. A Royal Commission in 1904 stated that 'as the family in some way created and sustained the defect, defectives should be removed from their families as soon as possible to prevent further damage and harm.'[200]

The growth in the eugenics movement, as described in 4.3, led to certain views about disability being hereditary. It also led to the laws in America which prevented marriage and allowed sterilisation of inmates such as in Buck v Bell.[201] After the Mental Deficiency Act of 1913 in the UK, there was a huge increase in the number of institutions.

It was not until the 1960's that people began to have reservations about these institutions, and a number of scandals emerged regarding treatment of the residents which further suggested they were not the best way of caring for the disabled.

Now it is accepted that institutions are 'punitive and entirely inappropriate'[202] and the emphasis has moved to care in the community. There has been gradual involvement of other professionals in the implementation of this policy and in 1971, responsibility for the education of severely handicapped children was moved from the department of health to education.

It has been argued that the workhouses began the process of assessment that still persists. The aim of these assessments was to prevent malingerers from entering and receiving help. This same system of medical assessment for eligibility for state services continues and

many feel that it is inappropriate. As I said before however, some form of assessment is required, but some authorities are moving away from solely using doctors as assessors. (p76)

Medical intervention in disability has always occurred, not all of it beneficially. Laurent Clerc (p60) described many strange and often very painful procedures he went through at school in order to cure his deafness. As stated in 3.2.1, many feel that the emphasis in special schools has always been on medical intervention to the detriment of education for the disabled.

Michael Oliver[203] has said there four occasions when medical intervention is appropriate:

1. Diagnosis of impairment
2. Stabilisation of medical condition after trauma
3. Treatment of illness independent of disability
4. Provision of medical rehabilitation

Rehabilitation has its critics among the disabled, many of whom have undergone it themselves following accidents. They argue that it based on an 'ideology of able-bodied normality.'[204]

But physical rehabilitation after trauma is necessary, as Michael Oliver admits, to regain as much functional ability as possible. Studies using Magnetic Resonance Imaging have now shown that the brain itself changes during rehabilitation. Different areas of the brain which had other functions can be 'trained' to take over new functions, a process described as brain plasticity.[205]

The disability movement argues that it is too excessive however and should concentrate on 'social and personal barriers to be overcome, rather than any functional limitations of the individual.'[206]

They would like to see a more integrated process of rehabilitation, which many authorities have now acknowledged and are starting to develop.

As Michael Oliver acknowledges, there is a need for medical input in the lives of disabled people. He and others argue that this must be appropriate and empowering, not oppressive. Doctors are part of the wider society and as the attitudes towards disability change there, so will their own. The empowerment approach to health is gaining ground and will undoubtedly also affect the disabled.

The role doctors play is changing and they are increasingly challenged by patients who want to know more about their treatment. As this continues the all powerful role that the disability movement argues doctors have over them will gradually change.

The interaction between doctors and those with impairments has not always been wholly successful. The past history has led many disabled people feeling very antagonistic towards the medical profession. This is perhaps not surprising given the way they have been treated especially through eugenic moves in the names of science, as seen in 4.2.

Diagnosis of specific problems in children is, as Michael Oliver has said, an acceptable form of medical intervention. But it is argued that 'from a medical perspective, the lives of disabled children appear as a problem that is to be treated.'[207] He has said that 'disability as a long-term state is not treatable and is certainly not curable.'[208]

Indeed it has been argued that one of the reasons for medicine's enthusiasm for PND and PGD is that it prevents the birth of children whose problems they cannot treat and is seen by some as further oppressive behaviour in the name of science.

Society is now moving toward more integration, and acknowledging the rights of disabled people. Medicine will continue to be a part of disabled people's lives but hopefully that interaction will acknowledge the wider concept of health with all that it entails, including empowerment of the individual and acknowledgement of other factors such as the environment.

Chapter 5

The status and rights of the embryo

The most fundamental objection to PGD, and PND in general, is that it is always wrong to take another human life. In other words, all human life is sacred and all have a right to life.

There has been much discussion about when human life begins and which rights are applicable at what stage. Michael Bayles summed it up by saying 'the underlying assumption has been that human beings have a right to life. Thus, when and if the foetus is human, it has a right to life.'[209]

I will consider the various stages at which human life could be thought to begin, the religious views and the legal position. I will then look at the rights that are considered to be due to humans and how these have developed.

5.1 The status of the embryo

The status of the preimplantation embryo has been discussed by many authors with regard to embryo research, In-vitro Fertilisation (IVF) and abortion. There are 6 proposed stages when the embryo/ foetus attains the status of a human being.

1. At the moment of conception, when fertilisation occurs and, in the words of the Church of Scotland, when 'a genetically complete conceptus'[210] is produced.
2. 14 days after fertilisation, when the primitive streak appears. This is the latest stage at which twinning can occur, so beyond this there is only one potential individual.
3. At the point when the nervous system starts to develop, the beginning of sentience. The neural tube folds develop around 20

days after fertilisation, the cerebral cortex starts to develop around 6 weeks, and connections in the nervous system appear at 14 weeks. Although the appearance of structures does not necessarily mean they are functioning, it is generally accepted that pain can be felt by the foetus around 9-10 weeks.

4. Quickening – when the mother can feel foetal movements, at around 19 weeks.
5. Viability – when the foetus can survive outside the womb, usually around 24 weeks.
6. Birth – when the baby attains a separate existence from the mother.

The first option is the one taken by many churches, with the majority stating that the embryo at this point is a new genetic entity and therefore a human being in God's image. The Church of Scotland states that 'with conception a new life begins, a new creation of God'[211] and reinforces this by adding 'the embryo is a potential person in that, given the right conditions, it becomes not something different but that which it already is.'[212]

The Catholic Church's viewpoint, as interpreted by the Centre for Bioethics at the Italian Catholic University in Rome, states that 'the embryo is potentially a child or a man, but it is not potentially a human being. That is what it already is.'[213] Their basis for this is that '[H]uman personhood is conferred by God in the act of creating a new human life.'[214] Thus 'the human embryo has the same status as a child or an adult and the fundamental right to life, furthermore to kill the life of an innocent is an especial moral outrage.'[215]

Given this view, one assumes that IVF, the creation of embryos outwith the uterus and an integral part of PGD, would be unacceptable, and indeed the Catholic University has stated that

'reproductive technologies degrade and reduce the conjugal act to a technical act.'[216] 'Therefore .....all artificial procreative technologies are condemned by the Vatican document.'[217]

The Church of Scotland, however, does agree with IVF so long as no external party's gametes are used and appreciates that the technique would not be available if embryo experimentation had not been used in its development. They say that they 'recognise that a certain latitude of judgement is to be expected among Christians.'[218]

The Methodist Church and the Church of England have taken a different approach, that of a 'gradualist perspective that while the human embryo is very special, recognition of its humanness,....is to be related to stages in its development as revealed in embryology.'[219] Thus they say that 'until the embryo has reached the first 14 days of its existence it is not yet entitled to the same respect and protection as an embryo implanted in the human womb and in which individuation has begun.'[220]

This was also the majority view of the Warnock committee, whose report[221] formed the basis for the Human fertilisation and Embryology Act[222] in the UK. They decided that the cut-off point for research on in-vitro embryos would be 14 days after fertilisation. This was due to the fact that, as stated in option 2, the primitive streak appears at this point and is the last stage at which twinning can occur. They stated that there was a 'morally significant difference between pre and post 14 day cells... and it is the human individual who must not be used for research and then destroyed.'[223]

They also stated that the human embryo should be accorded a 'special status'[224] and recommended 'that research conducted on human in vitro embryos and the handling of such embryos should be

permitted only under licence. We recommend that any unauthorised use of an in vitro embryo would in itself constitute a criminal offence.'[225]

If one compares the requirements for embryo research in the UK on humans and animals, however, there are more stringent laws regarding animals. Both require that one applies for a licence, stating the objectives of the research, and justifying the work, both have an overseeing authority that inspects premises and work practices and both require the applicant to have relevant experience. In order to carry out work on animals or their embryos, however, one is required to attend a 3 day course on welfare and law and pass an exam. There are no such requirements needed to work with human embryos.

Option 3 in the list is the beginning of sentience, when the foetus can feel pain. It has been argued that this is only appropriate 'if the attainment of sentience is linked to something else (like a theory of personhood) could it avoid the moral simplicity of saying that anything is licit as long as it causes no pain.'[226] John Marshall also says that 'if the embryo is thought to be a person, in the sense of someone who cannot be used as a means to an end, the fact that what is being done can be done without pain, becomes an irrelevance.'[227] Thus sentience is only relevant as the beginning of human life if it is thought to be a prerequisite for being human.

Quickening, option 4, was the ancient view of the start of human life. Before microscopic analysis of embryonic development and ultrasound, this was the first sign of foetal life. In law, this was when punishment for death of the foetus became manslaughter. Aristotle's view was that the foetus gradually acquired 'ensoulment'[228]. Thus it went from 'a vegetative existence' to the later foetus, 'resembling a little

animal' and with 'a sensitive soul' and finally to the fully formed foetus, 'recognisably human' and with 'a "rational" or "intellectual" soul.'[229]

Viability, the next option, was supported in the case of Roe v Wade in the states. In considering the limitations for abortion the court stated 'the compelling point [for the state to take an interest] is at viability. This is because the foetus then has the capacity of meaningful life outside the mother's womb. State regulation protective of foetal life after viability thus has both logical and biological justifications.'[230]

Birth is an obvious standpoint, as at this point a separate being is present. This is the view of Jewish religious thought 'on one fundamental principle there is complete agreement: full human status is not acquired until birth.'[231]

This is also the point at which the foetus attains legal status in the UK. This can also be retrospective, but the foetus has no legal rights unless it is born alive. It is accorded protection in utero from injury by third parties and can claim after birth for prenatal injury. In practice, as discussed in 1.3, the claims are usually only successful if brought by the parents.

All of these options appear to assume different qualities necessary to be a human. Thus to agree with 1, one has to decide that a new genetic entity is all that is required to be human. This individuality is also continued with the 14 day rule, when twinning is no longer possible. The ability to feel pain is not solely a human characteristic as animals also have this ability.

The stage of quickening is when the presence of another being is felt by the mother, but now, with the widespread use of ultrasound, foetal movements can be seen, if not felt, at much earlier stages.

Viability is said to be when the foetus can survive outside the womb, but this is not really the case. A 24 week foetus can survive but usually only with a great deal of medical assistance. Even after birth, a baby cannot fend for itself, requiring outside help for many years.

It has been said that 'there is one presupposition that all of these positions have in common. It is that there is an objectively correct answer to this question.'[232]

The argument about when human life begins is ongoing and, because many opinions are based on religious beliefs, is fiercely contested. It is difficult to pin down an exact moment when an embryo becomes a person but I would agree with Aristotle's view that as the foetus grows, so does its status as a person.

Society would also seem to agree with this view in that most people support the right to abortion. As with the abortion law, however, the view changes with regard to the length of the pregnancy, so that later abortions are seen as justified only in exceptional cases.

5.2 Human Rights

Mary Warnock said that 'if it can shown that the embryo is a person then it will follow that it has rights for certainly all persons have rights and it is sometimes held, only persons have rights.'[233] These rights are not just legal rights but moral rights. Morris Cranston said that 'A human right by definition is a universal moral right,..... something which is owing to every human being simply because he is human.'[234]

Historically the idea of universal moral rights of humans dates back to the natural law of the Greeks. They said this was 'a law to which everyone had access through individual conscience.' [235] In order for this law to be applicable they had to explore what qualities humans

had that made them different from other animals. Aristotle said that human beings ordered their actions in the light of rational understanding and that this rationality was the defining quality of being human.

The idea of moral rights for humans was continued by the Romans who enshrined them in a legal system. The moral theme of these rights was continued by the spread of Christianity. Both of these views created ' a relationship between a human being and his or her conscience.'[236]

The concept of rights for man was later expounded by philosophers such as John Locke who wrote of rights to life, property and liberty. These rights were also part of the Declaration of Independence of both France and the United States.

Feinberg has said of these rights, a 'man has a moral right when he has a claim, the recognition of which is called for not necessarily by legal rules but by moral principles or the principles of an enlightened conscience.'[237]

He has also said that if 'one wishes to say one has rights, then one must accept certain duties that go with those rights, certain obligations and it has been stated that one can only insist on rights if one can lay claim to them.'[238] If this is the case then the foetus and certainly the embryo cannot have these rights as they are unable to lay claim to them. They deserve to have what Warnock referred to as a 'special status' but not full rights. They are not full human beings, and it could also be argued that neither are young babies in that they cannot exhibit rational thought or claim their rights.

Jonathan Glover has listed certain criteria that must be met in order to have a right. These are that 'must already exist' 'at a level of

development where you can have the relevant desires' and one 'must have the desire whose satisfaction is in question.'[239]

Again neither the embryo nor the foetus could be said to satisfy these criteria, and the 'level of development' criteria also precludes babies and small children. This would seem to suggest that rather than attaining full human status with all its attendant rights during foetal development, it is not until much later, well after birth, that this happens.

It has been said that to 'argue that neither the embryo or the foetus is a bearer of rights is not to leave it without protection. We have duties towards it, because there is a strong presumption in its favour.'[240]

5.3 Conclusions

So the embryo at the stage when PGD is carried only has a status as a person in the eyes of the Catholic Church. The Church of Scotland has not condemned PGD, only raised doubts about its safety.

In terms of having human qualities that would confer rights on it, there is no question that an embryo has any such qualities. The changing status through time and growth as suggested by Aristotle seems to be the most acceptable view to the majority. Thus PGD is an acceptable technique in society, and may even be preferable to PND and later termination.

Conclusions

As discussed in Chapter 1, assessment of health and well-being is difficult, and value laden, in people already alive. The ability to predict it in those not yet born is almost impossible. As I said, these judgements are not made in isolation, they are value judgements which will derive from personal experience, clinical advice and societal attitudes. Any decision in PND or PGD for prospective parents will involve all of these factors.

The legal cases discussed in 1.3 will undoubtedly also influence clinicians – they do not want to be sued and so will be under pressure to provide all the tests they can. Patients will also be aware of these cases through media coverage. They imply that having a handicapped child is expensive and the need for compensation indicates that social welfare does not fully provide.

The very presence of testing during pregnancy influences decisions. If it's there it must be for a good reason and to provide benefit to the patient. Medical opinion is still highly regarded and their message is that parents must do the best for their babies, be that not eating certain foods or taking all available tests. As the tests are now an integral part of the antenatal service, the time given to discussion of tests and their consequences may be limited as they will be seen as the norm.

The media also influences societal attitudes. This year there were scare headlines regarding a screening programme in Sheffield.[241] It was portrayed as terrible that errors were made and 4 children with Down's syndrome were born as a result. Other mothers were interviewed on television and said that their pregnancies had become a nightmare because of the extra anxiety. Thus the message is given that

having a baby with Down's syndrome is a horrific experience to be avoided at all costs.

The combination of all these influences give out the message that handicap is horrific and that responsible people take advantage of all screening tests to abort all affected pregnancies.

As more and more 'genes for' are discovered, we are led to believe that this will benefit us all. In fact medical uses, apart from testing and aborting or PGD, will take many years to reach clinical practice. These scientific advances are not value neutral and can be used in many different ways, good or bad. The claims of scientists and doctors in Nazi Germany are there to remind everyone of the practices that science can be used to justify.

It is admirable to try and stop pain and suffering but assessment of another's pain and suffering is very difficult. If eradication of dreadful disease is the aim of PND and PGD, then we need to step back and consider what are dreadful diseases and why we consider then to be so. Is it dreadful for the sufferer, the parents, the doctor who cannot treat it or society who has to pay for their care?

As I argued in Chapter 1, suitable candidates for PGD could be those that cause unmanageable pain, complete lack of intellectual acuity or where there is a limited ability to medically treat. Embryos may not have the status of a human being but that should not allow us to discard them for trivial reasons.

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